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ADAPTABLE LIVES: AGENCY AND ACCOUNTABILITY IN A  
CANCER CLUSTER TOWN

BY

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DISSERTATION

Submitted in partial fulfillment of the requirements  
for the degree of Doctor of Philosophy in Sociology  
in the Graduate College of the  
University of Illinois at Urbana-Champaign, 2017

Urbana, Illinois

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## ABSTRACT

This dissertation provides an ethnographic account of the experiences of residents living within the cancer cluster town of Clyde, Ohio, where over 50 children have been diagnosed with or have died of cancers of the brain and central nervous system since the mid-1990s. My entry into the field coincided with the filing of a lawsuit against the town's largest employer, a Whirlpool Corporation plant, after the discovery of nine feet of toxic PCB sludge at a former community recreational park built by the company. Drawing on in-depth interviews, archival documents, and government reports, I examine systems of power at work within the community that hamper a collective sense of community subpolitics. Using a grounded theoretical approach to analysis informed by risk theory, I discovered that community-level responses to risk echo national logics that promote the concepts of deterrence and avoidance of harm as matters of individual preventive choice. Within a cultural context where efforts towards pinpointing the toxins responsible for the elevated cancer rates in Clyde have failed and there exists an imperative for self-protection that is impossible to achieve, residents experience serious psychosocial and practical conflicts as they adapt to the impact of cancer on their families. Furthermore, although risk and awareness of risk have penetrated the dialog of everyday life, townspeople have largely adapted to risk as a way of life rather than working to eliminate it. Examples of this are seen in the modification of residents' consumer and lifestyle choices, and the participation in an evolving system of support from the community's schools, businesses, and churches. I offer a theoretical framework for understanding the process through which the community changed to accommodate risk rather than to substantially alter it. This research bridges sociology and public health, and responds to a long-standing call to incorporate social theory into social epidemiological studies. It advances both the understanding of the ways in which residents are influenced by interactions with the State, as well as the occurrence of collective community inaction in cases of environmental contamination.

## ACKNOWLEDGEMENTS

I owe thanks to Moon-Kie Jung, Assata Zerai, Lisa Cacho, and Norman Denzin for their mentorship and for pushing me to think more deeply about social inequalities and social justice issues. I'm inspired by their scholarship and feel grateful to have had the opportunity to learn from them at UIUC. Thanks to Maryalice, Dawn, and Kit for all they have taught me about research and data analysis over the last six years. I leave the data-analytics group with a great appreciation for the role that wit, kindness, and curiosity play in creating productive work environments. I also appreciate their flexibility in allowing me to work remotely while having a baby and completing my degree, a benefit that I intend to pay forward. Thank you also to my mother. I would not have completed this dissertation without her babysitting help, and answers to my many grammatical questions. Thank you also to my father, late grandmother Tillie, Jesse, and Nathan for advocating for me. Finally, special thanks to the residents who so kindly allowed me to interview them as part of this process. Their input provided valuable insight into issues related to parental management of a child's illness, and more broadly, how communities respond to environmental health risks. The perseverance of some I interviewed, even when their actions were criticized or their motives questioned, is evidence of a strength I hope never to have to find. I have tremendous respect for them.

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## PROLOGUE

### THE TOWN OF WHIRLPOOL

McPherson Highway runs west and east through the town of Clyde, Ohio. It is not Main Street, which runs the other direction, but is perhaps the *new* Main Street serving as the focal point for retailing and socializing. Both independent and corporately owned businesses stand along McPherson Highway, and, like many small towns across America, offer services that people need to keep residents local. Clyde is home to a Whirlpool Corporation plant, which manufactures household appliances in a large industrial complex. Along McPherson Highway is also a diner, elements of which are most colloquially representative of what Clyde used to be, and that are perhaps a microcosm of the community itself. This story that I am going to tell you about Clyde begins at Gary's Diner because it is also the location where the story almost never began.

Clyde is a disease cluster community where children are being diagnosed with and dying of cancer at a statistically significant higher rate than the rest of the population. Many adults have been diagnosed with unusual cancers as well, although not reflected in the official health assessment conducted in the area. My visit to the community coincided with the recent filing of a lawsuit against Whirlpool Corporation by affected families claiming that the company was responsible for illness-causing toxins. I drove to Clyde to attend a public meeting held by the team of lawyers and scientists hired by the families to conduct independent environmental tests.

On the morning after the meeting, I stopped at Gary's Diner to organize my research papers before beginning my two-hour drive home to Northeast Ohio. The diner appeared to be converted from a mobile trailer and had elements of a 1950s retro decorative style, including a row of stools that ran along a counter. There were nine or so people inside, a few waitresses, and a male manager. Most of the patrons were older white men, all of whom stared at me when I entered. I walked to the farthest booth, and pulled out my notes from the previous night's public meeting. Almost immediately, a man warmly introduced himself to me as the owner of the diner and a member of the city council.

"I saw you at the meeting last night. What were you handing out?" He asked.

"Well, I'm a student and I'm writing my dissertation on the Clyde cancer cluster." I handed him a flyer, which provided more detail: I was interested in interviewing residents to more fully understand the social and psychological effects of living within a contaminated

community. He enthusiastically offered me his contact information for an interview and took a few of my project flyers to distribute to the men sitting at the counter. Upon receiving them, the men began to chatter. Out of a murmur of voices, one voice rose above the rest: “Some people are educated above their level of intelligence.” I sat silently without movement. I imagined myself freezing in time the activities of the diner and walking out—taking my flyers from the hands of the statues of people when I was leaving. Before I knew it, the older man with the voice was strutting towards me. As he sat down across from me, his hands struck the surface of the table like two wooden mallets.

“We all wanna know—what is a pretty girl like *you* doin’ here?”

His eyes were radiant against the backdrop of his weathered face, and they sparkled like glass. I greeted him politely. “Hi, my name is Laura.”

He extended a calloused hand. “I’m Don.” Within seconds, another man approached, put his hand on my shoulder, and jokingly whispered in my ear, “Be careful with this one.”

I introduced myself to Don as a student and explained my project to him: “I am studying the social and psychological effects of living within a disease cluster community—how people manage illness, how they cope.” This time, I wondered if I sounded too academic, and with unintended self-disparagement, girlishly added “things like that.” It became clear that Don didn’t know I had overheard him scoffing at me and my research. He insisted that I interview him, and we set the date for the next morning at the diner.

When I returned for the interview, Don came in on his lunch break with paint-splattered overalls. Without asking, a waitress brought him a Diet Coke and a club sandwich. I began the interview by asking Don to tell me a little bit about himself.

“Well, I’ve lived in this town 79 years,” he explained. “My family’s lived here all their lives, and they go back, way back. Probably really early 1800s. It’s a good town. I like everybody, I know everybody, and it’s been good to me. I’ve had a good life.” He paused, then added, “I had my funeral.”

“Say that again?”

“I had my funeral.”

“I’m not quite sure I follow.”

“2004. June 15<sup>th</sup>. They had the TV here from Toledo and everything. If you go down to the cemetery right in the middle in the front row, you’ll see a paint brush and that’s my

tombstone. There was 150 people at my funeral. And the bank president made a speech, the superintendent made a speech—everything like that. It was all on TV.”

“Wow. That’s interesting,” I said. “So how would you describe yourself?”

“I’m a happy-go-lucky person. Uh, I’m a big flirt.”

I laughed.

“I mean there are a few husbands that don’t like me, but overall I think 90% of people like me. Well, I was in politics. I was the township trustee. Politics is a popularity contest. I run against seven other people. They were great people, but I got it because I’ve painted for 57 years and I know everybody. I mean there ain’t a house around here that I haven’t been in. Not many people would still be workin’ at 79—specially climbin’ ladders like me.”

“Yeah, that’s impressive,” I said. “So you feel that your own health is pretty good?”

“Well, I had my hand smashed, found out I got sugar, but I’ve been lucky. I’ve been lucky.”

“And your family’s health?”

“I lost my dad to cancer when I was 20. On my dad’s side, all of the five kids had cancer but one.”

“Do you think it’s related to some of the stuff that’s going on here?”

“I think on my dad’s side, the gene is wrong. Now my dad, he worked in dust five days a week sanding knife handles, and he got leukemia. They said it could’ve been from his job, but back then, there was nothin’ you could do about that. My grandfather died with prostate cancer. My grandma died from sugar. They cut her leg off. Did you read the Clyde paper yesterday?”

“No.”

“Buy a Clyde paper and read the article in there that a guy put in about that cancer study—big ad, about the stuff that’s in your house, what’s it called?”

“Benzaldehyde?”

“Yeah, see what he says. He was born and raised here in Clyde. He put an ad in that says benzaldehyde is in food, perfume, hair spray—it’s in *everything*. Now I don’t know how these people can say that it got in their attic from Whirlpool. But I believe, well I know it—every home’s got it. You get that Clyde paper and read that article. The same guy wrote an article a few weeks ago about the orchards here. This whole area years ago was surrounded by orchards. Everywhere. High school was an orchard. There was an orchard right here. Two big orchards



north of town. And they all sprayed. When you went by on the road, you could see the spray runnin' out of a wagon, going up in the air. They've been doin' it for a hundred years. Now they're down to one orchard and the rest of 'em are all gone."

"I didn't know that."

"Clyde had a lot of factories that are not there anymore, but they never bring them up. They never bring them up. They're gone, burnt down. I don't wanna get involved. If they have ten more meetings, I'm not going. I just don't like the idea that they're blaming it on the Whirlpool Park, like PCBs. All these old transformers out here had PCBs in 'em. And the guy that hung 'em—one of 'em was my cousin. None of them guys ever got cancer. The class after me...I don't know how many's had cancer. But a whole mess. Probably close to 50%. But *that's* never come out. Never been mentioned. In fact the house I'm working on right now, his wife was in that class and she died of cancer. I talked to him about it this morning. He said it was such a rare rare cancer that they didn't even think there was any of that in this area, whatever she died of."

"Wow. So what stands out for you when you think about the first time that you heard that toxins might be causing illness in the community?"

"Well I mean, I feel sorry for the people. It's hard when you lose a kid, but I just can't see Whirlpool...there's been nobody at Whirlpool Park more than I've been in Whirlpool Park. I hunted it every October for duck. Every October. But I'll say one thing, everybody used that park. It was full all the time. All the time. And it was nice. But uh...I...and a lot of people think that they're goin' about it the wrong way. Well, I know a few in it for the money. A couple of weeks ago, there's a guy down there now, very big guy, my cousin—he told Warren he was barkin' up the wrong tree. Boy, ol' Warren, he went off the handle and he hasn't been in here much since. That was two weeks ago, but John said, 'you can't blame it on Whirlpool'...ya know, that's what John said. But Warren said, 'Well I ain't givin' up until I find out what killed my daughter!' And I can understand that part...I just wish...I do know a lot of the people that are suin' for money. Not *all* of them, but a lot of 'em. Well, if Whirlpool would leave, this county would die. My house would be worth 20,000 dollars if Whirlpool would ever leave."

"I see what you mean."

"You know what I mean? They've done a lot of stuff. They employ over 3,000 people!"

"Well, um, so you come here a lot?"

"Every day."

“Is it a hot topic here?”

“No. No.”

“People don’t talk about...?”

“No topic here.” He paused, then added, “I go to the Eagle, I go to VFW meetings and I’ve never seen anybody bring it up. Nobody. No. They don’t talk about it.”

“Okay. So what do you think affects health?”

Before Don could answer, a man approached him with a broken brass horn. “You think I could get anything for this?” He asked. “I got it at a garage sale.”

“I don’t think you’re gonna get much for that, no.”

“I don’t mean to interrupt. Those guys are just dyin’ to know who this girl is down here.”

“Tell ‘em I’ll be down.” Don chuckled. I could tell that he enjoyed the attention he was getting from his friends. “I’m an antique expert.”

“Do people consult with you a lot?”

“Yeah, I’m very knowledgeable on anything a hundred years old. About everything. Everything but coins. Probably have over 150 guns. My house might have more things in it than most museums.”

“That’s neat.”

“Anyway, I don’t know what trips the genes, but somethin’ trips the genes. Everybody in Clyde got somethin’. But anymore, 90% of us are gonna die of cancer if you live long enough. And I, when I just come in, my cousin was settin’ up there at the bar. Well, he just got the word—not good. Cancer.”

“Just now? When you came in today?”

“He found out yesterday. But it...I don’t know if it’s bad here or *everywhere*. I mean, I don’t know. I don’t know if Whirlpool trips the genes or what, but, uh, I think it’s O.L.D. down there, north of town—that was a disaster for Clyde.”

“O.L.D.?”

“Yeah. Ohio Liquid Disposal. But they had a class action suit. We won. I settled for 324 dollars. I lived on the edge...of the, how far they went, you know. And the people that lived right there got thousands and thousands, but that never, never comes up no more. But ya can’t do nothin’ about it anyway ‘cause the lawsuit’s over, it’s settled, and the people agreed to it.”

Don was referring to a facility located just north of Clyde in Vickery, Ohio, that currently

operates four Class I hazardous underground injection wells used to dispose of liquid industrial wastes and hazardous wastes generated off site by other companies. Three other wells at the facility have been plugged and abandoned. The injection well, formerly known as the Ohio Liquid Disposal (“O.L.D.”) site, was at the center of a class action lawsuit first filed in 1983. In what the court described as a multi-faceted complaint, the most salient of which alleged that the dump site operators were involved in the negligent “transportation, receipt, storage, and disposal of toxic, poisonous, hazardous, and disease-causing chemical substances.”<sup>1</sup> The Ohio Supreme Court affirmed both the court of appeals and trial courts’ decision that plaintiff-appellees be certified as a class, stating that “a class of people within five miles of the Vickery, Ohio facility suffered serious and debilitating emotional distress due to the operation of the facility.”<sup>2</sup> While official court records are not extant, a settlement was possibly reached as residents recall being compensated based on their proximity to the site.

I resumed my discussion with Don by asking him, “How has the community changed over time?”

“We didn’t have crime. We’ve had a few murders. But I was born here in ’34. Uh, high school was great. Well, uh, I never spoke to a black person till I joined the Navy when I was 18 years old because I never, I never saw one to talk to. And now, they’re not trouble or nothin’, but we got blacks in town now. But Whirlpool, when I graduated in ’52, I worked at Whirlpool for six months. There was two women in that plant, and no blacks. But now, you know, they hire everybody. But the town, it’s not much bigger. When I was 18 years old, I knew 95% of the people in this town. Now, I don’t know 30% of the people of this town, but when I grew up, I knew ‘em all. We got a very good educational system. I think teachers are overpaid—we got some teachers makin’ over \$70,000 a year. And that’s sort of a hang up for the people in this town. That’s why we failed five bond issues. But overall, uh, a lot less businesses. We used to have two pharmacies uptown. Now we got one down here on the corner and Drug Mart. We used to have a gas station on every corner, but they’re all gone. Overall I think the people are very friendly. Overall this town can’t be beat. If you wanna work, you’re gonna have a job. If you wanna work in this town, there’s work. And I’ve never been out of work in my whole life. All my friends and everybody, they love Clyde. They love Clyde. I was in the Navy four years during the Korean War and I couldn’t wait

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<sup>1</sup> *Warner v. Waste Mgmt.*, 36 Ohio St. 3d 91; 1988

<sup>2</sup> *Ibid.*:2.

to get back to Clyde. I couldn't wait to get back to Clyde. And I knew I would never move. I'd starve to death before I'd ever move outta Clyde. And it is still, it's a great community. But we got everything because of Whirlpool. I mean the city income tax—what a wealthy town. I mean we probably had all the first wheelchair ramps on all the sidewalks in town before anybody ever saw them. I mean it's just that, ya know, it's the town of Whirlpool.

If there was somebody in dire need that ever needed somethin', this town comes out by the hundreds. By the hundreds. We just had a fundraiser three or four weeks ago. The boy, he's 47, he got Lou Gehrig's Disease. Had a chicken barbecue, 1,500 chickens. They sold 'em out in a couple weeks.

“Okay. Does there seem to be a lot of those going on pretty regularly in the community?”

“No, but if they do have something, it's great. The people turn out by the ton.

I don't know why God let's 'em get sick. That little Brown girl. She was the sweetest little girl and she went through hell. And I have to say, I believe in God, but I just can't believe that he would make a little girl go through what she went through. I just, well, I really think it's just an act of God. That's my own personal thinking. I don't believe in God 100%, but I do believe in God. I don't know. Cancer's an ugly thing. Death—that's an ugly thing. My dad went from 210 pounds to 80 pounds. And that's another thing—my dad didn't swear, my dad didn't smoke, and I never heard him and my mother argue in their whole life, and he went through hell for two years. And that's why sometimes...where's God at when you need him, ya know? But when I was a little kid, I'll tell you this. When I was seven years old, my grandparents owned a farm west of here. I'm on a Sunday morning with my dad and my brother walking in the woods looking for mushrooms, now why this, but I said to God, 'I wish I would find a box of ammunition.' And why would I bring that up? I'm a hunter and a fisherman, but why would I bring it up? 'God, I wish I could find a box.' And we went through a fence and I stepped over, and there was a box of ammunition. Now ain't that weird?”

“Uh-huh.”

“I mean that's really weird. But then that makes ya think. Jeeze, you know. Ya just wonder why would there be a box of ammunition on a 180-acre farm out in the middle of the woods that somebody dropped or somethin' climbin' through the fence. Unbelievable. Yeah, but then it made me think, wow, God's really there. But then when God, when my dad was sick, God didn't help me. You know? He didn't help me. Well, I can understand these people but...I wish these people

would be happy, but I just wish they were suin' Whirlpool to find out the cause, but with no money involved.”

“Okay,” I nodded.

“When it’s ever settled, it’ll just go back to little old Clyde. I mean, overall about the town and everything you probably won't find out any more than what I told ya. The people that’ve lived here, have been here...their family have been here for over a hundred years. We're all happy and doing good.” He paused. “Go ahead and eat. This thing’ll be cold.” My oatmeal looked to have congealed into a solid mass.

“Thank you.”

Don got up to rejoin his friends. He pulled up a stool at the head of their table and talked quietly with them. From across the room, a few of them glared at me, while the owner of the diner sat near them holding his head low. I did not feel welcome.

I questioned my project on different levels. ‘Who am *I* to do this? To enter this little town as a stranger and ask its residents for so much?’ I reflected on the interview: the apple orchards, O.L.D., the class of ’53, genetics as the root of illness. I felt uncertain about everything I thought I knew. As the story I expected to tell about the effects of living within a contaminated community crumbled before me, a little boy interrupted my train of thought. Unbeknownst to his mother, he sat across from me at my table like Don had before him. He began playfully making gestures to me in the air with his hands until his mother discovered his whereabouts and led him away. Although I did not know this at the time, it would be my first of many interactions with little kids approaching me as I was out and about in the community. In retrospect, I wondered if I was perhaps noticing the children and unknowingly initiating eye contact with them, thereby inviting them to approach me. There were a few occasions wherein my eyes would be on my computer or notebook, and a child would sit by me without any prior acknowledgment. Each instance seemed like an act of friendship, but it was also as if to say, “I’m here. I’m a part of this story. Don’t forget me.”

## CHAPTER 1

### INTRODUCTION

My hometown of Mantua, Ohio, features rolling, uneven farmland bordering the Cuyahoga River, which has a southwesterly course that branches off into numerous streams and tributaries. I grew up on the northwest part of town tromping around the woods with my brother while he dug out old bottle dumps, walking the fields in search of arrowheads, and picking blackberries. As is the likely experience of many who spend their childhoods predominantly outdoors in rural locations, there were treasures to be found on our land, and our early lives were organized around finding these treasures.

When driving to Clyde, Ohio, for the first time to begin my field research, I experienced a sense of the familiar. Like my hometown, Clyde is an idyllic, rural community. Residents in present-day Clyde have a long history of family ties to the town. It is an ‘everybody knows everybody’ type of place. People will describe the many selling points of small town living—Clyde provides “safety”,<sup>3</sup> a peaceful lifestyle, beautiful nature, and is a place where one would want to raise children. Many have fond memories of growing up in the old-fashioned, small town atmosphere of Clyde, and will share stories about mushroom hunting, duck hunting, fishing, and swimming. While each has memories unique to their experience, there is a commonality about them that evokes nostalgia for a simple way of living. In spite of appearances, however, Clyde can no longer be viewed as the town it may have once been. Recently classified as a cancer cluster community, approximately 40 children in Clyde have been diagnosed with or died from cancer since the mid-1990s, most likely as a result of exposure to environmental toxins.

Upon approaching Ohio towns like these, one passes fields of corn, soybean crops, and occasional herds of dairy cattle. Yet, attentive passersby can now also catch a glimpse of billboards advertising the services of cancer centers, randomly placed indicators of portentous significance at odds with the picturesque scenery. Intrusions now exist within these rustic settings, as can be seen in the town of Clyde where a Cleveland Clinic Cancer Center is situated across from the Whirlpool factory. Such imagery has now, unfortunately, been absorbed into the contemporary landscape of these communities.

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<sup>3</sup> As was reflected in interviews and in a more generalized perception of the town, references to Clyde as a “safe” place to live were implicitly conflated with, and sometimes overtly expressed, as being related to race and crime.

The conflicting evolution that exists within Clyde and other communities is not unique and should be considered within the context of development that is common to most industrialized states. The Industrial Revolution of the 18th and 19th centuries involved technological, socioeconomic, and cultural changes that transformed a once agrarian culture into a modern, streamlined society. After the conclusion of the Civil War, Ohio evolved into a heavily industrialized state largely due to the natural attributes of the Great Lakes and rivers systems, which supported import and export shipping for iron ore and other products, and an infrastructure of railroads that supported the transport of goods and people throughout the state.<sup>4</sup> The population expansion paralleled rapid industrialization, as the appeal of job opportunities attracted hundreds of thousands of immigrants.<sup>5</sup>

Many early factories were developed to meet the demands of agriculture, producing farm machinery or processing farm products. As the need for machinery increased, Ohio's industrial importance to American economic growth came to be exemplified by companies such as the Hopewell Furnace company, an iron manufacturing facility established in 1804 and located near Youngstown, Ohio, and others. The development of these companies established northeast Ohio as the primary region for steel production by the end of the 19th century.<sup>6</sup> Development of the steel industry advanced with the discovery of coal deposits, leading to Ohio's ranking as the second largest steel producing state after Pennsylvania. Other natural resources also contributed to the state's industrial growth, including natural gas, oil, salt, iron ore, timber, and limestone. In addition, the Dow Chemical Company was also established in Cleveland in 1895<sup>7</sup> and, until their recently planned merge with DuPont takes effect,<sup>8</sup> remains the world's second largest chemical manufacturer. The impact of Ohio and other states' industrial evolution is evident in the environmental consequences that present in towns such as Clyde.

This dissertation explores two sociological aspects of disease clusters: 1) What are the processes related to community discovery of illness and remediation, and 2) How do impacted residents manage the practical and psychosocial impacts of cancer on their families and in the community? A central focus of this dissertation is the role of risk in the creation of toxic hazards,

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<sup>4</sup> "Cleveland, Ohio." Ohio History Central. Retrieved January 4, 2016. ([http://www.ohiohistorycentral.org/w/Cleveland,\\_Ohio](http://www.ohiohistorycentral.org/w/Cleveland,_Ohio))

<sup>5</sup> Cayton, Andrew R. L. 2012. *Ohio: The History of a People*. Columbus, OH: Ohio State University Press.

<sup>6</sup> "Cleveland, Ohio." Ohio History Central. Retrieved January 4, 2016. ([http://www.ohiohistorycentral.org/w/Cleveland,\\_Ohio](http://www.ohiohistorycentral.org/w/Cleveland,_Ohio))

<sup>7</sup> "Dow Chemical Company." Ohio History Central. Retrieved January 4, 2016. ([http://www.ohiohistorycentral.org/w/Dow\\_Chemical\\_Company](http://www.ohiohistorycentral.org/w/Dow_Chemical_Company))

<sup>8</sup> "DuPont, Dow Chemical Agree to Merge, Then Break Up Into Three Companies." *Wall Street Journal*. Retrieved January 4, 2016. (<http://www.wsj.com/articles/dupont-dow-chemical-agree-to-merge-1449834739>).

the management of risk, how risks are perceived, and how they are experienced. The theoretical underpinnings of my research are based broadly on political economy of health and social constructions of risk, illness, and identity.

German sociologist Ulrich Beck offers a useful framework for understanding the creation and management of hazards today. In his theory of the “risk society,” Beck argues that contemporary society must deal with new types of risks that are self-created as a result of industrialization processes over which we have little control.<sup>9</sup> They are distinguished from risks in what Beck terms “first modernity”, an earlier phase of industrialized society during which disasters were predominantly naturally occurring and perceived of as fateful events. These disasters were largely managed by a bureaucratic state which assumed responsibility for structuring people’s lives within the industrialized world. In turn, loyalty was given by the populace to the emerging institutions of modernity. Beck asserts that, by the latter half of the 20<sup>th</sup> century, the existing paradigm was challenged by the complexity of opportunity and risk associated with the spread of industrialization, resulting in risks and hazards unparalleled in human history. These “manufactured risks”, which have the added detriment of having little historical reference,<sup>10</sup> have emerged from advancements in science and technology. Beck argues that, with technological and social changes since the 1960s, we are entering a “second modernity” characterized by the increasing occupation with debating, preventing, and managing risks that modern society has itself produced.

According to Beck, risks are no longer confined by geographical or temporal boundaries, as they cross national lines and affect future generations. Issues such as climate change, the economy, terrorism, and nuclear threat illustrate the global commonality of risk. While risks in first modernity were managed (and manageable) by traditional institutions, such as the church, family, and the state, contemporary risk management is primarily under the jurisdiction of science, technology, and a market-driven economy. While scientific and industrial development plays a significant role in the creation of risks and hazards in the risk society, science has also become the primary institution for identifying and analyzing risks, and it operates with little transparency and poor accountability. Risk societies rely upon a more complex system of production that requires specialization for management, policy development, and overall

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<sup>9</sup> Beck, Ulrich. 1992. *Risk Society: Towards a New Modernity*. London: Sage.

<sup>10</sup> Giddens, Anthony. 1999. “Risk and Responsibility.” *Modern Law Review* 62(1):4.



understanding and interpretation. The necessity for such specialized expertise leads to both purposeful and unintentional barriers to public access in acquiring environmental hazard information.

Because the production of risks is difficult to attach to an identifiable actor or institution, actors or institutions are not held accountable for the hazards generated by the risk society. Beck refers to this as “organized irresponsibility.”<sup>11</sup> Furthermore, it is increasingly unlikely that individuals harmed by the generated dangers can receive recourse due to the convoluted nature of source and accountability, and the impossibility of calculating risk. Beck argues that a culture of fear emerges from the paradoxical fact that the institutions designed to control risk actually produce uncontrollability. He notes that “victims of hazards today are imperceptibly abandoned to the judgments, mistakes, and controversies of experts, and subjected to terrible psychological stresses.”<sup>12</sup> What is lost in the midst of the emphasis on scientific talk are the personal and social aspects of impacted people’s everyday lives.

In a risk society, the production and distribution of risks may become as important to quality of life as the production and distribution of wealth.<sup>13</sup> Beck argues that in the risk society, the concern is no longer with the distribution of “goods” but with the distribution of “bads”—namely, the realization of untoward risks. While acknowledging the differential distribution of risks, Beck argues that many risks do not respect class boundaries, putting everyone equally at risk. In what he refers to as the ‘boomerang effect,’ even those who produced or once profited from certain risks will be affected by them, thus ultimately eliminating class inequalities. This dissolution of social class means that social actors are “individualized,” existing on their own without the collective identity of social class. Individualism, what Beck argues is a key trait of second modernity, is partly the consequence of the inability of state institutions to manage modern risks. The benefits of having access to a wider range of selection and freedom is confounded by detachment from previously reliable structures, including the nuclear family.<sup>14</sup>

It is not that Beck’s theory rests with the conception of the world as an unsafe place in which to live. In the risk society, disproportionate amounts of risks lead to feelings of anxiety, to concern for safety and well-being.<sup>15</sup> The powerful production of risks acts as a catalyst in

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<sup>11</sup> Ibid:6.

<sup>12</sup> Ibid:27

<sup>13</sup> Beck, Ulrich. 1992. *Risk Society: Towards a New Modernity*. London: Sage.

<sup>14</sup> Beck and Beck-Gernsheim. 2002. *Individualization*. London: Sage.

<sup>15</sup> Beck, Ulrich. 1992. *Risk Society: Towards a New Modernity*. London: Sage.

changing public perceptions and reasons to act in certain ways. In this equation, risk and individualization become pivotal in the process of cultural change itself. Beck asserts that one of the outcomes of the increase in individualization is that politics have expanded beyond state driven bureaucracy to now incorporate the politicization of individuals' everyday lives, thus redefining politics as being both institutionalized and non-institutionalized.

Drawing from Giddens' concept of 'reflexive modernization,'<sup>16</sup> Beck argues that in order for societies to evolve, modernization must become "reflexive." Giddens defines reflexivity as the fact that "social practices are constantly examined and reformed in the light of incoming information about those very practices."<sup>17</sup> From the perspective of risk theory, it is a process whereby modernity focuses on the process of modernization itself.<sup>18</sup> Reflexivity is operating today, for example, within the critique of science. Science's once unassailably authoritative role is increasingly being challenged by environmental movements and the general public. Like Giddens,<sup>19</sup> Beck supports the idea that individuals shape social life through the process of reflexivity. Social actors—independent of institutions and empowered by knowledge—also challenge the status quo and through social movements alter scientific and social institutions—a change Beck refers to as "subpolitics" or the "self-organization of politics."<sup>20</sup> Subpolitics, which involves forms of active citizenship, such as grassroots community action, has positive implications for both the environment and social justice, and its consequences may be as significant as traditional politics.<sup>21</sup> For Beck, power is thus centered on the origin and diffusion of knowledge about risks.<sup>22</sup>

Risk society theory, however, does not quite capture the possibility of risk as reinforcing as well as undermining social control,<sup>23</sup> and how the threat of unknown risks can be used to push people towards particular agendas. As will be seen in this dissertation, risks such as job loss are

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<sup>16</sup> Giddens, Anthony. 1990. *The Consequences of Modernity*. Stanford: Stanford University Press.

<sup>17</sup> Ibid:38.

<sup>18</sup> Beck, Ulrich, Wolfgang Bonss, and Christoph Lau. 2003. "The Theory of Reflexive Modernization: Problematic, Hypotheses, and Research Programme." *Theory, Culture, & Society* 20(2):1-33.

<sup>19</sup> Giddens, Anthony. 1991. *Modernity and Self-Identity: Self and Society in the Late Modern Age*. Stanford: Stanford University Press.

<sup>20</sup> Ibid. See also Beck, Ulrich. 1996. *The Reinvention of Politics: Rethinking Modernity in the Global Social Order*. Cambridge, UK: Polity Press.

<sup>21</sup> Beck, Ulrich. 1994. "The Reinvention of Politics: Towards a Theory of Reflexive Modernization.." Pp. 1-55 in *Reflexive Modernization: Politics, Tradition and Aesthetics in the Modern Social Order*, edited by U. Beck, A. Giddens, and S. Lash. Stanford, CA: Stanford University Press. See also Beck, Ulrich. 1992. *Risk Society: Towards a New Modernity*. London: Sage.

<sup>22</sup> Beck, Ulrich. 1992. *Risk Society: Towards a New Modernity*. London: Sage.

<sup>23</sup> Mython, Gabe. 2005. "From 'Goods' to 'Bads'? Revisiting the Political Economy of Risk." *Sociological Research Online* 10 (3). Retrieved February 5, 2015 (<http://www.socresonline.org.uk/10/3/mythen.html>).

equally powerful means through which uneven power relationships are maintained. Furthermore, it will be shown that social and political responses to toxic risk in Clyde have been and will likely continue to be influenced by social habits and cultural circumstances.<sup>24</sup> Class and gender inequalities, as well as age, especially surface throughout the dissertation with regard to differential experiences related to risk—specifically, who it impacts and how it is mediated. Rurality and length of residency are also explored as mediating factors to the experience of risk, the response to risk, and community identity.

A related critique of Beck's claims is that the power of individualization for impacting social change is over-reaching. While change is evident in existing social structures, it can be argued that family, work, and class have not been entirely redefined by an overriding process of individualization. As will be shown later in this dissertation, the reverse of this argument was true in the case of affected families in Clyde, particularly as related to the nuclear family.

Inherent in critiques of Beck is the ongoing sociological debate regarding the extent to which social phenomena is determined by either social structure or agency.<sup>25</sup> In the case of Clyde, risk theory is arguably inadequate as it relates to collective community response to the cancer cluster. Literature that theorizes individualization of risk as a technique of governance may broaden understanding about this issue. From this perspective, which is informed by poststructuralist theory, individualization is understood as a feature of personal responsibility and as part of the larger ideology of neoliberal governance, wherein citizens must rely on themselves as self-governing agents as a consequence of weakened traditional institutions intended to safeguard public welfare. Within this framework individuals manage their personal exposure to risk through monitoring and changing their personal behavior.<sup>26</sup> The market has been identified as a predominant medium through which individuals manage their own exposure to risk.<sup>27</sup> This will be shown in the analysis of narratives of Clyde residents and in their consumer choice practices.

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<sup>24</sup> Alaszewski, A. 2005. "Risk Communication: Identifying the Importance of Social Context." *Health, Risk and Society* 7:101-105.

<sup>25</sup> Social structure refers to the relatively enduring features of society which establish the social arrangement in society. Agency refers to the capacity of individuals to act independently and to make their own free choices. See Bottomore, T. and R. Nisbet (eds.). 1978. *A History of Sociological Analysis*. London: Heinemann.

<sup>26</sup> Dean, M. 1999. *Governmentality: Power and Rule in Modern Society*. Thousand Oaks, CA: Sage. See also O'Malley, Pat. 2004. *Risk, Uncertainty and Government*. London:

<sup>27</sup> Beck, Ulrich. 2006. "Living in the World Risk Society." *Economy and Society*. 35(3):329-345.

### *Toxic Exposure and the Risk Society*

Characteristic of risks in the risk society, toxins are a by-product of industrialization, and they differ from risks of the past through the globally distributed threat that endangers all forms of life. Toxins are largely imperceptible. They are not confined by geographical or temporal boundaries. They defy generational limits, leaving future generations affected in unknowable ways. They induce often irreversible harm, and the scope of damage that their unforeseen consequences deliver is widespread and often removed from its initial source of manufacture.

Agriculture is the leading source of pollution of rivers and streams,<sup>28</sup> and some of the most severe water pollution problems occur in the industrialized Northeast and Midwest where agricultural wastes filter into waterways and enter the food chain. Many of these include fertilizers and pesticides which are endocrine disruptors that have been banned in the European Union.<sup>29</sup> More than 90 percent of the corn, soy, wheat, and potatoes grown in the U.S. are treated with pesticides.<sup>30</sup> In addition to their presence in food, pesticides bind to soil particles and enter the air as dust, enter groundwater, streams, and creeks, evaporate, fall in rain, and are detectable in fog.<sup>31</sup> Many pesticides do not break down for years,<sup>32</sup> so that, in spite of the banning of PCBs and the pesticides DDT and chlordane, environmental traces of these carcinogens continue to be present in the environment.<sup>33</sup> DDT, for example, continues to be found in food crops, migratory birds, and freshwater fish.<sup>34</sup> Prior to the banning of DDT (dichloro diphenyl trichloroethane) for agricultural use in 1972 and PCBs (polychlorinated biphenyls) in 1979, researchers had already identified a link between these pesticides and breast cancer in rodents.

Another insidious manner in which pollutants are distributed is through their release into air in warmer climates where they evaporate and are carried to cooler areas in a process referred to as global distillation. Although the exact origins of these toxins remain unknown, in part due

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<sup>28</sup> Environmental Protection Agency. 2002. "Rivers and Streams," in *National Water Quality Inventory: Report 2002*. EPA.

<sup>29</sup> Ackerman, Frank. 2007. "The Economics of Atrazine." *International Journal of Occupational and Environmental Health* 13:441-449.

<sup>30</sup> U.S. Department of Agriculture Economic Research Service. "Production Practices for Major Crops in U.S. Agriculture." Economic Research Service/USDA. Retrieved October 10, 2015. (<http://ers.usda.gov/Data-products/organic-production.aspx>)

<sup>31</sup> Steingraber, Sandra. 2010. *Living Downstream: An Ecologist's Personal Investigation of Cancer and the Environment*. Cambridge, MA: Da Capo Press.

<sup>32</sup> Raloff, J. 1996. "The Pesticide Shuffle." *Science News* 149:174-175.

<sup>33</sup> Steingraber, Sandra. 2010. *Living Downstream: An Ecologist's Personal Investigation of Cancer and the Environment*. Cambridge, MA: Da Capo Press.

<sup>34</sup> Ibid; Hovinga, Mary E., Maryfran Sowers, and Harold E.B. Humphrey. 1993. "Environmental Exposure and Lifestyle Predictors of Lead, Cadmium, PCB, and DDT Levels in Great Lakes Fish Eaters." *Archives of Environmental Health* 48:98-104.

to the magnitude of missing data on pesticide exports,<sup>35</sup> studies have found concentrations of chemicals such as DDT and PCBs in trees, leaves, fish, and soil in geographic locations thousands of miles from locations where the chemical was originally used or manufactured,<sup>36</sup> reinforcing the interconnectedness of both the global ecosystem and global social system.

Like pesticides, industrial chemicals, including heavy metals such as mercury and zinc, filter into ground and surface waters. Metal degreasers and dry-cleaning fluids, which have been linked to cancers in humans, are common contaminants of glacial aquifers.<sup>37</sup> Dioxins and dioxin-like compounds, which are frequently the by-products of industrial processes, have been linked to diabetes,<sup>38</sup> reproductive and developmental problems, damage to the immune system, interference with hormones, and cancer.<sup>39</sup> Additionally, over half of the toxins emitted by industries are released into air.<sup>40</sup> The 1990 Clean Air Act requires the EPA to set standards for permissible levels of air pollutants.<sup>41</sup> Yet, despite progress in improving air quality, recent data from the World Health Organization shows that many U.S. cities and cities across the world fail to meet air pollution guidelines.<sup>42</sup> Toxic and hazardous wastes that pose a major threat to health and the environment to this day continue to be frequently disposed of in illegal, insecure, and unsafe ways.<sup>43</sup> Ominously, toxic and hazardous wastes can also harm communities far removed from the original toxic waste sites and/or the chemical industries that produce or use them.<sup>44</sup>

There exist within Ohio other disease cluster communities. Located in central Ohio, the Village of Wellington is another one of five disease clusters in the state. In the mid-1990s, the Ohio EPA began receiving complaints from Wellington residents regarding dust fallout and

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<sup>35</sup> Raloff, J. 1996. "The Pesticide Shuffle." *Science News* 149:174-175.

<sup>36</sup> Simonich, S.L. and R.A. Hites. 1995. "Global Distribution of Persistent Organochlorine Compounds." *Science* 269:1851-1854.

<sup>37</sup> Grand River Conservation Authority. 2006. "Studies Take a Look at Groundwater Quality." Watershed Report. Retrieved October 9, 2015. ([www.grandriver.ca](http://www.grandriver.ca))

<sup>38</sup> Porta, M. 2006. "Persistent Organic Pollutants and the Burden of Diabetes." *The Lancet* 368:558-559.

<sup>39</sup> World Health Organization. 2010. *Environment and Health Risks: A Review of the Influence and Effects of Social Inequalities*. WHO.

<sup>40</sup> Steingraber, Sandra. 2010. *Living Downstream: An Ecologist's Personal Investigation of Cancer and the Environment*. Cambridge, MA: Da Capo Press.

<sup>41</sup> Environmental Protection Agency. 2009. *Air Quality Index: A Guide to Air Quality and Your Health*. Research Triangle Park, NC: EPA.

<sup>42</sup> World Health Organization. 2014. "WHO's Ambient Air Pollution Database-Update 2014." Retrieved October 8, 2015. ([http://www.who.int/phe/health\\_topics/outdoorair/databases/cities/en/](http://www.who.int/phe/health_topics/outdoorair/databases/cities/en/))

<sup>43</sup> Schlanger, Zoe. 2015. "EPA Causes Massive Spill of Mining Waste Water in Colorado, Turns Animas River Bright Orange." *Newsweek*. Retrieved October 9, 2015. (<http://www.newsweek.com/epa-causes-massive-colorado-spill-1-million-gallons-mining-waste-turns-river-361019>)

<sup>44</sup> Environmental Protection Agency. 1983. "Joint Federal/State Action Taken to Relocate Times Beach Residents" Retrieved April 2, 2012 (<http://www.epa.gov/aboutepa/history/topics/times/02.html>).

odors from the Sterling Foundry, a facility that produced gray and ductile iron castings, primarily for heavy industry.<sup>45</sup> Shortly after these complaints were made, Wellington residents began to voice concerns about environmental toxins and the high rates of illness within their community. A 1998 study by the Ohio Department of Health and the Lorain County Health Department, which used data from the National Health Interview Survey, identified that residents there were 3.7 times more likely to develop Multiple Sclerosis (MS) than the rest of the country. Wellington residents have also expressed concerns about the occurrences of cancer, fibromyalgia, and lupus within their community. In 2003, a resident petitioned the Agency for Toxic Substances and Disease Registry (ATSDR) to conduct a public health assessment. Although environmental contaminants and local industries were implicated,<sup>46</sup> experts were unable to pinpoint the exact cause of the higher rates of disease within the community. No additional sampling was recommended by ATSDR, in part because of the closing of the local facilities in question.

In the late 1990s in Marion County, Ohio, residents began questioning the high cancer rates among graduates of the River Valley schools. The Ohio EPA discovered that the high school and middle school were built on a former U.S. army waste dump where students could have been exposed to more than 75 hazardous contaminants. After families fought to close the schools, the district relocated the schools three miles away. However, the state health department ended the investigation of 83 leukemia cases after five years without determining a cause because of a lack of direct evidence that the chemicals caused the cancer.<sup>47</sup> Marysville, Ohio, is the location of another leukemia cluster, the cause of which also remains unknown. It can be argued that the assortment of disease clusters in Ohio, as well as in other industrialized states, are markers of a perceptible change in the identity of small town living.

### *Overview of the Dissertation*

This dissertation focuses on community and institutional response to residential toxic exposure in the company town of Clyde, Ohio, where risk and awareness of risk have penetrated the dialog of everyday life. Using a historical and ethnographic approach, I examine these topics through the analysis of impacted residents' narratives. The theoretical underpinnings of this research are

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<sup>45</sup> Agency for Toxic Substances and Disease Registry. 2005. "Health Consultation: Village of Wellington." Retrieved October 15<sup>th</sup>, 2012. ([www.atsdr.cdc.gov/hac/pha/VillageofWellington031705OH/VillageofWellington031705-OH.pdf](http://www.atsdr.cdc.gov/hac/pha/VillageofWellington031705OH/VillageofWellington031705-OH.pdf).)

<sup>46</sup> Ibid.

<sup>47</sup> Barry, Ashleigh. 2013. "Return to River Valley: Some Families Still Believe School Grounds Led to Cancer." *10TV.com*. Retrieved January 4, 2015. (<http://www.10tv.com/content/stories/2013/05/13/marion-return-to-river-valley-cancer-concerns.html>)

based on the political economy of health and social constructions of risk, illness, and identity. Broadly speaking, this research advances the understanding of community inaction and the complexities surrounding disease cluster communities.

I begin this dissertation by briefly establishing the “eco-historical” context<sup>48</sup> of Clyde and Green-Springs, Ohio. The second chapter outlines the events that led to the discovery of cancer and the discovery of contamination in this area, as well as the involvement of local, state, and federal agencies, lawyers, and scientists. Through the framework of risk theory and the individualization of risk, the remaining three chapters analyze issues relevant to the cancer cluster. All three analytical chapters draw on the same broad theoretical contributions described above, each re-articulating these issues in more specific ways with reference to my field research. Each chapter lays the groundwork for my theoretical contribution, which I refer to as “risk community adaptation theory” and discuss in more detail in the concluding chapter.

In the first analytical chapter (chapter three), I focus on the expansion of the chemical industry in the U.S., chemical regulation, occupational risk with regard to toxins, as well as maternal and child vulnerability. I examine the scientific uncertainty of risk assessment in disease clusters, and the increasing emphasis on self-protection by public health organizations, consumerism, and in the media, which often targets women and mothers. This chapter concludes with an exploration of potential strategies in risk governance of uncertainty.

In chapter four, I show how competing interpretations of contamination and health risk perpetuate contention within the community, and I argue that important cultural influences such as economy and community identity anchor interpretations of risk. Through the framework of risk theory, I illustrate the imposition of risk in residents’ everyday lives and the politics of knowledge at the community level. I examine the individualization of risk as it presents within the narratives of residents, and its consequences for determining accountability. Both chapters three and four explore the impact of risk on institutional trust.

In chapter five, I give attention to the connection between risk and security by building upon the literature related to causes and consequences of psychological stresses that result from the presence of multiple cancers of undetermined causation in the town. Drawing on in-depth interviews with 30 residents, this chapter explores how the notion of personal responsibility for risk protection is internalized by the parents of affected children. I argue that, within this cultural

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<sup>48</sup>Edelstein, Michael R. 2004. *Contaminated Communities: Coping with Residential Toxic Exposure*. Boulder, CO: Westview.

context wherein there is an impossible imperative for self-protection, residents experience serious psychosocial and practical conflicts as they adapt to the impact of cancer on their families and in their community.

Following the analytical component of the dissertation is a conclusion section that summarizes the chapters, outlines the main findings, and ties together findings across all of the chapters. In this last section, I offer a theoretical framework to describe a process through which communities threatened by catastrophe and risk change to accommodate risk, rather than substantially alter it. This is presented as an outcome of inadequate responses to initial encounters with risk, and is characterized by heightened public risk consciousness. It involves the interplay between macro and micro-level discourses of risk that legitimizes risk through individualization and normalization. I attend to questions surrounding the self-organization of politics in Clyde and implications for social justice.



## CHAPTER 2

### A Brief History of Clyde and Green-Springs, Ohio

Like much of central and northwest Ohio, land surrounding the area of Clyde and the adjacent portions of Green Creek Township and eastern Sandusky County is primarily agricultural. Seventy-six percent of the total land area in Sandusky County is farmed with major crops, including soybeans, corn, and wheat, as well as a wide variety of specialty crops.<sup>49</sup> These largely rural areas are situated on a broad, mostly level, glacial lake plain approximately 15 miles south of Lake Erie.<sup>50</sup>

Within archives about this area, there are two stories of its early settlers discovering springs of water that became highly valued for their healing properties. In the late nineteenth century, Thomas Dewey, the owner of two farms approximately one mile west of Clyde, was “fortunate enough to strike a mineral fountain spring [...], the water possessing great healing and medicinal properties. It is highly valued by the people of this vicinity, who resort to it in large numbers to drink of and secure supplies of this valued water.”<sup>51</sup> Green Springs, the town adjacent to Clyde, is known for having the largest natural sulfur spring in the world. It acquired its name from the emerald rich color of the water produced by the sulfur and other minerals contained within it. The overflow runs into Green Creek and eventually into Sandusky Bay and Lake Erie. In the early 19th century, the first water-powered saw mill and grist mills were established there, which attracted many new settlers to the area.<sup>52</sup> The springs were reputed to possess highly curative medicinal properties, and people from many parts of Ohio came to be near the water. As part of a national trend of the time, the mineral water was also bottled and sold throughout the country for its medicinal qualities.<sup>53</sup> This contributed to the attraction of this area as being both wholesome and idyllic, and was integral to its bucolic identity.

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<sup>49</sup> Ohio State University Extension Service. 2011. Online data for Sandusky County. <http://sandusky.osu.ed/topics/agriculture-and-naturalresources>. June, 2011.

<sup>50</sup> ODH. 2011. Evaluation of Ohio EPA Soil Sampling in Support of the Clyde and Eastern Sandusky County Childhood Cancer Investigation. Prepared by Health Assessment Section, Ohio Department of Health. July 28, 2011.

<sup>51</sup> Meek, Basil. 1909. *Twentieth Century History of Sandusky County, Ohio and Representative Citizens*. Richmond-Arnold Publishing Co.: Chicago, IL.

<sup>52</sup> Ibid.

<sup>53</sup> Dolly Todd Madison Chapter. 1915. *Ohio Early State and Local History*. Spahr & Glenn printers: Columbus, OH.

Clyde began its transition into a more industrialized town in the late nineteenth century with the emergence of new manufacturing businesses. In the 1890s, Clyde—like the nearby cities of Cleveland and Toledo—joined the automobile revolution. It hosted a brass-era company until the company was bought out by General Motors and became defunct in 1912.<sup>54</sup> Clyde Cutlery was established in 1904, and at one time employed over 200 workers.<sup>55</sup> The company remained in business until a fire destroyed the manufacturing division in 1970. Other early industries included The Hughes Granite & Marble Company and Clyde's Silver Fleece Kraut Company. Prior to 1945, Clyde Porcelain Steel Corporation was the village's biggest industry. Between 800 and 1,000 people worked at the plant, which manufactured end connectors for tanks and spark arresters for the government.<sup>56</sup> It burned in 1945 (see Figure 1 in Appendix A), and was then rebuilt.

#### *The Establishment of Whirlpool Corporation in Clyde*

In 1952, the Whirlpool manufacturing company purchased the 250,000 square ft. facility from Clyde Porcelain Steel. Two years later, Whirlpool purchased an adjacent 170,000 square ft. facility from Bendix Corporation, a washing machine maker. With gradual expansions the factory slowly grew to its current size, and is today a 240 acre campus in Clyde. The building itself is a sprawling facility of 2.4 million square ft., the equivalent of 55 football fields. Whirlpool Corporation's Clyde Division is the largest automatic washing machine plant in the world.<sup>57</sup>

Sandusky County Economic Development Corporation (SCEDC) has assisted this company in various ways, including facilitating tax incentives and, more specifically, through the recruitment of potential suppliers to this community, with the development of a skilled and available workforce, and through facilitating relationships with state and local governments.<sup>58</sup>

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<sup>54</sup> "From Bicycles to Automobiles." *Sandusky County Scrapbook*. Last updated 23 August 2001. Accessed 26 May 2013. <http://www.sandusky-county-scrapbook.net/Elmore/Beginning.htm>.

<sup>55</sup> "Clyde Cutlery." *Thaddeus B. Hurd Digital Archive*. Clyde Public Library, 29 March 2011. Web. Accessed 21 May 2015. <http://www.ohiomemory.org/cdm/ref/collection/p15005coll19/id/1470>.

<sup>56</sup> "Clyde Porcelain Steel Fire, Clyde, Ohio." 1945. Hale's Portrait Studio, Clyde, Ohio. *Thaddeus B. Hurd Digital Archive*. Clyde Public Library, 21 September 2010. Web. Accessed 21 May 2015.

<http://www.ohiomemory.org/cdm/ref/collection/p15005coll19/id/1024>

<sup>57</sup> SCEDC. 2014. *Sandusky County Economic Development Corporation Success Stories*. SCEDC. 2014. Web. Accessed 21 May 2015. <http://www.sanduskycountyedc.net/index.php?page=our-success-stories>

<sup>58</sup> *Ibid.*

As a result, Whirlpool Corporation has provided economic stability to the town, and changed the identity from a diversely employed community to that of a factory town.

The company has woven itself into the social fabric of the town as well. In 1953, it built a recreational park, Whirlpool Park, in Green-Springs. This family-friendly space was open to relatives and friends of Whirlpool workers, providing a source of entertainment with its pool, basketball court, and playground. It also promoted a sense of exclusivity among Whirlpool workers and their families that, in the words of one resident, “made outsiders want to be a part of it” (see Figures 2 and 3 in Appendix A). For over fifteen years, the communications section of the Industrial Relations Division of Whirlpool printed a widely circulated publication called *Clyde-O-Scope*, the content of which focused on employee and company activities both in plant operations and in recreations. Some residents remember these publications as promoting family values and quality of life within the community (see Figure 4 in Appendix A).

Today, the presence of Whirlpool permeates the town, reinforcing its importance to Clyde’s identity. The company is cited with pride on community web pages, and a local community pub features a “Whirlpool pork sandwich” on its menu. The company employs about 3,000 residents from Clyde, a community of approximately 6,500 people, and the surrounding area.

### *Community Profile*

The city of Clyde has a population of approximately 6,350 residents with a median age of 37.4.<sup>59</sup> The median household income in Clyde in 2013 was \$44, 071, which was slightly less compared with the state median level of approximately \$48,308.<sup>60</sup> Unemployment in 2013 was 5.9%, which was much lower than the Ohio state average of 6.4%. Approximately 89.3% of the population was white, 7.5% Hispanic or Latino, and .5% Asian. The Black population, as well as the “foreign-born” population percentage was significantly below the state average.<sup>61</sup> Additionally, length of residence since moving is above the state average.<sup>62</sup> Ninety-three percent of the population holds a high school degree or higher, which is slightly higher than the state

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<sup>59</sup> U.S. Census Bureau, 2009-2013 5-Year American Community Survey: Clyde, Ohio 2013. Retrieved March 23, 2016.

<sup>60</sup> Ibid.

<sup>61</sup> Ibid.

<sup>62</sup> Ibid.

average of 88.5%; 17.4% holds a bachelor's degree, which is much lower than the state average of 25.2%.<sup>63</sup>

### *Discovering Cancer within the Community*

Residents became aware that something troubling was going on within their community around the year 2006 when increasing numbers of children in Clyde began being diagnosed with cancer. Although there did not seem to be a common denominator among the affected children, parents were beginning to notice the prevalence of cancer diagnoses within their circles of acquaintances and within their own families. They recall that their initial reaction was not extremely dramatic. Rather, they thought it was “odd” that so many children were being diagnosed. It was in 2006 that an eight year old girl named Alexa Brown was diagnosed with medulloblastoma, a brain tumor. Many remember this time as a turning point in which their curiosity and speculation grew. Betty, a 69 year old resident of Clyde, remembers when Alexa became ill:

What really caught my attention was Alexa Brown. We used to go down to the old McDonalds where the [Old Fort Banking Company] is, and we would see the mother, Wendy, there with her son. Then one day she told us she was pregnant again. You know, she was going to have Alexa. I knew Wendy when was pregnant, during her pregnancy, and then she had the baby and brought her in. I don't know the family personally, but we were acquaintances. It really shocked me when I heard that Alexa had cancer. I thought, ‘What?’ you know ‘what’s going on?’ I think that’s what caught me is when Alexa had cancer. Then other kids—young ones—had cancer, passed away, or were in remission. That’s when I started questioning why because it’s such a small town. It kinda blew my mind for a while. I kinda shrugged it off hoping that, you know, it really wasn’t true that all this was going on. But then we heard there were more and more kids. More and more teenagers, young adults.

Alexa’s journey is documented in an online blog kept by her parents. When Alexa began experiencing headaches, blurry and double vision, and dizziness, her parents, Wendy and

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<sup>63</sup> Ibid.

Warren, thought she might be having eye problems and took her to the family doctor. After being unable to perform a straight line walk, the doctor ordered an MRI, which showed a tumor in Alexa's brain. She underwent surgery, and a malignant tumor was removed. Alexa developed delayed onset loss of speech, unsteadiness, and irritability—a syndrome known as cerebellar mutism—and underwent speech, physical, and occupational therapy. She underwent radiation therapy and nine cycles of chemotherapy, but the cancer returned after two years. This time, it was treated with a combination of chemotherapy and stem cell therapy, the harvesting and transplant of which took place in Columbus, Ohio.

At the time of Alexa's diagnosis, residents remember a whirlwind of occurrences of other cases. Five-year-old Chase Berger had a thumb-sized malignant tumor called rhabdomyosarcoma removed from behind his eye in 2006. Tyler Hisey was diagnosed with acute myeloid leukemia (her younger brother would be diagnosed with acute lymphoblastic leukemia in 2008). Kole Keller died of medulloblastoma two days before his sixth birthday in April 2007. Twenty year old Shilah Donnersbach died of Ewing's Sarcoma in December of 2007.

The school nurse was at the forefront of those noticing an increase in the occurrence of several different cancers, especially among elementary-age kids. Knowing that it wasn't typical for a small town to coincidentally have so many children with cancer at the same time, she was one of the first in the community to notify the local health department. In response to the increasing concerns from residents, the Sandusky County Department of Public Health (SCDPH) requested assistance from the Ohio Department of Health (ODH) in determining the incidence of childhood cancer among residents of Clyde City and Green Creek Township. The SCDPH also inquired if the incidence of cancer differed in a statistically significant way from that expected based on national cancer incidence rates.<sup>64</sup> Cancer cases were identified through the Ohio Cancer Incidence Surveillance System (OCISS)<sup>65</sup>. Invasive cancers diagnosed from 1996-2006 were used in the analysis, and additional efforts were made to confirm that the data was as accurate and complete as possible, including contacting hospitals in Sandusky County to identify cancers not yet reported to the OCISS. The incidence of cancer among the study populations was

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<sup>64</sup> ODH. 2007. *Cancer Incidence among Childhood Residents of Clyde City and Green Creek Township, Sandusky County, Ohio, 1996-2006*. Chronic Disease and Behavioral Epidemiology Section and the Ohio Cancer Incidence Surveillance System, Ohio Department of Health and the Sandusky County Department of Public Health. Final Report, April 17, 2007.

<sup>65</sup> All cancers diagnosed among Ohio residents on or after January 1, 1992, with the exception of basal and squamous cell carcinoma of the skin and cervical cancer *in situ*, are required to be reported to OCISS.

compared to national cancer incidence rates from the Surveillance Epidemiology and End Results (SEER) Program of the National Cancer Institute.<sup>66</sup>

The agency's findings, released in the spring of 2007, indicated that a total of 10 invasive cases of cancer were diagnosed from 1996-2006 among childhood residents of Clyde City and Green Creek Township.<sup>67</sup> Males and females were affected equally, with the largest number being diagnosed in the 15-19 years of age group. Brain and central nervous system cancers were the most commonly diagnosed cancers. One case of each of the following cancers was also diagnosed: Ewing's sarcoma (soft tissue), Hodgkin's lymphoma, leukemia, osteosarcoma (bone), rhabdomyosarcoma, and testis. The number of cases observed was about twice the number expected, although this difference was not statistically significant at the 95 percent confidence interval. When expanding the study site to also include Riley, Townsend, and York Townships, however, the four-township region was determined to have a statistically significantly higher number of cancers than expected based on national comparison rates. Yet again, other than the cases of brain and other central nervous system cancer, no commonalities were found among the cases in the expanded scope of study. In contrast to the analyses for the 11-year period, the ODH found statistically significantly higher than expected numbers of cancers for the five-year period of 2002-2006 for Clyde City and Green Creek Township, as well as the four-township population. Figure 5 in Appendix A shows the radius of the cancer cluster.

Even at the time of the ODH's health assessment, some affected families remember that, although the problem of cancer was in the forefront of their minds, nobody was yet using the phrase "cancer cluster." Environmental toxins were also not initially discussed by health officials, and the community was slow to consider the possible role of toxins. However, there were exceptions within some families. A close friend to the Keller family, for instance, remembers that Kole Keller's doctors at Saint Jude Children's Research Hospital informed the family that what Kole had "was not something that was hereditary," and it was "very likely to have been caused by something environmental." During the ODH meeting when the results of the Cancer Incidence Report were shared, families at the meeting expressed concerns about the possible role of environmental contamination and requested the involvement of the Ohio EPA and the ODH Bureau of Environmental Health.

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<sup>66</sup> Ibid.

<sup>67</sup> Ibid.

In December 2008, the Sandusky County Combined General Health District (SCCGHD), the ODH Chronic Disease & Behavioral Epidemiological Section, the ODH Health Assessment Section (HAS), and the Ohio EPA Northwest District Office (NWDO) staff met with impacted families to discuss and address environmental concerns. The ODH discussed the five components of the completed exposure pathway, a measurement tool used by epidemiologists to identify how humans are exposed to chemicals in the environment, and how all five must be present in order to determine if the community's health was impacted. SCDPH staff conducted a case review of the Clyde City and Green Creek Township area for the years 1996-2006 using a standardized questionnaire developed by the ODH. The questionnaire gathered information concerning potential exposures to the child during fetal development; medical history; potential exposure in the home environment to chemicals, pesticides, tobacco smoke, parental occupations; drinking water sources; school attendance; history of cancer in the family; and other information in an attempt to identify factors that may have played a role in the development of these cancers. In February 2008, the case-review was released to the public. It did not reveal any common or individual factors that may have played a role in the childhood cancers.

Josephine, a former resident of Green-Springs who lived near Whirlpool Park but moved after four bouts with cancer, had a suspicion that she wanted to share with someone at the time of the first public meeting. Her quote illustrates the issue of people in the community trying to make a difference in their own little ways, but not knowing exactly what to do:

Something just told me...move, get away from here. And the park shut down. And I used to love there. I used to swim over there. We'd picnic over there and people used to say, 'doesn't the noise bother you?' I said, 'that's not noise. That's joy! Those kids over there and those people are having a blast!' I enjoyed it. I enjoyed every minute back there. And then when this cancer cluster thing all started, my wheels started turnin'. And, they had a meeting at the high school. It was evening and I knew that the office wasn't going to be open, but I just wanted to reach out and tell somebody that I kinda had a suspicion, you know, about Whirlpool. Nobody called me back. I just left message. I said, 'I think I know a little bit about what's going on. I don't know for sure. I just got this intuition. And please call me. Nobody ever called me. So I kind of, you know.

Parents began to wonder if the commonalities between the cases were based on the histories of the parents, rather than the impacted children. The perceived thread that existed among the parents was loosely connected to their swimming at Whirlpool Park. Rumors were circulating that Whirlpool had dumped chemicals nearby the park, and that they had pumped the pool full of water from the nearby creek, which might have been contaminated with chemicals. Alexa's mother Wendy recalls swimming at Whirlpool Park:

We didn't belong to Whirlpool but I had friends who took me there and then I spent a lot of time 'cause my best friend in high school...her boyfriend was the manager there. So we went there. [...] So then you wonder, 'Okay, is this something that could have gotten into my molecular cell structure?' Because Alexa never, *she* never went swimming there. The other kids—they went there, but Alexa never went swimming there. So then you wonder, 'Is it something that *I* passed onto her?'

Coinciding with the cancer cluster investigation, Whirlpool closed the park in 2006. It sold the property in 2008 to a family that planned to build a house there.

Following the reports of two additional child cancer cases in the Clyde area over the 2008 summer months, renewed community concerns again centered on the environment as a likely cause—specifically the release of chemicals into air, land and water from two nearby facilities—Whirlpool and the Vickery Environmental deep well injection waste disposal facility named after the nearby town of Vickery, Ohio. The topic of the environment remained peripheral to the concerns of the ODH, however. Alexa's mother, Wendy, recalls that around the year 2008, the director of the ODH, Robert Indian, informed the affected families that “there was nothing more he could do, and it would be up to them to ask the EPA for assistance.” Wendy remembers thinking:

By the time they got involved, it was like...you've got to be kidding. This was something that he should have talked about. It should have been brought up then so that they could have started checking environmentally right away, but I mean it was like two years later.



Finally, in January 2009, the Ohio EPA began monitoring both short and long-term air quality samples throughout the area. They found no elevated levels of pollutants that would indicate a public health concern, including VOCs or heavy metals.<sup>68</sup> The agency also evaluated drinking water quality from public water systems (City of Clyde and Northern Ohio Rural Water) and six private wells used by residents with impacted children. However, while a few naturally-occurring substances were identified at elevated concentrations in the water well samples, those that exceeded a U.S. EPA health advisory level or secondary maximum contaminant level did not have carcinogenic health implications.<sup>69</sup> The Ohio EPA also inspected eight local industries' compliance with environmental laws, but again, no environmental risk related to a cancer-causing agent or condition was identified. Also in January 2009, the ODH BEH Indoor Environments Section met with SCCGHD and reviewed inspection reports for the period 1990-2008 of six area schools, but no significant environmental quality or safety issues were identified. A later report would rule out the possibility of radiation at the schools, along with other locations in the area.<sup>70</sup> The Ohio EPA would also rule out the possibility of toxic chemicals at levels of public health concern in tested soils in the area.<sup>71</sup>

By the spring of 2009, Alexa Brown had lost the use of her legs and the cancer had worsened in her spine. Her parents took her to a hospital in Vermont with hopes of having Alexa participate in an experimental trial. The new trial required that participants not receive chemotherapy for at least three weeks. During that time, cancer cells attacked Alexa's body, and she was sent home because the MRI results disqualified her. The MRI showed that the cancer in her spine had grown and also returned in her brain. She was put on an aggressive nutritional supplement plan. On July 3, 2009 Alexa had an excruciatingly painful headache and was taken to the hospital. In the middle of the night, she became unable to communicate. She was sent home with hospice care, where her family had a month to spend with her before she died. Alexa's father Warren remembers his daughter's final month:

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<sup>68</sup> OEPA. 2010. Air Quality Report for Clyde and Green Springs. OEPA Division of Air Pollution Control. May 14, 2010

<sup>69</sup> OEPA. 2009. Water Quality Sampling to Support the Ohio Department of Health Childhood Cancer Investigation, City of Clyde and Surrounding Townships April 9, 2009. OEPA Division of Drinking and Ground Waters. See also OEPA. 2009. Addendum to Drinking Water Quality Sampling to Support the Ohio Department of Health Childhood Cancer Investigation, City of Clyde and Surrounding Townships. OEPA Division of Drinking and Ground Waters. August 19, 2009.

<sup>70</sup> ODH. 2009. Report on ODH Radiological Screening of 20 Schools in Eastern Sandusky County. ODH Bureau of Radiation Protection (BRP). Final Report November 19, 2009.

<sup>71</sup> ODH. 2011. Evaluation of Ohio EPA Soil Sampling in Support of the Clyde and Eastern Sandusky County Childhood Cancer Investigation. ODH Health Assessment Section. July 28, 2011.

I was on the front porch, and I spent most of my time during all of Alexa's trials on the front porch of our house especially as she got closer to the end, and I would write in the journal, or I would just sit out there and think or I would read or I would try to do something. But one of the things that stands in my memory and I'll never forget is I stood out on the front porch, it was late at night, very late at night actually because no one was sleeping. The closer she got to the end, no one was sleeping. Everybody was with her all the time. I stood out there and I talked to God. I asked Him to heal her immediately and restore her to where she was three years ago.

Eleven-year old Alexa died on Thursday, August 6, 2009. After she died, the Brown family travelled to Washington D.C. to promote childhood cancer funding. They met and received support from Ohio Senator Sherrod Brown who became an advocate for them in their search for federal attention to the issue. In November of that year, Senator Sherrod Brown's office contacted the CDC to request their involvement in the Clyde cancer investigation, but after reviewing ODH's cancer investigation efforts, representatives from the CDC responded stating that the ODH investigation was comprehensive and exhaustive and that no further action was warranted by their agency. In February 2011, Senator Sherrod Brown sent another letter to the CDC, as well as to U.S. EPA Administrator Lisa Jackson's office, requesting increased involvement from the federal agencies in the Clyde cancer investigation. Again, the CDC responded by calling the efforts of the supporting agencies "comprehensive and exhaustive."

It was not until five years after the ODH became involved in studying the cancer cluster, that a supplemental questionnaire was developed and administered to include additional questions about the possible role of environmental toxins, and in May 2011, a decision was made to expand the 2007 case review to 35 cases in the area.

Investigative Reporter Scott Taylor from Cleveland's 19 Action News questioned then federal EPA Director Lisa Jackson in June 2011 as she toured the headquarters of the Moen faucet manufacturing corporation in North Olmsted, Ohio. He asked her when the federal EPA would meet with parents in Clyde, but she stated that she was not aware of the Clyde Cancer Cluster. The EPA later sent a statement to 19 Action News stating that Lisa Jackson and her senior regional staff would "meet with the residents of Clyde, and will fulfill that

commitment.”<sup>72</sup> However, Jackson never fulfilled that promise, adding to residents’ sense of disillusionment with the lack of follow-through and governmental intervention. A recurring feeling that residents expressed was a need for reassurance that this issue would be taken care of. Contributing to the sense of betrayal some felt by the government, residents were also frustrated by the length of time that the situation had remained unresolved, and that the response to the problem was not strong and immediate. In the words of one resident, Marilyn:

Who’s helping these people?! They can’t get no answers, they can get no answers!  
That’s what makes me angry, that’s when I say, why is not, why isn’t anyone gonna  
help the children? Whose gonna protect the children if we don’t?!

In 2012, Robert Indian, chief of the state’s comprehensive cancer-control program at the Ohio Department of Health, announced that the department would take a “very 21<sup>st</sup>-century” approach to cancer—one that involved avoiding time spent on cancer cluster cases whenever possible, and spending more time boosting prevention and early detection of disease. “There’s more payoff in that, and it does more good than continuing to pursue these will-o’-the-wisp things,” he said. Cancer-cluster investigations “use a lot of resources, raise expectations, and you find nothing.”<sup>73</sup> Indian’s comment describing disease clusters as “will-o-the-wisp things” conveyed a defeatist, passive attitude that was disconcerting to the families in Clyde fighting to find answers on behalf of their children. From Alexa’s mother’s perspective, it meant “we don’t wanna find out.” It also reinforced a suspicion that ODH began the investigation with predetermined ideas that nothing would be found.

Additionally, when Indian redirected the focus of his health agency to encouraging preventive measures among the populace, he was confronting the fact that his agency in all probability did not have the capacity to fix problems such as disease clusters. Consequently, the responsibility for protection was turned back onto the community of Clyde itself.

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<sup>72</sup> 19 Action News. 2011. “Ohio’s Federal EPA Director Questioned about the Clyde Cancer Cluster.” *19 Action News*. 17 June 2011. 19actionnews.com. Web. 18 May 2014.

<sup>73</sup> Crane, Misti. “State Wary of Cancer Clusters but will Continue Investigations.” *The Columbus Dispatch*. 11 June 2012. Dispatch.com. Web. 18 May 2014.

Though not included in the public health assessments, many adults in the communities of Clyde and Green-Springs have also been affected by illness and disease, and have presented with an inordinate number of unusual and multiple cancers, including spine cancer, eye tumors, and cancer of the spleen. Betty, a sixty-nine-year old resident recalls coming to this realization with her husband when she was being treated for her cancer:

We started looking around saying, ‘jeez it’s not just the kids--it’s the adults.’ And I started taking chemo and everything down here at North Coast. There were a lot of people. People I knew, you know, ‘What are you doing in here? Why are you in here?’ ‘Well, I have cancer.’ ‘Yeah, I do too.’

In February 2012, six years after the initial involvement of the ODH and Ohio EPA, the U.S. EPA finally became involved. There was a perception among some affected families that, whether an issue of territoriality or competency, the Ohio EPA took offense to their request for U.S. EPA involvement. Nevertheless, the U.S. EPA stepped in and conducted an assessment of 14 dumpsites identified by the Ohio EPA and Clyde residents, but did not discover contaminants that warranted removal.<sup>74</sup> During the initial investigation of these sites, the EPA established a telephone hotline to elicit information from local residents regarding additional potential dump sites in the area. They received approximately 90 anonymous calls to the hotline, with enough information to warrant site assessments at three additional locations.

Contaminants were found at a residential property on the west side of Clyde, which included Semivolatile Organic Compounds (SVOCs), Target Analyte List (TAL) Metals, and Toxicity Characteristic Leaching Procedure (TCLP) Metals.<sup>75</sup> A number of contaminants were found at the former Clyde Paint and Supply Co. site that exceeded the applicable screening criterion, including a number of Volatile Organic Compounds (VOCs), Semivolatile Organic Compounds (SVOCs), Target Analyte List (TAL) Metals, and Polychlorinated biphenals (PCBs), a carcinogen banned in 1979 that has been linked to endocrine disruption and

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<sup>74</sup> US EPA. 2012. Site Assessment Report Eastern Sandusky County Dumps Site Clyde, Sandusky County, Ohio. Site Assessment Report for the Whirlpool Park Site, Green Springs, Sandusky County, Ohio. U.S. EPA - Region 5, Superfund Emergency Response Section. July 2012.

<sup>75</sup> Weston Solutions, Inc. 2012. Site Assessment Report for the Shaw Road Site, Green Springs, Sandusky County, Ohio. September 27, 2012.

neurotoxicity.<sup>76</sup> In addition, the hotline tips included information that Whirlpool had filled in the area surrounding and under the basketball court in the former Whirlpool Park site with a black sludge-like material.<sup>77</sup> In September 2012, the federal agency completed six soil borings at the former Whirlpool Park site. Results found PCBs present at levels that exceeded U.S. EPA Regional Screening Levels for residential properties. PCBs were detected around the basketball court, ranging from two to nine feet thick. In addition, the metals Cobalt and Nickel were also identified at levels that exceeded the EPA's screening criterion.<sup>78</sup>

The U.S. EPA did not notify residents about the discovery of the toxic sludge at the former Whirlpool Park site. Rather, members of the community discovered the report online in November 2012. Karen, who lives near the site, expressed frustration that the EPA did not adequately inform local residents of the nearby danger of toxins at the time of the house visits they had made over the summer. To residents, withholding that information felt dishonest and disrespectful. Karen stated:

I mean the EPA came and sat came and sat at our table and they asked us if we witnessed any kind of dumping and trucks, they asked us you know kind of illness that you had. At the time they came here they knew exactly what was found over there. I can't believe that they that they do not tell the immediate people within the... at least I mean when I looked up the hazards, cautions, and cleanup, it said it went out like maybe 1500 feet, maybe 2000 feet that they would evacuate people or have people not be drinking their water, you know, boil. And I'm thinking we are all right here and they're disturbing soil that they already know has PCBs. It's like they don't give us the courtesy and consideration.

As a result of requiring impacted families to become their own advocates when the traditional avenues of recourse failed, residents educated themselves on toxins and cancer. Through social media, a network developed among concerned residents. Members also began informing

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<sup>76</sup> Weston Solutions, Inc. 2012. Site Assessment Report for the Clyde Paint and Supply Company Site, Clyde, Sandusky County, Ohio. September 28, 2012.

<sup>77</sup> US EPA. 2013. Interim Site Assessment Report for the Whirlpool Park Site. U.S. EPA split sampling of the Whirlpool Park site. June 2013.

<sup>78</sup> US EPA. 2012. Site Assessment Report for the Whirlpool Park Site, Green Springs, Sandusky County, Ohio. U.S. EPA - Region 5, Superfund Emergency Response Section. September 2012.

themselves through online resources. Michelle, who lived in close proximity to Whirlpool Park, remembered learning about the report from a friend on Facebook:

It was in spring when the EPA found the PCBs up front, but they did not release the report until the fall and they didn't notify anyone. My girlfriend must have seen it on Facebook. I had talked to Wendy after that came out about the PCBs. Wendy came to my house and left a note on my door because I wasn't home. I had talked to her when I was really concerned because they found the PCBs. And I went on the Internet and looked up PCBs and exactly what they're from and what they can cause. My main concern was my well water because my well is right in front of the house here. And at first my assumption was they had drilled down nine feet and found PCBs there, not the fact that PCBs sludge they found was nine feet thick. When I found out that it was nine feet thick, I was really concerned about that living out here. And I had two dogs that died. We lost Bear that spring, and he was age five. Then last year we lost Max around the same time, and he was age six. They should live longer than that. The only thing we gave them other than dog food was water.

To add to locals' frustration, residents were never notified about clean-up efforts, and there were concerns that disrupting the PCB-laced soil would put them at a greater risk of toxin exposure. They wanted to be given a choice to leave their homes at the time of clean-up. Adding to the confusion, the EPA did not provide residents with the agency's contact information at the time of the house visits. When some residents finally made phone contact with the EPA in an attempt to clarify unanswered questions, they were sidelined by a string of transfers, disconnections, and recorded responses.

To this day, residents are upset that the PCB sludge has not been cleaned up, and locals have not been informed of plans for its removal. Locals worry that they will not be notified of any future findings. The park exists now as a large, abandoned, fenced-in lot overgrown with weeds (see Figure 6 in Appendix A).

Residents expressed frustration not only with the quality of OEPA, ODH, and US EPA investigations, but also with the promptness of their response and noted systemic failures from

the local to state to federal levels. Alexa Brown's father remembers having an early suspicion that the agencies' efforts would not materialize:

Initially, I thought that they were coming in, you know and I still hold to this day, I think their investigations were well-intentioned but I believe they were underfunded, undermanned, and possibly performed by those who don't have quite the skill set that those on the federal level maintain. Now I'm still concerned about the amount of attention the federal level has given this cancer cluster study as well. I was reading a document today that was produced from the public meeting we held in 2008 at the Clyde High School. Alexa accompanied us to this meeting. And I sat there and I can remember hearing Robert Indian and others from Ohio EPA and Ohio Department of Health speak, and I recall distinctly thinking how skeptical I was. You know I just, you know you're saying all the right words, but are you really gonna follow through what you're doing, do you really actually even know what you're doing? So skepticism is probably the best word I can apply to the way I felt about ODH and Ohio EPA's approach to this. I was encouraged when the US EPA came in because they seem to have a much higher level of skills and they were bringing equipment that was far more technical to what Ohio EPA had. But again, the luster they had in my eyes at that point in time has become very lack luster now because they've not stayed the task. I don't think they're going far enough. At least they did come and try to do something, but they just didn't do enough.

Ultimately, impacted families turned to the legal system and to alternative sources of scientific proof in their pursuit of identifying who was responsible, and who would be held accountable. Frustrated with the slow progress being made, affected families hired Alan Mortensen, a Utah-based personal injury attorney with ties to the area, along with Toledo-based firm Charles E. Boyk Law Offices, LLC, for legal help with their search for answers. When Mortensen became involved, the families had a renewed sense of hope for resolution as the lawyers and their team of scientists conducted independent environmental tests on their behalf. One of the tests performed involved testing the air and dust in the attics of affected families' homes. While the team of lawyers and scientists were expecting to find evidence of PCBs in the dust, since PCBs (among other hazardous chemicals) were discovered at Whirlpool Park, the environmental tests

revealed high levels of benzaldehyde instead. The levels of benzaldehyde indicated to the scientists that other chemicals may have once been present in the homes. In a sense, they interpreted benzaldehyde as a marker chemical—perhaps a remnant of two other chemicals that had burned and vaporized. With these findings, a class action lawsuit was filed against Whirlpool Corporation, citing, in part, the use of benzaldehyde in their manufacturing process. The lawsuit claimed that when Whirlpool ran out of places to dump sludge, the company resorted to burning the waste, causing the residual benzaldehyde to “blanket the entire Clyde area.”<sup>79</sup> The lawsuit also claimed that benzaldehyde and other toxins were responsible for illness among the plaintiffs.

A study by Kluwe et al. revealed negative health effects of exposure to benzaldehyde in rats and mice, but studies within the toxicology literature remain sparse.<sup>80</sup> For this reason, benzaldehyde has not undergone a complete evaluation and determination under the U.S. EPA’s Integrated Risk Information System (IRIS) program for evidence of human carcinogenic potential.<sup>81</sup> In contrast, the U.S. FDA has stated that the substance is “generally regarded as safe.”<sup>82</sup>

The day after the lawyers and their team released their benzaldehyde findings, the Ohio Department of Health released an informational sheet stating that the chemical is non-toxic and commonly found in food and household items (see Figure 7 in Appendix A). Graphics on the flyer included colorful gumballs, ripe cherries, a bountiful harvest of fruit, a tray of baked goods, and a cup of frozen yogurt—innocuous illustrations of Americana.

While the type of graphics added to this particular fact sheet may be surprising to some, the illustrations on this example are not an out-of-the-ordinary model for fact sheets that the Ohio Department of Health has released in the past. Yet, one might speculate as to the timing of the release of the informational sheet, which was quickly and widely distributed. It was published in the local newspaper, and according to one interviewee, was even handed out at the building where residents pay utility bills. The families were irked by the ODH’s flyer and expressed concern that this was an attempt to undermine their work. Some felt that, although it was the Health Department that led the community to believe that illness was likely linked to

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<sup>79</sup> Brown v. Whirlpool Corp., 996 F. Supp. 2d 623; 2014

<sup>80</sup> Kluwe, W.M., C.A. Montgomery, H.D. Giles and J.D. Prejeau. 1983. Encephalopathy in Rats and Nephropathy in Rats and Mice after Subchronic Oral exposure to Benzaldehyde. *Food and Chemical Toxicology*. 21(3):245-250.

<sup>81</sup> US EPA. 2014. Integrated Risk Information System, Benzaldehyde. US EPA. 2014. Web. Accessed 21 May 2015. <http://www.epa.gov/iris/subst/0332.htm>

<sup>82</sup> Brühne, Friedrich and Elaine Wright. 2007. "Benzaldehyde," *Ullmann's Encyclopedia of Industrial Chemistry* (7th ed.). Wiley:11.



environmental toxins, they were now backpedaling on the issue. However, after the Agency for Toxic Substances and Disease Registry (ATSDR) reviewed the indoor dust sampling conducted by the scientists at the request of the U.S. EPA, ATSDR identified factual inaccuracies. They determined that all of the Benzaldehyde levels were calculated incorrectly and were actually at levels below the EPA Preliminary Remediation Goals (PRGs).<sup>83</sup>

Meanwhile, under the supervision of the U.S. EPA, Whirlpool Corporation was given the authority to conduct its own site assessment of Whirlpool Park using AECOM, an outside contractor with roots in the manufacturing and chemical distribution industry. EPA's contractors, Weston Solutions, Inc. (Weston) provided oversight during the site assessment conducted by Whirlpool. The EPA collected a subset of split samples during the site assessment which was equal to about 5% of the total samples collected by AECOM.<sup>84</sup> In addition to EPA oversight with Weston, HzW Environmental Consultants, LLC, represented the current property owner and collected split samples during the site assessment. The site assessment activities focused on identifying potential sources of soil and water contamination.<sup>85</sup> After reviewing the findings submitted by Whirlpool's contractor, the U.S. EPA determined that the sampling activities were conducted in accordance with the approved guidelines. In line with AECOM's findings, the U.S. EPA determined that PCBs were the only contaminants of concern found to be above regulatory standards.<sup>86</sup> Removal of PCB-contaminated waste was set to be regulated for cleanup and disposal in accordance with the EPA's protocols for the management of PCB waste.

Some felt that Whirlpool spokesman Jeff Noel downplayed the presence of PCBs when he stated that "it's not uncommon to find these items in what is clearly fill material, fill dirt."<sup>87</sup> Whirlpool denied responsibility for the dumping, and released a statement to the public. The statement reads:

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<sup>83</sup> ATSDR. 2013. ATSDR Letter to U.S. EPA. ATSDR Region V. June 14, 2013.

<sup>84</sup> US EPA. 2013. Interim Site Assessment Report for the Whirlpool Park Site. U.S. EPA split sampling of the Whirlpool Park site. June 2013.

<sup>85</sup> AECOM. 2013. Final Site Assessment Report, Former Whirlpool Park Site, Green Springs, Sandusky County, Ohio. AECOM. October 29, 2013.

<sup>86</sup> U.S. EPA. 2013. Review of Draft Site Assessment Report for the Former Whirlpool Park Site: U.S. EPA letter response to the AECOM Site Assessment Report. October 30, 2013.

<sup>87</sup> Jackson, Tom. "Report: PCBs found in Whirlpool Park." *Sandusky Register*. 1 Nov 2013. SanduskyRegister.com. Web. 18 May 2015.

In conclusion, the site assessment found no health risk and no evidence of hazardous illegal dumping. Using the site assessment as a scientific basis, Whirlpool will now work with the U.S. EPA and the OEPA on the development and implementation of an appropriate remediation plan.<sup>88</sup>

The statement revealed an attempt to conflate science with two unsubstantiated claims that the study found “no health risk and no evidence of hazardous illegal dumping.” While refusing to allow victims to have the sites in question independently tested, Whirlpool’s representative, the vice president of communications and public affairs was careful not to alienate the community. He explained, “We understand where the families are coming from. We have great empathy for the families. Our issue is with attorneys who have used no science, no fact.”<sup>89</sup>

Indeed, there are benefits and limitations to the use of science as a definitive tool for evaluating health risks. Whirlpool’s selective interpretation of the site assessment data draws attention to yet another dilemma faced by cancer cluster communities, wherein the tool of science is manipulated to bolster claims denying accountability. By attaching itself to science and its inherent authoritative implications, Whirlpool implies an alignment with the very discipline required for the neutral determination of cause, thereby skewing the balance of accuracy and, consequently, negating future findings. While the calamity faced by the Clyde community would appear to require an educated, coordinated, and immediate response from all involved parties, there exists instead a sense of sequestration and mistrust, and, as has been seen in other disease clusters in Ohio and elsewhere, a climate wherein accountability remains undetermined.

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<sup>88</sup> Whirlpool Corporation 2013. Site Assessment Report Executive Summary, Former Whirlpool Park Site, Green Springs, Sandusky County, Ohio. October 31, 2013.

<sup>89</sup> Henry, Tom. “Whirlpool Contractor Exonerates Clyde Site.” *The Toledo Blade*. 1 Nov. 2013. ToledoBlade.com. Web. 18 May 2014.

## CHAPTER 3

### SCIENCE, HEALTH, AND “WILL-O-THE-WISP” THINGS

#### *Chemical Regulation in the U.S.*

The inceptions of major U.S. chemical companies, including DuPont, Monsanto, Union Carbide, and Dow Chemicals, were rooted in the production of weaponry and war materials beginning prior to World War I.<sup>1</sup> By-products of explosives were later used to develop insecticides.<sup>2</sup> The production of polyvinyl chloride (PVC), polystyrene, and polyethylene, developed before WWII, contributed to increased demand for new, lightweight products to be used for a variety of items ranging from weaponry to food packaging. When, at the conclusion of the war, attention was directed toward marketing plastic goods to the American public, lucrative possibilities for the chemical industry expanded. After World War II, as engineers developed increasingly diverse plastic products, chemical companies looking for new avenues for production employed strategic advertising to alter their wartime image to that as manufacturers of more utilitarian and beneficial products.<sup>3</sup> Companies such as Dow, Monsanto, and DuPont, launched extensive advertising campaigns that promoted the modern versatility of their products with a focus upon manufacturing plastic goods for use in postwar households, allowing for capitalization of the country's rapid economic growth. “Better things for better living...through chemistry” was the DuPont motto used to define the burgeoning industry.<sup>4</sup> Yet, although the proliferation of plastic products made consumer goods readily available to the average American and provided a more equitable affordability of conveniences, it also infiltrated homes with thousands of unregulated chemicals that had potentially deleterious effects on the health of people using them.<sup>5</sup>

As early as the 1950s, scientists and lawmakers were becoming aware of public health risks associated with unregulated chemicals. Early documentation indicates unwillingness and subterfuge on the part of chemical companies in releasing findings regarding potentially harmful

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<sup>1</sup> DuPont. 2015. “1915 Pierre S. du Pont.” Retrieved October 13, 2015. (<http://www.dupont.com/corporate-functions/our-company/dupont-history.html>). See also Chemical Heritage Foundation. 2002. “Henry Herbert Dow 1866-1930.” Retrieved October 13, 2015. (<http://www.chemheritage.org/discover/online-resources/chemistry-in-history/themes/electrochemistry/dow.aspx>)

<sup>2</sup> Russell III, Edmund P. “‘Speaking of Annihilation’: Mobilizing for War Against Human and Insect Enemies, 1914-1945,” *Journal of American History* 82:1505-1529.

<sup>3</sup> Rogers, Heather. 2006. *Gone Tomorrow: The Hidden Life of Garbage*. NY: The New Press.

<sup>4</sup> “News from Du Pont,” Display ad in the New York Times, January 9, 1961.

<sup>5</sup> Harris, D. Kenwin. 1953. “Health Problems in the Manufacture and Use of Plastics.” *British Journal of Industrial Medicine* 10:255-267.

chemicals to the public.<sup>6</sup> When the U.S. Congress attempted to intervene and protect consumers by writing legislation that would require the study of adverse health effects of chemicals used in food and cosmetics, a committee led by Congressman James T. Delaney wrote three amendments: the Pesticide Amendment (1954), the Food Additives Amendment (1958), and the Color Additive Amendment (1960). These amendments significantly changed the U.S. food and drug law. With them, no substance could be legally introduced into the U.S. food supply unless it had been predetermined to be safe—placing the burden of that determination on manufacturers.<sup>7</sup> However, their attempts to regulate chemicals were met with strong opposition from a powerful, influential chemical industry whose promotion of plastic in the media not only emphasized its popularity and benefit to postwar society, but also encouraged consumer trust in science and technology. Tactics were implemented by chemical makers to contradict data identifying the toxicity of their products. By using their own scientists to refute data and/or discredit proponents of chemical regulation,<sup>8</sup> the chemical industry was able to redirect the outcome by obfuscating contradictory information. Subsequently, when the Food Additives Bill of 1958 was passed, existing chemicals that had never been proven to be safe were grandfathered in as being safe.

In the early 1970s, the environmental movement helped to raise public awareness of toxins. Attempts at Congressional regulation were again initiated, this time centered on allowing the EPA to examine chemical use and toxicity. The Toxic Substances Control Act (TSCA) of 1976 authorized the EPA to control chemicals that posed an unreasonable risk to human health or the environment. However, strong lobbying and PR advertising by the chemical industry again reduced the impact of the legislation as it permitted the grandfathering in of existing chemicals without any evaluation.<sup>9</sup> The TSCA Inventory contains over 84,000 chemicals, most of which have never been evaluated for their risks to children.<sup>10</sup> Furthermore, the statute did not give the EPA authority to reevaluate existing chemicals, nor did it give the agency authority to force

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<sup>6</sup> Rowe, V.K. Letter to Director of Department of Industrial Hygiene and Toxicology, The B.F. Goodrich Company. 12 May 1959. Letter. Retrieved October 10, 2015. (<http://www.pbs.org/tradesecrets/program/vinyl.html>). See also Smyth, Henry P. Jr. Inter-company Correspondence, Union Carbide Company. 24 Nov. 1964. Letter. Retrieved October 10, 2015. (<http://www.pbs.org/tradesecrets/program/vinyl.html>)

<sup>7</sup> Janssen, Wallace F. 1981. "The Story of Laws Behind the Labels." *FDA Consumer*. Retrieved October 14, 2015. (<http://www.fda.gov/AboutFDA/WhatWeDo/History/Overviews/ucm056044.htm>)

<sup>8</sup> Darby, William J. 1962. "Silence, Miss Carson." *Chemical & Engineering News* (Oct. 1):62-63.

<sup>9</sup> Owens, Steve. 2010. *Testimony of Assistant Administrator Office of Chemical Safety and Pollution Prevention (EPA) before the Subcommittee on Commerce, Trade, and Consumer Protection Committee on Energy and Commerce U.S. House of Representatives*. Print.

<sup>10</sup> *Ibid.*

companies to provide toxicity data. As a result, to this day, the EPA has only been able to require testing on around 200 of the 84,000 chemicals on the market.<sup>11</sup>

### *U.S. Influence on the Global Market for Chemicals*

Under the current model in the U.S., communities impacted by environmental contamination such as that seen in Clyde, carry the burden of proving that a substance is dangerous. U.S. environmental policies are based on the highest “acceptable” amount of toxic exposure, rather than upon avoiding harm from toxic chemicals in the first place. In contrast, the European Union uses a precautionary model, under which a substance needs to be proven safe before it is exposed to the public. Given the global demand for pesticides and agricultural products, however, the E.U. is under increasing pressure to conform to U.S. regulations, which are less stringent than those in Europe.<sup>12</sup> Specifically, the E.U. is under pressure to alter their definition, and consequently loosen their regulation of endocrine-disrupting chemicals, which interfere with hormones, and are particularly dangerous to young children. The U.S. government’s position largely echoes the positions taken by chemical industry groups, such as CropLife America and the American Chemistry Council, that have a vested interest in the financial implications of chemical regulation<sup>13</sup> where revenues of over 52 billion U.S. dollars for the global market of crop protection products in 2019 have been forecasted by market analysts.<sup>14</sup>

Chemicals such as DDT, lindane, chlordane, dieldrin, aldrin, and heptachlor<sup>15</sup> that have been banned for use in the U.S., continue to be shipped abroad, although both chlordane and heptachlor have been linked to leukemia and childhood cancers. In 2011, the U.S. exported about \$27 million dollars’ worth of asbestos products.<sup>16</sup> Lead house paint, which was banned in the U.S. in 1978, is also exported to and sold in developing countries, most often without health warnings on the products.<sup>17</sup> Toxins are transported between states within the U.S. as well. For example, the current U.S. gas and oil boom is generating millions of tons of waste. Pennsylvania

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<sup>11</sup> Ibid.

<sup>12</sup> Grossman, Elizabeth. 2015. “The U.S. Government is Pressuring Europe to Dial Back its Pesticide Rules.” *Mother Jones* March 17, 2015. Retrieved October 15, 2015. (<http://www.motherjones.com/environment/2015/03/europe-pesticides-endocrine-disruptors>)

<sup>13</sup> Ibid.

<sup>14</sup> Ceresana. 2012. “Market Study: Crop Protection.” *Ceresana Research*. Retrieved October 15, 2015 (<http://www.ceresana.com/en/market-studies/agriculture/crop-protection/>)

<sup>15</sup> Raloff, J. 1996. “The Pesticide Shuffle.” *Science News* 149:174-175.

<sup>16</sup> Virtha, Robert L. 2012. “2011 Minerals Yearbook: Asbestos.” U.S. Geological Survey.

<sup>17</sup> Gottesfeld, P. et al. 2013. “Lead Concentrations in Labeling of New Paint in Cameroon.” *Journal of Occupational and Environmental Hygiene* 10(5):243-249.

sends millions of gallons of its wastewater from hydraulic fracturing to Ohio, which now has more than 200 active injection wells for oil and gas waste.<sup>18</sup> Few studies have explored health outcomes with relation to hydraulic fracturing, but a recent publication by researchers at Johns Hopkins Bloomberg School of Public Health reveals that living near active drilling and production activity is associated with a 40 percent increase in the likelihood of a woman prematurely giving birth.<sup>19</sup> This broad spectrum of potentially disastrous weakness in manufacture, storage, transportation, and faulty regulatory practice, has converged to impose hazardous environmental consequences on the global community.

### *Health Implications of Unregulated Chemicals—a Scientific Overview*

#### Occupational Exposures

The lack of responsible and effective regulation on the production, generation, and release of chemicals into the environment is illustrative of the inadequacy and failure of governments to safeguard its citizenry through legislative means. This is punctuated by the fact that synthetic chemicals are present in all human bodies.<sup>20</sup> Exposure to carcinogenic agents is thought to account for about 6% of cancer deaths in the U.S., which corresponded to approximately 34,320 deaths in 2011.<sup>21</sup> Hazardous substances are often found in higher levels in the workplace than in the general environment. Exposure to occupational and environmental carcinogens in the U.S. disproportionately affects lower-income workers and communities, contributing to disparities in the cancer burden.

With industrialization and the growth of the chemical industry, workers from the middle to the end of the 20<sup>th</sup> century were exposed to concentrations of chemicals at levels much higher than those that are considered acceptable today.<sup>22</sup> While some white-collar jobs such as

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<sup>18</sup> Ohio Department of Natural Resources Division of Oil & Gas Resources. 2015. Ohio Oil & Gas Well Locator. Retrieved October 8, 2015. (<http://oilandgas.ohiodnr.gov/well-information/oil-gas-well-locator>)

<sup>19</sup> Casey, Joan A., David A Savitz, Sara G. Rasmussen, Elizabeth L. Ogburn, Jonathan Pollak, Dione G. Mercer, Brian S. Schwartz. 2015. “Unconventional Natural Gas Development and Birth Outcomes in Pennsylvania, USA.” *Epidemiology*. Retrieved October 24, 2015.

([http://journals.lww.com/epidem/Abstract/publishahead/Unconventional\\_Natural\\_Gas\\_Development\\_and\\_Birth.99128.aspx](http://journals.lww.com/epidem/Abstract/publishahead/Unconventional_Natural_Gas_Development_and_Birth.99128.aspx))

<sup>20</sup> Vogel, Sarah A. and Jody A. Roberts. 2011. “Why the Toxic Substances Control Act Needs an Overhaul, and How to Strengthen Oversight of Chemicals in the Interim.” *Health Affairs* 30:898-905.

<sup>21</sup> American Cancer Society. Cancer Facts and Figures 2014. Retrieved September 29, 2015. (<http://www.cancer.org/Research/CancerFactsFigures/index>).

<sup>22</sup> Fontham, ET, MJ Thun, E. Ward, AJ Balch, JOL Delancey, and J Samet. 2009. “American Cancer Society Perspectives on Environmental Factors and Cancer.” *CA Cancer Journal for Clinicians* 59:6.

dentistry and chemical engineering have been associated with high rates of cancer,<sup>23</sup> the working class continues to have higher rates of morbidity and mortality due to unhealthy working environments and exposure to industrial carcinogens such as asbestos, heavy metals, and chemicals.<sup>24</sup> For example, asthma, which has been linked to cleaning chemicals,<sup>25</sup> has been found to be more prevalent in women who have been employed as domestic cleaners.<sup>26</sup> Occupational studies have also revealed elevated cancer rates among rubber and plastics factory workers, painters, barbers and hairdressers, farmers, welders, asbestos workers, dye and fabric makers, miners, printers, and radiation workers.<sup>27</sup> Additionally, as some have suspected to be true in the Clyde cancer cluster, studies have found links between the occupational exposures of parents and consequent cancers, particularly leukemia and nervous system cancers, in their children.<sup>28</sup>

### Reproductive, Maternal, and Child Health

Reproductive, maternal, and child health are especially vulnerable to environmental toxins, leading some scholars to frame the issue of environmental health as a women's rights issue. Women are more susceptible to autoimmune conditions than men due to their higher percentage of body fat, where larger amounts of lipophilic<sup>29</sup> chemicals are stored.<sup>30</sup> Researchers have found associations between chemical exposure and adverse pregnancy outcomes, including preterm delivery, the leading cause of perinatal mortality.<sup>31</sup> Because the placenta is unable to block most

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<sup>23</sup> Steingraber, Sandra. 2010. *Living Downstream: An Ecologist's Personal Investigation of Cancer and the Environment*. Cambridge, MA: Da Capo Press.

<sup>24</sup> Graff, J.J., N. Sathiakumar, M. Macaluso, G. Maldonado, R. Matthews, and E. Delzell. "Chemical Exposures in the Synthetic Rubber Industry and Lymphohematopoietic Cancer Mortality." *Journal of Occupational and Environmental Medicine* 47(9):916-932. See also Luippold, R.S., K.A. Mundt, L.D. Dell, and T. Birk. 2005. "Low-Level Hexavalent Chromium Exposure and Rate of Mortality among U.S. Chromate Production Employees." *Journal of Occupational and Environmental Medicine* 47(4):381-385.

<sup>25</sup> Zock, Jan-Paul et al. 2007. "The Use of Household Cleaning Sprays and Adult Asthma." *American Journal of Respiratory and Critical Care Medicine* 176:735-741.

<sup>26</sup> Medina-Ramon, et al. 2005. "Asthma, Chronic Bronchitis, and Exposure to Irritant Agents in Occupational Domestic Cleaning: A Nested Case-control Study." *Occupational and Environmental Medicine* 62:598-606.

<sup>27</sup> Steingraber, Sandra. 2010. *Living Downstream: An Ecologist's Personal Investigation of Cancer and the Environment*. Cambridge, MA: Da Capo Press. See also Alavanja, M.C., D.P. Sandler, C.F. Lynch, C. Knott, J.H. Lubin, R. Tarone, K. Thomas, M. Dosemeci, J. Barker, J.A. Hoppin, and A. Blair. 2005. "Cancer Incidence in the Agricultural Health Study." *Scandinavian Journal of Work and Environment* 31:39-45.

<sup>28</sup> Colt, J.S. and A. Blair. 1998. "Parental Occupational Exposures and Risk of Childhood Cancer." *Environmental Health Perspective* 106(3):909-925.

<sup>29</sup> Lipophilic chemicals are those that have a tendency to dissolve in fat-like solvents.

<sup>30</sup> Botella, B., J. Crespo, A. Rivas, I. Cerrillo, MF. Olea-Serrano, and N. Olea. 2004. "Exposure of Women to Organochlorine Pesticides in Southern Spain." *Environmental Research* 96:34-40.

<sup>31</sup> Berhman, R.E. and A.S. Butler. 2006. *Preterm Birth: Causes, Consequences, and Prevention*. Report From the Institute of Medicine's Committee on Understanding Premature Birth and Assuring Healthy Outcome. Washington, D.C.: National Academies Press. See also Leem, Jong-Han, Brian M. Kaplan, Youn K. Shim, Hana R. Pohl, Carol A. Gotway, Stevan M.

synthetic chemicals stored in a woman's body fat, chemicals have the ability to cause subtle damage to the developing fetus, repercussions of which may manifest in the form of behavioral and cognition problems, as well as birth defects.<sup>32</sup> Up to 300 synthetic chemicals have been found in body fat and in breast milk.<sup>33</sup> Exposure to toxic chemicals may also impair a woman's ability to lactate and breastfeed successfully.<sup>34</sup> As breastfeeding has been determined to be protective against breast cancer, this illustrates how environmental contaminants can affect lifestyle choices, and in turn, affect cancer risk.

Women born in the U.S. between 1947 and 1958 have almost three times the rates of breast cancer than their great grandmothers did when they were the same age.<sup>35</sup> Some argue that a comprehensive understanding of the link between DDT, a pesticide commonly used during that time, and breast cancer must account for combined exposures wherein a large number of pollutants can act together to increase estrogen levels and cause breast cancer.<sup>36</sup>

The types of cancers that develop in children and adolescents differ from those that develop in adults. Predominant types of pediatric cancers (ages 0-19) are leukemia (26%), cancers of the brain and central nervous system (CNS) (18%), and lymphoma (14%). Some of the cancers that develop in children are rarely seen in adults, notably those cancers that arise from embryonic cells and originate in developing tissues and organ systems.<sup>37</sup>

In general, the incidence of pediatric cancer is higher in industrialized countries than in developing countries, but patterns differ by cancer type.<sup>38</sup> Geographic variations in cancer occurrence reflect differences in environmental exposures, socioeconomic factors related to population demographics, and screening behaviors. From 1975 to 2010, the overall incidence of

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Bullard, J. Felix Rogers, Melissa M. Smith, and Carolyn A. Tylanda. 2006. "Exposure to Air Pollutants During Pregnancy and Preterm Delivery." *Environmental Health Perspectives* 114(6):905-910 and Maroziene, Ligita and Regina Grazuleviciene. 2002. "Maternal Exposure to Low-level Air Pollution and Pregnancy Outcomes: A Population-based Study." *Environmental Health* 1:1-13.

<sup>32</sup> Hurst, C.H., B. Abbott, J.E. Schmid, and L.S. Birnbaum. 2002. "2,3,7,8-Tetrachlorodibenzo-p-dioxin (TCDD) Disrupt Early Morphogenetic Events that Form the Lower Reproductive Tract in Female Rat Fetuses." *Toxicological Sciences* 65:87-98.

<sup>33</sup> Del Rio Gomez, I. and L.E. Campaigns. 2007. *Gender and Environmental Chemicals*. Women's Environmental Network.

<sup>34</sup> Rudel, Ruthann A., Suzanne E. Fenton, Janet M. Ackerman, Susan Y. Euling, and Susan L. Makris. 2011. "Environmental Exposures and Mammary Gland Development: State of the Science, Public Health Implications, and Research Recommendations." *Environmental Health Perspectives* 119(8):1053-1061.

<sup>35</sup> Steingraber, Sandra. 2010. *Living Downstream: An Ecologist's Personal Investigation of Cancer and the Environment*. Cambridge, MA: Da Capo Press.

<sup>36</sup> Kortenkamp, A. 2006. "Breast Cancer, Oestrogens and Environmental Pollutants: A Reevaluation from a Mixture Perspective." *International Journal of Andrology* 29:193-198.

<sup>37</sup> Ibid.

<sup>38</sup> Bunin, GR. 2004. "Nongenetic Causes of Childhood Cancers: Evidence from International Variation, Time Trends, and Risk Factor Studies." *Toxicology and Applied Pharmacology* 199:91-103. See also Stiller CA, and DM Parkin. 1996. "Geographic and Ethnic Variations in the Incidence of Childhood Cancer." *British Medical Bulletin* 52:682-703.



pediatric cancer in the U.S. slightly increased by an average of .6% per year.<sup>39</sup> Environmental factors may be responsible for some of this increase,<sup>40</sup> with improved diagnosis and access to medical care over time contributing to more cases being identified and statistically included. An estimated 10,450 new cases and 1,350 cancer deaths were expected to occur among children (ages 0-14) in 2014. The corresponding figures among adolescents (ages 15-19) are 5,330 new cases and 610 cancer deaths.<sup>41</sup> Non-Hispanic white and Hispanic children have the highest incidence rates for childhood and adolescent cancers.<sup>42</sup> Unlike many adult cancers, incidence is not consistently higher among populations with lower socioeconomic status.<sup>43</sup>

The most rapid periods of growth occur in utero, during infancy, and during puberty.<sup>44</sup> These periods of accelerated growth, which involve an increase in the number of cells in the body, are also periods of heightened sensitivity to toxic substances.<sup>45</sup> In addition to having higher rates of cell proliferation, which are positively correlated with an increased susceptibility to carcinogens, children have less developed detoxifying mechanisms.<sup>46</sup> A child's body composition, the proportion of body weight made up of fat tissue, and the distribution of fat may also have an important influence on childhood risks from pesticides.<sup>47</sup>

Another reason that children are more vulnerable to toxins than are adults is that some toxins, referred to as "initiators," are not capable of inducing tumors alone, but are believed to require later exposure to chemical "promoters," "which further alter the genetic code governing cell reproduction."<sup>48</sup> Thus, exposure to toxins during childhood increases the probability that the initiated cells will be "promoted through additionally necessary stages of tumor development," given that a child has a longer period of time during which exposure to promoters may occur.<sup>49</sup>

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<sup>39</sup> Howlander N., AM Noone, M. Krapcho, et al. "SEER Cancer Statistics Review, 1975-2010." [http://seer.cancer.gov/csr/1975\\_2010/](http://seer.cancer.gov/csr/1975_2010/), based on November 2012 SEER data submission. Bethesda, MD: National Cancer Institute, 2013.

<sup>40</sup> American Cancer Society. *Cancer Facts and Figures 2014*. Retrieved September 29, 2015. (<http://www.cancer.org/Research/CancerFactsFigures/index>).

<sup>41</sup> Ibid.

<sup>42</sup> Ibid.

<sup>43</sup> Pan, IJ, JL Daniels, and K. Zhu. 2010. "Poverty and Childhood Cancer Incidence in the United States." *Cancer Causes Control*. 21:1139-1145.

<sup>44</sup> Landrigan, PJ, and LR Goldman. 2011. "Children's Vulnerability to Toxic Chemicals: A Challenge and Opportunity to Strengthen Health and Environmental Policy." *Health Affairs* 30:842-850.

<sup>45</sup> Ibid.

<sup>46</sup> Wargo, John. 1998. *Our Children's Toxic Legacy: How Science and Law Fail to Protect Us From Pesticides*. Yale University Press.

<sup>47</sup> Ibid.

<sup>48</sup> Ibid.

<sup>49</sup> Ibid:176.

Exposure to endocrine-disrupting chemicals,<sup>50</sup> such as phthalates and bisphenol A, has been cited as a risk factor for early puberty.<sup>51</sup> These hormonally active chemicals are used to make synthetics malleable and are found in consumer products, including children's toys, shower curtains, and water bottles, as well as pesticides, packaging, and building materials. Consequently, children are continuously exposed to low-level endocrine disruptors in their diet, drinking water, air supply, and consumer products.<sup>52</sup>

### *Self-protection and Maternal Responsibility*

From the perspective of risk theory, constructions and definitions of risk are fluid, leaving them open to interpretation and redefinition. The media, science, and legal professions create definitions of risk, and consequently possess the greatest social and political authority in this regard.<sup>53</sup> Where the media shapes public understandings of the causes of environmental degradation, as well as understandings regarding who is responsible in the management of risk,<sup>54</sup> it plays a major role in the social construction of risk.<sup>55</sup> An increasing focus on self-protection is presented in media articles related to the human health consequences of environmental pollution. These materials highlight "personal health" models, many of which focus on consumer goods as a medium through which people are exposed to chemicals, rather than focusing on collective responsibility and institutional complicity.<sup>56</sup> This conveys a sense of individual empowerment and agency through acts of "green" consumption.<sup>57</sup> The result is that the risk of chemical exposure is perceived as being manageable at the individual-level, while simultaneously deflecting attention from states and industries' mismanagement of manufacture and distribution of chemicals.

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<sup>50</sup> An endocrine disruptor is defined as a chemical agent that interferes with the synthesis, secretion, transport, binding, action or elimination of natural hormones in the body.

<sup>51</sup> Steingraber, Sandra 2007. "The Falling Age of Puberty in U.S. Girls: What We Know, What We Need to Know." Breast Cancer Fund.

<sup>52</sup> Ibid.

<sup>53</sup> Beck, Ulrich. 1992. *Risk Society: Towards a New Modernity*. Newbury Park, CA: Sage.

<sup>54</sup> Brown, Phil, Stephen M. Zavestoski, Sabrina McCormick, Joshua Mandelbaum, and Theo Luebke. 2001. "Print Media Coverage of Environmental Causation of Breast Cancer." *Sociology of Health & Illness*. 23(6):747-775.

<sup>55</sup> Adam, Barbara, Stuart Allan, Cynthia Carter, and Ulrich Beck (editors). 1999. *Environmental Risks and the Media*. New York, NY: Routledge.

<sup>56</sup> Brown, Phil, Stephen M. Zavestoski, Sabrina McCormick, Joshua Mandelbaum, and Theo Luebke. 2001. "Print Media Coverage of Environmental Causation of Breast Cancer." *Sociology of Health & Illness*. 23(6):747-775.

<sup>57</sup> Maniates, Michael. 2002. "Individualization: Plant a Tree, Buy a Bike, Save the World? Pp. 43-66 in *Confronting Consumption*, edited by T. Princen, K. Conca, and M. Maniates. Cambridge, MA: MIT Press.

U.S. public health organizations, including the American Cancer Society (ACS) and the Centers for Disease Control and Prevention (CDC), also emphasize self-protection. These institutions take a less active approach to the prevention of cancers linked to toxins, and primarily focus on modifiable anthropogenic risk factors, such as nutrition, tobacco use, and excessive sun exposure. One reason for this is that factors such as these have yielded the most measurable results with regard to lowering cancer risk in the general population, and thus have resulted in successful policy and program interventions.<sup>58</sup> However, in distributing materials on contaminant avoidance,<sup>59</sup> these institutions also minimize the role of larger social and political structures in contributing to environmental risk and their negative health consequences. Suggestions are provided, for example, for reducing dioxin exposure by using fat-free or low-fat milk and using butter moderation. To reduce arsenic risk, the National Institute of Health recommends testing one's drinking water, and eating a "well-balanced diet for good nutrition."<sup>60</sup> These inconsistencies extend to health research and public health policies, where models often present individual responsibility and cultural explanations as organizing and theorizing principles. For example, the model of disease causation that dominates social epidemiological studies today draws attention to a number of interacting factors that might contribute to disease.<sup>61</sup> Demographic characteristics, such as gender and race, become further decontextualized within a "spiderless" web of causation,<sup>62</sup> and the significance of these factors in determining health outcomes is distorted.

An abundance of popular literature, shopping guides, and health promotion materials have been published on the topic of green consumption, safe consumer selection, and non-toxic choices.<sup>63</sup> These primarily target pregnant women and parents of young children, with a focus upon protecting the fragility of children's growing bodies from exposure to toxins.<sup>64</sup> These

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<sup>58</sup> Fontham, ET, MJ Thun, E. Ward, AJ Balch, JOL Delancey, and J Samet. 2009. "American Cancer Society Perspectives on Environmental Factors and Cancer." *CA Cancer Journal for Clinicians* 59:6.

<sup>59</sup> National Institute of Health. 2015. "Arsenic." *National Institute of Environmental Health Sciences*. Retrieved January 7, 2016. (<https://www.niehs.nih.gov/health/topics/agents/arsenic/index.cfm>)

<sup>60</sup> National Institute of Health. 2012. "Dioxins." *National Institute of Environmental Health Sciences*. Retrieved January 7, 2016. (<http://www.niehs.nih.gov/health/topics/agents/dioxins/index.cfm>)

<sup>61</sup> Diez-Roux, AV. 1998. "Bringing Context Back into Epidemiology: Variables and Fallacies in Multilevel Analysis." *American Journal of Public Health* 88(2):216-222.

<sup>62</sup> Krieger, Nancy. 2001. "Theories for Social Epidemiology in the 21<sup>st</sup> Century: An Ecosocial Perspective." *International Journal of Epidemiology* 30:668-677.

<sup>63</sup> Mackendrick, Norah. 2014. *Gender & Society* 28(5):705-728.

<sup>64</sup> Kukla, Rebecca. 2010. "The Ethics and Cultural Politics of Reproductive Risk Warnings: A Case Study of California's Proposition 65." *Health, Risk & Society* 12:323-334.

materials encourage participation in what MacKendrick calls “precautionary consumption,” wherein the consumer examines food, household, or cosmetic product contents for synthetic chemicals, in an effort to reduce exposure to toxins.<sup>65</sup> Attention is heavily directed toward all aspects of maternity, including the protection of pre-pregnancy maternal health.<sup>66</sup> As such, the process of such levels of self-monitoring, as well as the management of child health exposures, is labor-intensive.<sup>67</sup> What can reasonably be garnered from these institutions’ emphasis on the individualization of risk and self-protection is that chemical exposure is an issue that can be mediated at the individual and family-levels. Furthermore, the management of exposure to toxins becomes constructed as a caregiving responsibility that is traditionally defined as a role for women and mothers.

### *Risk Assessment and Scientific Uncertainty*

The National Toxicology Program (NTP), established in 1978, coordinates the identification and evaluation of carcinogens in the U.S. The International Agency for Research on Cancer (IARC), a branch of the World Health Organization, promotes international collaboration in cancer research, with emphasis on environmental factors.<sup>68</sup> Yet there are currently only 108 substances classified by IARC as carcinogenic to humans.<sup>69</sup> Carcinogens are usually identified on the basis of epidemiological studies or by testing on animals. It is more difficult to study the relationship between exposure to potentially carcinogenic substances and cancer risk in the general population because of uncertainties about exposure and the challenges of long-term follow up. Additionally, evaluation of many substances is inhibited by a lack of data on industrial and commercial chemicals.<sup>70</sup>

The Centers for Disease Control and Prevention (CDC), the National Cancer Institute (NCI), and the EPA assist states with investigating disease clusters. Each year, state and local health departments respond to more than 1,000 inquiries about suspected cancer clusters,<sup>71</sup> with

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<sup>65</sup> Ibid.

<sup>66</sup> Waggoner, Miranda. 2013. Motherhood Preconceived: The Emergence of the Preconception Health and Health Care Initiative. *Journal of Health Politics, Policy and Law* 38:345-71.

<sup>67</sup> Ibid.

<sup>68</sup> WHO. 2015. “IARC’s Mission: Cancer Research for Cancer Prevention.” World Health Organization. Retrieved October 28, 2015. (<http://www.iarc.fr/en/about/index.php>).

<sup>69</sup> Fonham, ET, MJ Thun, E. Ward, AJ Balch, JOL Delancey, and J Samet. 2009. “American Cancer Society Perspectives on Environmental Factors and Cancer.” *CA Cancer Journal for Clinicians* 59:6.

<sup>70</sup> Ibid.

<sup>71</sup> Thun, Michael J. and Thomas Sinks. 2004. “Understanding Cancer Clusters.” *CA: A Cancer Journal for Clinicians* 54:273-280.

most being determined to not be cancer clusters through the process of telephone interviewing.<sup>72</sup> When health officials do investigate a suspected disease cluster community, it is usually the result of political pressure, public attention, and/or the media,<sup>73</sup> as was the case with Clyde. The slow response from the local, state, and the federal government to investigate the cause of disease in Clyde reflects a political resistance common to other disease cluster cases. In Love Canal, for example, rather than addressing the actual problems related to citizens' health, the legal system ignored scientific evidence and conveniently favored corporate interests.<sup>74</sup> Rather than being objectively grounded in science, this instance became an example of how risk assessment, amplified in part by the limited resources allotted to operate regulatory systems, supported the socio-political status quo.<sup>75</sup>

In 2011, some U.S. senators, including Ohio's Democratic Senator Sherrod Brown, began pushing for a federal law that would strengthen protection requirements for children and communities from disease clusters, in part by increasing federal funding towards such investigations.<sup>76</sup> While environmental groups such as the Natural Resources Defense Council believe that toxic chemicals are likely to be responsible for the dozens of disease clusters identified across the U.S., and therefore should be better regulated, some Republicans on congressional environmental committees have expressed concerns about over-regulation by the EPA—especially with a lack of scientific proof.<sup>77</sup>

Residents of Clyde perceived a political resistance on the part of the Ohio Department of Health and the EPA with regard to investigating the suspected toxin/illness link within their community. Although perhaps his chosen words were insensitive, former Ohio Department of Health Director Robert Indian's statement about disease clusters as "will-o-the-wisp things" was likely conflated with the limitations of the current systems for effective risk assessment.

What is known about toxins and their impact on health largely exists within the parameters of scientific knowledge. In line with risks as defined in the risk society, this knowledge is based on causal interpretations. Epidemiologists' rely on environmental science,

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<sup>72</sup> Ibid.

<sup>73</sup> Lester, Stephen. 2010. "Assessing Health Problems in Communities." *Center for Health, Environment & Justice*.

<sup>74</sup> Levine, Adeline. 1982. *Love Canal: Science, Politics, and People*. Lexington, MA: Lexington Books.

<sup>75</sup> O'Brien, Mary. 2000. *Making Better Environmental Decisions: An Alternative to Risk Assessment*. Cambridge, MA: MIT Press.

<sup>76</sup> Strengthening Protections for Children and Communities from Disease Clusters Act, S. 76, 112<sup>th</sup> Cong. (2011).

<sup>77</sup> Koff, Stephen. 2011. "Senators want better investigations of 'disease clusters,' but may disagree on methods." March 30, 2011. Retrieved October 25, 2015. ([http://www.cleveland.com/open/index.ssf/2011/03/senators\\_want\\_better\\_investiga.html](http://www.cleveland.com/open/index.ssf/2011/03/senators_want_better_investiga.html))

lifestyle factors, and biostatistics to determine whether a suspected cluster is truly evidence of an excess of cancer cases.<sup>78</sup> Most are determined not to be clusters, and many are believed to occur by chance. Those that are more likely to represent true clusters, are usually characterized by having a large number of cases of one type of cancer, a rare type of cancer, and/or an increased number of cases of a certain type of cancer in an age group that is not usually affected by that type of cancer.<sup>79</sup> Historically, higher profile cancer clusters, such as those connected to AIDS identification or the presence of asbestos, had one or more of these characteristics.

Determining whether a community has a statistically significantly higher cancer risk than the general population requires current and complete information on the incidence of disease within that community. However, many states do not have accurate tracking systems, and many do not track the full range of conditions that may be linked to toxic exposure.<sup>80</sup> This causes delays in investigations, prevents the identification of disease trends, inhibits the identification of true clusters, and reduces the number of investigations conducted by states.<sup>81</sup>

Studies of suspected clusters typically focus on both genetics and environment, including behavior and lifestyle. Scientifically establishing a genetic-environmental interaction requires long-term studies of large populations.<sup>82</sup> Much has yet to be understood regarding the roles that genetics and environmental exposures play in carcinogenesis, but one recent discovery is that of germline mutations, wherein some genetic changes that increase the risk of cancer can be passed from parent to child.<sup>83</sup>

To determine whether illnesses within a community are the result of environmental toxins, epidemiologists assess exposures by measuring how much of a contaminant can be absorbed by an exposed individual, in what form, at what rate, and how much of the absorbed amount is actually available to produce a biological effect. All five of the following elements must be present for an “exposure pathway” to be considered complete: 1) Source (where the chemical came from), 2) Environmental Transport (the way the chemical moves from the source

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<sup>78</sup> National Cancer Institute. 2014. “Cancer Clusters Fact Sheet.” *U.S. Department of Health and Human Services, National Institutes of Health*. Retrieved October 23, 2015. (<http://www.cancer.gov/about-cancer/causes-prevention/risk/substances/cancer-clusters-fact-sheet>)

<sup>79</sup> Ibid.

<sup>80</sup> Dutzik, Tony and Jeremiah Baumann. 2002. “Health Tracking & Disease Custers.” U.S. PIRG Education Fund.

<sup>81</sup> Ibid.

<sup>82</sup> National Cancer Institute. 2014. “Cancer Clusters Fact Sheet.” *U.S. Department of Health and Human Services, National Institutes of Health*. Retrieved October 23, 2015. (<http://www.cancer.gov/about-cancer/causes-prevention/risk/substances/cancer-clusters-fact-sheet>)

<sup>83</sup> Ibid.

to the individual), 3) Point of Exposure (where contact with the chemical is made), 4) Route of Exposure (how the chemical enters the body), and 5) People who might be exposed (those who are most likely to come into physical contact with a chemical).<sup>84</sup> Consequently, the risk to exposed individuals varies according to the intensity, potency, and duration of the exposure, as well as other potential factors, including exposures to other carcinogens. Levels of exposure to industrial and agricultural pollutants are difficult to assess in non-occupational settings, in part due to the populations at risk being less clearly defined.<sup>85</sup> Even in the 5-15% of reported cases wherein statistical testing confirms that the number of observed cases exceeds the number of expected cases, further epidemiologic investigation almost never identifies the underlying cause of disease with confidence.<sup>86</sup> Current systems for identifying and classifying evidence for carcinogenicity (at every level) and risk assessment share a common constraint—the scientific complexity of the issues at hand.

Determining the causal effect of a single toxin on health is challenging because individuals are exposed to a complex mixture of carcinogenic compounds throughout their lifetimes.<sup>87</sup> Additionally, the “specific mechanism by which carcinogens act is often unknown.”<sup>88</sup> Some toxins, for example, are referred to as “initiators”. They are not capable of inducing tumors alone, but are believed to require later exposure to chemical “promoters,” which “further alter the genetic code governing cell reproduction.”<sup>89</sup> It is very difficult to predict exposure to the substances now presumed to be a complex mixture of initiators and promoters.<sup>90</sup> It has been shown that when compounds interact with one another, toxic effects can be more harmful than those resulting from singular exposure.<sup>91</sup> However, when testing chemicals for their potential danger to human health or determining acceptable limits of exposure, the U.S. regulatory system considers them in isolation from each other and does not account for the transformation of these compounds via interaction. Yet the unwillingness to consider the effects of compounding chemicals further delays efforts towards the prevention of disease.

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<sup>84</sup> Agency for Toxic Substances & Disease Registry. 2005. “Exposure Evaluation: Evaluating Exposure Pathways.” ATSDR. Retrieved October 23, 2015. (<http://www.atsdr.cdc.gov/HAC/PHAManual/ch6.html>)

<sup>85</sup> Thun, Michael J. and Thomas Sinks. 2004. “Understanding Cancer Clusters.” *CA: A Cancer Journal for Clinicians* 54:273-280.

<sup>86</sup> Ibid.

<sup>87</sup> Wargo, John. 1998. *Our Children’s Toxic Legacy: How Science and Law Fail to Protect Us From Pesticides*. Yale University Press.

<sup>88</sup> Ibid.

<sup>89</sup> Ibid:173.

<sup>90</sup> Ibid.

<sup>91</sup> Ibid.

Contributing to the conundrum, scientific methods are not very successful with regard to assessing the level of threat posed by carcinogens to communities.<sup>92</sup> Conservative cut-offs for statistical significance mean that disease clusters in small communities may be overlooked, and consequently, opportunities are lost for creating meaningful policy. The ambiguous nature of toxin exposure results contributes to lack of accountability, and ultimately benefits corporations and regulatory bodies.

*Risk Assessment as “Organized Irresponsibility”*

Beck argues that the calculation of risk, as it has been established so far by science and legal institutions, collapses because the “normative bases of their calculation do not fit the basic dimensions of modern threats.”<sup>93</sup> Dealing with today’s risks in normal terms of risk is a “false but nevertheless very effective way of legitimizing them.”<sup>94</sup> Furthermore, risk and responsibility are intrinsically connected. Because the production of risks is difficult to attach to an identifiable actor or institution, actors or institutions are not held accountable for the hazards generated by the risk society in what Beck refers to as “organized irresponsibility.”<sup>95</sup> It is increasingly unlikely that individuals affected by the generated dangers can receive recourse due to the convoluted nature of source and accountability, and the impossibility of calculating risk.<sup>96</sup>

Though not included in the public health assessments conducted in Clyde and the surrounding area, it is profoundly notable that many adults also have presented with an inordinate number of unusual and multiple cancers. Their lack of inclusion in public health assessments highlights a diminished scrutiny within the U.S. regulatory system, and the limits on resources directed to research, tracking, and prevention of toxic exposures. As we have seen in the interviews, families in Clyde searching for answers were keenly aware of these weaknesses. With regard to public health assessments, they questioned why health agencies were only searching for known causes of illness when there might be other existing chemicals or combinations therein that had not yet been linked to cancer. Some in Clyde implicitly identified the limitations of health tracking data as related to the current status of illnesses within the

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<sup>92</sup> Edwards, Nelta. 2008. “An Ounce of Precaution.” *Contexts* 7(20):26-30.

<sup>93</sup> Beck, Ulrich. 1992. *Risk Society: Towards a New Modernity*. Newbury Park, CA: Sage.

<sup>94</sup> *Ibid*:22.

<sup>95</sup> *Ibid*:6.

<sup>96</sup> *Ibid*.



community, noting that several new cases of childhood cancer since the 2006 assessment were not reflected in the statistics.

Some advocate for greater participation of citizens<sup>97</sup> in the production and utilization of scientific data in disease cluster investigations—what has been termed “popular epidemiology.”<sup>98</sup> Public participation in the research processes of contaminated communities consists of both community members and stakeholders, including site owners and industry and business.<sup>99</sup> Collaboration between citizens and epidemiologists with regard to identifying and resolving environmental illness patterns is important for accomplishing public health goals. The need for collaborative research is supported from a number of professional associations and regulatory institutions, including The National Institute of Environmental Health Sciences, National Institute of Allergies and Infectious Diseases, U.S. EPA, and CDC.<sup>100</sup>

While the narrowly ranged voices of experts were previously considered to be the most valid, emerging in the risk society is the declining belief in their authority. The rise of social movements has elevated lay voices to the status of being equally valid, and has challenged traditional methods of reducing uncertainty to the point of making risks manageable.<sup>101</sup> However, while popular epidemiology may be a promising path forward, it is not yet a widely used method, and was not done in Clyde. Furthermore, not all communities achieve successful outcomes with regard to both collaboration and identifying causes of disease. Pessimism generated by lack of receptiveness of government institutions leads to suspicions that the government only pays lip service to the open-ended process of public inclusion in participatory processes of discovery.<sup>102</sup> This attaches a moral dimension to issues of responsibility, justice, and fairness. Even in cases including public participation, victims remain largely unheard and marginalized, with governmental agents only listening to expert voices.<sup>103</sup> Cantelli et al. (2010) highlight the value of including soft sciences for the anticipation of concerns such as

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<sup>97</sup> The term “citizens” is seemingly used in environmental health studies to invoke the spirit of democratic processes, or often the lack thereof, when environmental and health decisions are made.

<sup>98</sup> Brown, P. 2003. “Qualitative Methods in Environmental Health Research.” *Environmental Health Perspectives* 111(14):1789-1798.

<sup>99</sup> Ashford, Nicholas and Kathleen Rest. 1999. *The Importance of Public Participation in Contaminated Communities*. Center for Technology, Policy, and Industrial Development. Massachusetts Institute of Technology.

<sup>100</sup> Ibid.

<sup>101</sup> Cantelli, Fabrizio, Naonori Kodate, and Kristian Krieger. 2010. “Questioning World Risk Society: Three Challenges for Research on the Governance of Uncertainty.” *Global Policy*

<sup>102</sup> Ibid.

<sup>103</sup> Fortmann, Louise. 2008. *Participatory Research in Conservation and Rural Livelihoods: Doing Science Together*. New York: Wiley Blackwell.

communication and voice-receptive agency, lay participation, and democratization of risk management.

The community of Clyde faced institutional barriers that inhibited growth of equitable forms of risk governance and the political agency of citizens. Like impacted families elsewhere, families in Clyde were forced to become their own advocates. Some turned to the literature on toxins to self-educate. One family even reached out to well-known environmental whistleblower Erin Brockovich for help. When the plaintiffs felt that they had exhausted all other options, they turned to attorneys and experts to take the lead in the search for answers. Paradoxically, residents increasingly became dependent on science and experts in their efforts to find justice and resolution. The willingness to challenge Whirlpool and stand up against the unassailable science, albeit with their own experts, was propelled in part by a questioning in the effectiveness of modern governmental health and environmental agencies. These acts of self-agency indicate a shift towards reflexive modernity, yet, the empowerment implied within that concept was hampered when even the plaintiffs' team of "experts" lost their ability to provide certainty. The eventual withdrawal of the lawsuit further illustrates the difficulties of seeking resolution for toxic contamination within a system where legal decisions must be based on specific evidence.

To add to the problem, the community divided over the filing of the lawsuit against Whirlpool Corporation. In the next chapter, I move from an analysis of the individualization of responsibility at the institutional level to how it manifests at the individual-level through popular beliefs and everyday practices. I argue that this notion, along with other social factors, anchors perceptions of risk and illness within the community of Clyde.

## CHAPTER 4

### TRUTHS AND FALSEHOODS

*Winesburg, Ohio* is a 1919 collection of short stories by Sherwood Anderson.<sup>1</sup> The fictional town of Winesburg is largely based on the writer's memories of his own childhood town of Clyde, Ohio. Winesburg provides a picturesque setting for Anderson's stories—a quaint rural Ohio community reminiscent of an era when people farmed and owned independent businesses. While the time period of Anderson's stories is post-Civil War, the author describes Winesburg as being somewhat isolated from the social and cultural influences of the Industrial Revolution. This distinction implies that the town of Winesburg existed on the cusp of change from a traditional, pre-industrial society, and was transitioning slowly to a society characterized by the spread of industrialization. The prologue in Anderson's collection, titled "The Book of the Grotesque," lays the foundation for the stories that follow. It centers on an epiphany of an old writer:

In the beginning when the world was young there were a great many thoughts but no such thing as a truth. Man made the truths himself and each truth was a composite of a great many vague thoughts. All about in the world were the truths and they were all beautiful [...] And then the people came along. Each as he appeared snatched up one of the truths and some who were quite strong snatched up a dozen of them. It was the truths that made the people grotesques [...] the moment one of the people took one of the truths to himself, called it his truth, and tried to live his life by it, he became a grotesque and the truth he embraced became a falsehood.

When the old man has a vision of grotesques appearing before him, he obsessively writes hundreds and hundreds of pages on the subject with the intention of writing a book. In so doing, Anderson explains that the old man almost becomes a grotesque himself, and in the end the fictional character never publishes the book. The reader comes to understand that *Winesburg, Ohio* is the book of the grotesque—each short story examining the life of a Winesburg character

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<sup>1</sup> See Anderson, Sherwood. 1919. *Winesburg, Ohio*. New York: B.W. Huebsch.

by exposing his or her private troubles and vulnerabilities. Loneliness, restlessness, disillusionment, and isolation are a few of the prevailing themes that paint a picture of a town composed of disenfranchised inhabitants who, although geographically close, have no real sense of community.

After publication of Anderson's book, residents of Clyde viewed it as being a derogatory portrayal of their community to the extent that the library initially "kept a single copy in a locked closet with other bad books."<sup>2</sup> Today, Clyde honors Sherwood Anderson in its museum and on signs posted throughout the community. Clyde's other claim to fame is that it is the "washing machine capital of the world." At The Clyde Public Library, one will find a "Whirlpool Room," while yet there is no such space reserved to honor Sherwood Anderson.

It is perhaps not surprising that residents would grapple with Anderson's portrayal of their community. The word "grotesque" itself has a negative connotation and suggests characters and images that are implicitly unpleasant. Aside from the implicit negativity of the word, the relevance of Anderson's characterization of truths and falsehoods in Winesburg offers an ironic parallel to the current dilemma in the town in Clyde. In a sense, it reflects one of the prevailing issues concerning the present-day cancer cluster.

Human responses to environmental hazards are mediated by interpretative processes<sup>3</sup> and affected residents often perceive environmental risks in different ways. The emergence of dissenting factions is a common occurrence within contaminated communities, and, in the case of Clyde, it is engendered in part by the ambiguity associated the undetermined etiology of the disease cluster. Differing interpretations of risk often underscore the conflicts that arise between groups.<sup>4</sup> The invisibility of contaminants makes them largely imperceptible,<sup>5</sup> which adds to confusion regarding point of origin. Ambiguity is advanced by regulating entities, such as state, local, or corporate officials, who either withhold information entirely or present information that

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<sup>2</sup> Putre, Laura. "Unfavorite Son: A Small Town Shuns its Most Famous Dead Resident." *Cleveland Scene Magazine*. Retrieved March 2, 2016 (<http://www.clevescene.com/cleveland/unfavorite-son/Content?oid=1478063>)

<sup>3</sup> Kroll-Smith, J.S. and S.R. Couch. 1993. "Symbols, Ecology, and Contamination: Case Studies in the Ecological-Symbolic Approach to Disaster." *Research in Social Problems and Public Policy* 5:47-73.

<sup>4</sup> Shriver, Thomas E. and Dennis K. Kennedy. 2005. "Contested Environmental Hazards and Community Conflict Over Relocation." *Rural Sociology* 70(4):491-513. See also Capek, S.M. 1993. "The 'Environmental Justice' Frame: A Conceptual Discussion and an Application." *Social Problems* 40:5-24.

<sup>5</sup> Beck, Ulrich. 1992. *Risk Society: Toward a New Modernity*. London: Sage. See also Erikson, K. 1991. "A New Species of Trouble." Pp. 11-29 in *Communities at Risk: Collective Responses to Technological Hazards*, edited by S.R. Couch and J.S. Kroll-Smith. New York: Peter Lang.

is contradictory in nature. Consequently, affected residents must make assessments of harm and corrective decisions based upon differing sets of criteria.<sup>6</sup>

Several prominent areas of contention in Clyde related to the debate surrounding what constitutes legitimate knowledge. Science, albeit prone to obfuscation, was the definitive platform for most of these debates. In spite of the federal EPA's discovery of PCBs at the former Whirlpool Park, the biggest conflict that emerged was among the residents themselves regarding what caused the cancer, rather than between the community and Whirlpool Corporation as the cause of contamination. The filing of the lawsuit against Whirlpool Corporation in March 2013 brought wider attention to the Clyde cancer cluster. The lawsuit divided the community into different camps: those who supported it, those who supported Whirlpool, and those who chose not to take a public stance on the issue. As has been seen in other cases of contaminated communities, the division among residents in Clyde was coupled with "diversionary reframing,"<sup>7</sup> a tactic used by competing groups to discredit one another.

Existing among those who were involved with or supported the lawsuit was a strong belief that the root of the cancer problem in Clyde was likely due to environmental toxins, in part because physicians and health officials led them to believe that this was the case. Stories circulated involving eye-witness accounts of the corporation appropriating the community's natural resources and using them as distribution points for waste without consent. Accounts of dumping in the creek, Whirlpool Park, and sites west of town were accepted as common knowledge by many. One resident, Josephine, a four-time cancer survivor who had previously lived near Whirlpool Park, had her well tested for toxins and was told that there were 15 cancer-causing chemicals in her water. She remembers seeing Whirlpool employees dump at the park:

Well, I'm not an analyst—I didn't analyze those chemicals, but there *were* chemicals. I was suspicious. I used to run out there and say, 'what are you doing?' It was usually on the closing day—they were closed on Mondays...it wasn't every Monday, but it was often...and they would bring a big dump truck and they would open up the gates, back it into this little area and dump this garbage— canisters,

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<sup>6</sup> Shriver, Thomas E. and Dennis K. Kennedy. 2005. "Contested Environmental Hazards and Community Conflict Over Relocation." *Rural Sociology* 70(4):491-513.

<sup>7</sup> Freudenburg, W.R. and R. Gramling. 1994. "Mid-range Theory and Cutting Edge Sociology: A Call for Cumulation." *Environment, Technology and Society* 76:3-6.

barrels, sometimes cement, buckets. I often walked in that woods. I never did photograph the trucks. I wasn't out to get anybody—I've never been that kind of a person. I did call the EPA, and they never got back to me. And that water that filled the pool came outta the creek. So that stuff that they were dumpin' in that pile went into the creek and then went into a slight filtration system they had and that water went right into the swimming pool all those years. It was mess down there. I hated it because it was so beautiful back there. I just loved to walk the woods.

After the filing of the lawsuit, concerns were expressed that the Whirlpool factory was releasing toxic fumes at night because they detected a noxious odor surrounding the plant. Indeed, I also experienced this smell during my first visit to the community in the spring of 2013 when I booked a room at a hotel adjacent to the factory. Upon stepping outside to retrieve something from my car that night, I was struck by a potent burning chemical/plastic odor that permeated the air. The "Whirlpool smell" at night became a talking point at public meetings. Observers stated that shortly after the filing of the lawsuit, the smell went away. During my subsequent stay and many other visits to the community, I also noticed that the Whirlpool smell was no longer there.

Suspicious were shared about occupational hazards within the Whirlpool facility itself. Carl, who suffered from heart problems and Parkinson's disease, questioned whether his heart problems were related to his 36 years in management at Whirlpool:

I worked in finishes, we worked with a lot of hazardous chemicals in that area, but when we first put in a powder coat system, at that time, we didn't know when we first put it in, but the makeup of that powder coat had a known carcinogen in it and could form mutations. And I, we did lose some operators with heart issues from there. Uh shortly after that they changed the formula on that, but I mean, and then those guys died after that time. But it was just kind of strange that three of the guys passed away. We've had some cancer in the area where they had a lot of oil mess, but you know, I think that that doesn't, to me, that's not any different than any other manufacturing plant that has the hazardous chemicals or has the oil misting process. I think it's just the nature of the work, so I guess that's kinda...I don't like to say that it's definitely Whirlpool. But yeah we have had deaths that I've questioned whether, I thought probably came from the work conditions, but.

Erika, also a longtime Whirlpool employee, expressed her early suspicion that the working environment there might be making employees sick:

I have worked at Whirlpool for 37 years, and my best friend from the time I was four, she developed breast cancer at 34, and she worked at Whirlpool. This was before anything about the cancer cluster. She said, ‘I think it was some of the chemicals that I worked with, in paint and porcelain.’ And of course, I had always heard rumors at work that Whirlpool dumped in the creek out there just to get rid of stuff without having to pay to have it hauled away. I heard it from guys who were told to do it. And then when I was about six, my dad and I would go mushroom huntin’ just west of town right outside the city limits. There used to be an apple orchard and back in one corner there was a bunch of old barrels. They were green, with different colored stuff coming out of ‘em, and my dad would say, ‘don’t go back there.’ It was one of [Whirlpool’s] dumping grounds and my dad was employed at Whirlpool for probably 40 years. So I remember from back then, him saying that stuff was there. And then there was that place on Main Street that a friend of mine grew up in, and my dad said Whirlpool had buried barrels in their front yard [...] So when all these kids started getting it, and they said it could be the PCBs and all that...then I kind of started wondering if what my girlfriend— ‘cause my girlfriend eventually died in 2000—I thought, I wonder if that odd comment she made back then really was true. [...] I live with my boyfriend, and his sister’s boyfriend just found out he had cancer. They took a mass off his spine, told him it was cancer, and two weeks later he was dead. My ex-sister-in-law, her husband died of cancer of the spine and he also worked at Whirlpool, so...and there’s a really unusual number of people at Whirlpool that have had it and died from it or just gone through the treatment, so.

Whirlpool was quick to suppress concerns at the plant by distributing pamphlets that reiterated the ODH assertion regarding the safety of benzaldehyde. In addition to public statements clearing themselves of responsibility, it was explained to me that the company sent employees

home with a paper that made it clear that they would “vigorously defend our company, our community, and our employees.”

*Dissenting Voices: Seeking Resolution and Justice*

Perceptions of harm were amplified for some because of the profound impact on so many children, serving as the impetus for mobilization among affected residents seeking redress for the contamination. This group, as well as those sympathetic to the lawsuit, represented a minority of residents who dissented from the majority opinion regarding the problem of cancer and how to resolve it. It is of interest that those at the forefront of the lawsuit were more likely to express environmental concern, seek relevant information, and become more educated on environmental hazards than were those not personally impacted.

A reasonable belief existed that the cancer cluster was linked to environmental toxins since it was authoritatively determined to be so by family physicians and health department officials. However, after approximately seven years of frustration and failed attempts to achieve resolution through ODH and the EPA, litigation seemed to be the only way to get answers and draw attention to the issue. The plaintiffs believed that attorneys and experts would advocate for them and take the lead in determining who was responsible for environmental contamination within the community. Every plaintiff that I interviewed emphasized that they did not have a particular agenda against Whirlpool, and that they did not want the company’s Clyde plant to close. They simply wanted answers, and Whirlpool was not cooperating with their efforts towards finding them. The lawsuit was a last resort that they viewed as the only alternative in determining why so many people were getting sick. Plaintiffs knew that a lawsuit would allow them access to records and information in the discovery process that they would not otherwise be able to view.

Additionally, plaintiffs and others in support of the lawsuit wanted Whirlpool to live up to their positive reputation within the community. If it was discovered that Whirlpool was responsible for cancer-causing pollution, they wanted Whirlpool to stop polluting and to clean up the contaminants for which they were responsible, essentially living up to its reputation. They wanted to prevent pollution from happening in the future, and protect other residents’ from experiencing illness within their families. If Whirlpool were found to be responsible, the plaintiffs wanted the company to be held accountable as a preventive measure in protecting other



communities. They were also convinced that taking no action against the company would make other companies think that they could get away with similar offenses.

Another motive for the lawsuit was the belief that affected families should be compensated for their losses. Josephine explained:

Money has never meant anything to me—I have always been poor. A working poor person, but I'd be a liar if I didn't say hell yeah, it's gonna help my life. You know, I'm moving from here because my financial...is so tight. I can't afford a handyman to keep this place up. And sure, I think it's going to bring some joy in my life. And I'm looking forward to it, and I deserve it. You wouldn't believe what I've been through. I went through pictures of the radiation to my eye, the surgery. The bone marrow transplant. I know the pain those parents are feeling. And you never get rid of it. And there's too many we're burying. Too many children are being buried over there in Clyde. And being sick right now as we speak. And it's gotta stop. Somebody's gotta pay. I'm a bawl-baby. I cry about everything, Laura.

Forty-four year old Dave expressed a justifiable sense of advocacy for his sick children on both a financial and emotional level in that they not only deserved to be supported for what they have been through, but also for what could possibly happen to them in the future because of the consequences of their illness:

I'm gonna say partially it is about money. Because our lives have been changed, and their lives have been changed. We wanna find the answers and we want to get to the bottom of it, however if somebody or some corporation has done this then I feel my kids deserve to have a better life in the future because their life may be one more year, may be five, it may be 20. But there's a good chance they're gonna have problems down the road. So if money from somebody, who caused something or did something, be it unintentionally maybe, I feel that they deserve a little break in life. [...] My family I think is what keeps me in it because if somebody did do something wrong, I do feel, it needs to get fixed, but I do feel my family deserves a break, and if that means that we get some money, our house gets paid for, my wife can help with the kids more, you know and spend more time with them, and

help them with school...because it does affect some of your learning and stuff like that. I don't know, I just I can't believe anybody would fault me for believing that if somebody did cause this that to make their lives a little bit easier, and our lives a little easier that we do deserve it. Some people don't wanna hear that, but it's the truth.

Most plaintiffs expressed a desire to believe that someone in the legal system would help them find justice. In light of what was known about health consequences of PCB exposure, as well as the prevalence of disease within their community, some believed that the case would likely be ruled in their favor.

### *Protecting Whirlpool*

The question remains as to why, in the face of so many eyewitness accounts of Whirlpool dumping, there would be any resistance at all to investigating Whirlpool as a possible source of contamination in the community. Yet, when asked how elevated rates of cancer in such a small area could be explained, a number of possible theories were proposed among those defending Whirlpool. Some perceived cancer as being unpreventable by attributing its cause to genes and heredity. Others cited lifestyle variables as the cause. In reflecting on the relationship between toxins and disease, Julie, a 50-year-old bookkeeper, attributed the healthy lifestyle habits of her own family as the likely reason they have not been affected by disease:

We've been very fortunate not to have family members and if you ask me why, I think that our family, I'm a firm believer in eating good food. I told you we had a garden, my mom always did, my husband's mom always did. We've canned our own things, we don't buy a lot of processed foods. [...] None of us have any type of diseases like that. And I contribute it to food and keeping your mind healthy and busy and all that. Our immediate family hasn't been affected by it, which we're very lucky, very fortunate that God's blessed us not to have that kind of illness in our families. For the most part, we're a pretty healthy family. And we haven't had a lot of catastrophes in our family, so. I just think it's, we personally think it's all over. I mean that's why we're not picking up our family and moving. Um, we're trying to be a little healthier within our own household or maybe go back to some of old

values of cooking. You know rinsing things good when you buy things, try to buy organic, that kind of thing.

A local school nurse also expressed her firm belief that “eating healthy, exercising, and keeping your body well” are the key factors in staying healthy. She shared with me her own regimen for promoting wellness and recovery, and cited nutrition as the most promising avenue of cancer research.

Some discounted evidence of a mass occurrence of cancer by generalizing the disease as inevitable and something that would occur anyway. Fifty-year-old Shelby explained:

I'm not worried about whether or not I'm going to get cancer. For me, my faith is, if I'm, if I'm supposed to have cancer, I'm going to get it. If I'm not supposed to, I won't.

Others minimized the significance of the disease cluster by asserting that it is not unique to Clyde, and that one's life is predetermined by God. In Julie's words:

Other places have hurricanes, and more tornadoes than we have, and so there are other forms of problems. God's kinda got a plan for you and it's gonna get you no matter where you're at. [...] How are we compared to everywhere else? I haven't seen, we haven't become real involved I guess with, um, absolute facts.

Residents skeptical of the environmental/toxin link were confounded by the lack of a common denominator among the cancer cases. Specifically they wondered why certain family members in the same household who were exposed to the same air, water, and other environmental factors got cancer, while other members of the household did not. Others stated that they would be more concerned about chemical contamination and pollution from Whirlpool if only they had “scientific proof.” For them, without scientific data, it was not fair to corporations or individuals to point fingers.

Complicating the issue were implications that, if there were chemicals in Clyde, they were likely legacy chemicals from prior agricultural and industrial sources. After the filing of the lawsuit, a long-time resident submitted an article to the widely circulated local paper, *The Clyde*

*Enterprise*, which directed the community's attention to the hazardous spray used on the fruit farms on the outskirts of town in the past. Another improbable explanation that residents shared with me was the suspicion that trains traveling from the south may be dispersing toxins throughout the community via the wind.

The prevalence of illness at the Whirlpool facility itself, as described by many employees and others, was considered by some to be an expected occupational hazard. Nevertheless, although there seemed to be substantial evidence for further investigation of Whirlpool as a possible source of contamination in the face of the PCB discovery at Whirlpool Park, some residents were not even convinced that Whirlpool was responsible for the PCB sludge buried there. One woman speculated that perhaps another company from out of town trespassed onto the property and dumped the contaminants there without Whirlpool's knowledge. This concern for equity for Whirlpool, a company which sometimes employed three generations of family members, exemplified the community's loyalty to the company and the complexity of interdependence that existed. For many, a threat to Whirlpool was a threat to the community itself. References were made describing Whirlpool as a "good neighbor," a point punctuated by the frequent personification of the company. Tom, a 52-year-old banker, expressed concern that even if Whirlpool were cleared of responsibility, Whirlpool might leave the town anyway because the company would feel "hurt" that the community turned on them.

Resentment towards the plaintiffs was also present, and manifested in the form of multiple complaints. Insinuations were made that the plaintiffs were emotionally misguided—namely because the lawsuit would not bring their loved ones back. Similarly, others stated that the plaintiffs just "wanted somebody to blame." Questions arose as to the motives of specific individuals participating in the lawsuit, and as to their worthiness with regard to receiving financial support. By thus undermining the legitimacy of the lawsuit, describing it as a selfish pursuit, it was implied that plaintiffs' incentives were predominantly financial in nature. Further questioning of the plaintiffs' motives emerged through criticism of their lifestyles, with an inference that their parenting skills were suspect. Julie explained:

You know, I don't know if it's right or wrong or if they're gonna accomplish anything or if they're just gonna you know hurt themselves in the long run because it's gonna take so much of their time and maybe away from their current family and

their current lives, their involvement in their church, those kinds of things. That's the sad part, I feel for their families because I know like if the parents are really, really active in this and they're going to all these meetings and the other kids in the family seem to suffer a little bit because they're not you know going to their activities, they're not getting the current attention. Attention is still on the person that died rather than on the living. So I don't know, I don't know if it's gonna be good or bad for them.

One resident, when asked if she thought political ideology influences the way a person perceives the cluster, made a distinction between those in support of the lawsuit as being “liberal,” and those defending Whirlpool as being “conservative.” It was not clear if the misunderstanding was political or personal, yet the preponderance of evidence hinted at an existing cultural division in Clyde wherein conservative “blue-collar” values were at odds with the perception of liberal activism. Ultimately the plaintiffs’ commitment to the community came into question, and some expressed a sense of betrayal that the affected families, who had been previously supported by the community in the form of fundraisers, were going to “take the community down” with their lawsuit against Whirlpool. “If Whirlpool goes, Clyde goes, and we would become a ghost town,” another resident explained. “Sandusky County would dry up and blow away because there would be no employment here for anyone,” another resident added.

Some residents held the plaintiffs responsible for drawing negative attention to Clyde, and lamented being labeled as a “cancer cluster” with its resulting stigma. An article in the paper with the heading “Cancer City, Ohio” was particularly stinging. It is Edelstein’s observation that, aside from the negative impact upon the community as a whole, residents themselves are stigmatized by association with the contaminated community.<sup>8</sup> Referring to the plaintiffs, one woman explained to me, “Once they made the decision to make us a cancer cluster and make that known to everyone, you can't take it back. It's done, it's over.” In a sense, the lawsuit against Whirlpool seemed to be threatening the core meaning of “small town Clyde” and all of its real and imagined charms.

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<sup>8</sup> Edelstein, Michael. “When the Honeymoon is Over: Environmental Stigma and Distrust in the Siting of Hazardous Waste Disposal Facility in Niagara Falls, New York.” *Research in Social Problems and Public Policy* 5:75-95.

An April 2014 article in the *Clyde Enterprise* captures the essence of this attempt to preserve Clyde's old identity.<sup>9</sup> When asked by a Clyde resident to provide some murals for downtown Clyde for the community's 160 year celebration, a local artist expressed the desire to make the murals "look like the people of Clyde who lived in the town in the 1920s." In light of the "negative reviews by the media concerning the Clyde kids cancer cluster," the artist, a cancer survivor herself, wanted to "take the negative and turn it into a positive." Figures and portraits of people in 1920s attire would be displayed in sepia and brown earth tones on the outside of a café in downtown Clyde. "The overall plan is to put Clyde on the map," the artist said. "We want to be the center of attention with the historical celebration of Clyde 160."

Like the fictional town of Winesburg, present-day Clyde has a pre-industrial feel where the pace of modernization has been slow. Residents are attached to the identity of Clyde as an older, rural, community removed from the fast zone, and want to protect that identity. Yet, like the perceptions that they hold onto, loyalty remains for the preservation of this ideal in spite of the fact that it is currently being challenged by a more dangerous threat than any cultural identity shift could impose.

### *Choosing to be Uninvolved*

While theories and accusations were circulating throughout the town, and sides were being taken, a greater number of residents were choosing to remain uninvolved, a point illustrated by the poor turnout at public meetings concerning the cancer cluster. Still, some plaintiffs felt certain that, given the large number of calls to the EPA tip line, with more information surfacing about dumping in the community, someone would surely come forward to help their case. But this did not happen. Keith, a 55-year-old press operator at Whirlpool, met with a former laborer inside the plant who disclosed to him questionable practices regarding the disposal of waste. When asked if she intended to become involved, the laborer declined, saying "I don't want any part to do with talking." Another former employee of Whirlpool was enthusiastic about helping the lawyers expose the potential liability of the company, then to the surprise of some plaintiffs, backed out saying that he did not want anything to do with it. Betty, who suffered from cancer of the spleen, expressed surprise as to why more residents were not on board:

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<sup>9</sup> Massman, Bradley. "Robinson's Murals Bring Vintage Identity Back to Clyde." 2014. *The Clyde Enterprise*. April 30, 2014.

People just don't wanna talk about it. I don't get involved in too many things. I mean, you know, we stay to ourselves and that. But, you know, more people oughta get behind this. And I know a lot of people that worked at Whirlpool. I had an aunt that worked there. She had ovarian cancer. I had a cousin work there for many years. He was never a smoker and that, but he could hardly breathe. He came outta there when he retired and I think he was on oxygen. My mother lived over in Green Springs not too far from Whirlpool Park—she had multiple myeloma. That's cancer of the bone and blood. You know, I-I don't know, I just, when I hear these people talk at the meetings about where they live and like what's not living in the water anymore, not even frogs. I mean there's something going on. Too many children—not only children, but the adults. You know that just... they're springing up every day. There's something, you can't close your eyes and say, 'oh no it's not happening you know.' It's scary but you just gotta push on. I'll be supportive of them, that's for sure.

During my interviews, stories were shared with me about Whirlpool employees that participants knew who were ill themselves or had an ill child, but who were choosing to remain in the shadows. In fact, of the families whose children had become ill or died within the community, less than one quarter of them were active in the lawsuit. Townspeople speculated that these disengaged families were affiliated with Whirlpool and were afraid of the consequences of standing up against the company. They faced a dilemma in choosing between the health or financial security of their families, and sometimes these two considerations were interdependent. As has been seen in other cases of contaminated communities, it is more likely that residents opt to maintain employment in the face of uncertain outcomes.<sup>10</sup>

Rumors began to spread about repercussions from Whirlpool for personal involvement in the case, and were perhaps also contributing to most employees' reluctance to speak about the issue. One such rumor that circulated created confusion regarding the legal right of stock holders to question Whirlpool. It was based on the idea that if employees were stockholders, they were legally bound to not speak negatively about the company. As one woman put it, "if you have stock in this company, you *are* this company." Another man that I interviewed expressed

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<sup>10</sup> Matthews, Todd L. 2010. "The Enduring Conflict of "Jobs versus the Environment": Local Pollution Havens as an Integrative Empirical Measure of Economy versus Environment." *Sociological Spectrum* 31(1): 59-85.

concern that Whirlpool would retaliate by countersuing the plaintiffs for defamation. “That’s why I say they’d better be darn sure. I would wanna be really really sure what the evidence was before they went after somebody like *that*.”

Stories in Clyde circulated that employees were threatened for their participation in the public meeting, including an incident where an employee was approached and told, “you don’t know who you’re f-ing with.” Information also spread that a Whirlpool employee was reprimanded and written up for speaking at a public meeting about the cancer cluster. One family, the mother of which worked at Whirlpool and who had two children with leukemia, was told to minimize their media exposure. The concern and fear surrounding Whirlpool employees was detectable to me when a man who worked at Whirlpool came home while I was interviewing his family and insisted on knowing who I was and what I was doing. His family was quick to defend me as a student. “Just don’t use *my* name,” he said. He explained that he had been an exemplary employee and wanted to keep a low profile because he and his family needed him to have that job. Participation in the lawsuit also elicited concern from the man’s coworkers, some of whom expressed disbelief that anyone would risk speaking out against Whirlpool. He was told, ‘I can’t believe you’re doing that—they’re gonna fire you. You better not turn your back on them.’ Because of their concern about losing their jobs if they were to join the lawsuit, most Whirlpool employees would only talk about the likely culpability of the company in private, rather than in open settings. Whether truth or fiction, stories such as these worked to the advantage of Whirlpool. Perhaps equally effective was the statement by Whirlpool that the company cared about them, and most residents believed this.

Hearsay also raised suspicion that if the community turned on Whirlpool, the company would leave and relocate to another country, causing people to lose their jobs, life savings, and sense of security. Indeed, their concern was not without merit. In 2010, although the company took approximately \$19 million dollars in stimulus money through the American Recovery and Reinvestment Act, Whirlpool relocated an Indiana refrigerator factory to Mexico in a move that cost the community approximately 1,100 jobs.<sup>11</sup> In 2012, Whirlpool closed a plant in Fort Smith, Arkansas, eliminating more than 1,000 jobs and again outsourcing its manufacturing to

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<sup>11</sup> Ensinger, Dustin. 2010. “Whirlpool Moving Jobs to Mexico.” *Economy in Crisis*. EconomyInCrisis.org. Retrieved January 5, 2016. (<http://economyincrisis.org/content/whirlpool-moving-jobs-mexico>)



Mexico.<sup>12</sup> Whirlpool Corporation is one of many U.S. companies to relocate in order to take advantage of low-cost manufacturing regions, where the implementation of the North American Free Trade Agreement has significantly weakened both labor and environmental laws.

Many Clyde residents would not voice any opinion on the issue of the cancer cluster for fear of being labeled a troublemaker, publicity hound, or “out to get money,” as some of the plaintiffs had been. It is notable that many of the town’s prominent citizens, including members of the city council, aligned themselves with Whirlpool. Opinions were stated through letters to the editor in support of Whirlpool to the local newspaper, *The Clyde Enterprise*. Their perspectives were known to the public, and likely had an inhibitive effect on challenging views, as evidenced by the number of interviewees who made reference to them.

### *Understanding Collective Community Inaction*

There exist many cases of citizen-led action that followed the sudden discovery of toxic threat.<sup>13</sup> More recently, scholars have directed their attention to cases of communities where little or no collective mobilization occurs.<sup>14</sup> As indicated in the narratives in this chapter, the lack of a unified response in Clyde relates to the town’s dependence on Whirlpool for its economic survival. Residents’ personal circumstances, including their need for jobs, demanded that they maintain the status quo. In line with Neumann’s findings in a community case that involved dangerously high lead levels,<sup>15</sup> not only concern about potential job loss, but also the significance of place and collective self-understandings play important roles in shaping perceptions of risk and suppressing collective community action. The importance of maintaining the sense of small town community was often present in conversation. The complexity occurred because Whirlpool had an important role within the community. Indeed, the Whirlpool Corporation made a concerted effort to be seen as a friendly neighbor with family and community values.

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<sup>12</sup> “Whirlpool Closing Fort Smith Plant.” Arkansas Online. Retrieved January 5, 2016. (<http://www.arkansasonline.com/news/2011/oct/27/whirlpool-closing-fort-smith-plant/>)

<sup>13</sup> Brown, Phil. 1992. “Popular Epidemiology and Toxic Waste Contamination: Lay and Professional Ways of Knowing.” *Journal of Health and Social Behavior* 33:267-281. See also Kroll-Smith, S.J. and S.R. Couch. 1991. “What is a Disaster? An Ecological-Symbolic Approach to Resolving the Definitional Debate.” *International Journal of Mass Emergencies and Disasters* 9:355–366 and Lerner, Steve. 2005. *Diamond: A Struggle for Environmental Justice in Louisiana’s Chemical Corridor*. Cambridge, MA: MIT Press.

<sup>14</sup> Shriver, Thomas E., Sherry Cable, and Dennis Kennedy. 2008. “Mining for Conflict and Staking Claims: Contested Illness at the Tar Creek Superfund Site.” *Sociological Inquiry* 78(4): 558-579.

<sup>15</sup> Neumann, Pamela. 2016. “Toxic Talk and Collective (In)action in a Company Town: The Case of La Oroya, Peru.” Forthcoming in *Social Problems*.

Another possible explanation for collective community inaction relates to the unknowable threat of toxins. Whereas Edelstein found that psychosocial stress for contaminated communities is rooted in the inherent uncertainty of the unknown—imperceptible toxins of which the source is undetermined—in Clyde the unknown created a sense of, ‘how can you worry when it’s out of your control?’ Thus, the absence of a strong culture of fear may be *due to* the unknowable nature of the threat of toxins, adding to the dynamics that resulted in community inaction. A lack of community consensus about the problem of contamination or its solutions is another possible determinant for community inaction. However, the significant amount of anecdotal evidence, as well as the EPA discovery of PCB sludge at the former Whirlpool Park, coupled with the many residents who chose to not inform themselves about the issue, indicates that there was a resistance to wanting to know about the problem in the first place. Additionally, for most people in Clyde, there was still a general expectation that the state would step in and fix the problem.

Edelstein argues that contamination affects normal assumptions about life, what he terms “lifescape.” That is, that toxic exposure directly assails fundamental social beliefs that humans hold dominion over nature, people control their own destiny, technology and science are positive progressive forces, experts know best, the marketplace is self-regulating, and government exists to help. Adherence to these presumptions can be so strong that denial, rationalization, or ignoring issues such as toxic exposure are techniques used to maintain their existing lifescape.<sup>16</sup>

The fundamental beliefs about how the government is supposed to work seem to have been shaken by the cancer cluster issue in Clyde. Many residents held onto the perception that the government protects its citizens. Josephine explained, ‘You gotta trust ‘em, you know? We can’t do anything about it. What do we know?’

Some residents were entrenched in an idealized, patriotic interpretation of their world. Marilyn, a 64-year-old breast cancer survivor, exclaimed: “I’m supposed to be free,” and “I’m an American—we’re not supposed to live like this.” She expressed a sense of her rights being trampled on:

They don’t wanna be accountable for hurting anyone or be responsible for fixing the problem or to accept responsibility for creating the problem, and that’s what

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<sup>16</sup> Edelstein, Michael R. 2004. *Contaminated Communities: Coping with Residential Toxic Exposure*. Boulder, CO: Westview.

makes it so difficult for *we the people* that don't have the education to know who to contact, how to know what questions to ask, how to understand the question that was asked, and understand what it meant. Somewhere along the line somebody has got to be accountable for that. A *good neighbor*'s gotta stop and say, 'Hey we did that, we're gonna clean it up.' That's a good neighbor. And I'm a big one for *made in America*. I'm very patriotic. I'm very much a USA girl. [...] I think it's just, *we the people* are lost here somewhere. We're just lost. I don't know how you get it back. How do you get it back? Do you have children die to get it back? 9/11, man, everybody had a flag flyin' on their cars...where are they at now?

In one way, Clyde residents' impression of betrayal of the rights of "Americans" mingled with the perception that, while other countries might face catastrophes like theirs, a healthy living environment was an unassailable entitlement for U.S. citizens. There existed a conviction that cancer clusters were not something that one would expect to occur in the U.S. Furthermore, consternation was voiced in making comparisons to incidents such as the 9/11 terrorist attacks, in that those events are commonly viewed as a collective American tragedy, while cancer clusters are not.

It is probable that this outdated identity of "Americanism" was rooted in the fact that this country was built primarily upon small towns like Clyde. The discrepancy occurs in the fact that Clyde has remained largely unchanged in terms of its white/rural/middle-American/small town identity, and that residents still cling to this version of American identity.

Defeatism associated with the improbability of resolution was also detectable in the narratives of residents, perhaps because the problem was so convoluted. Fatalistic comments such as "the damage to my health has already been done" seemed to camouflage residents' anxiety about having an illness, about Whirlpool leaving, their losing jobs, and the changing identity of the town. Barb likened the disease cluster to that of the natural phenomenon of tornados in Oklahoma:

"It's kinda like the Oklahoma people. We're coming out of our storm shelters, and well, you know, we're Oklahomans—what can you do? We're gonna stay here. I mean, what are you gonna do?"

The assumption that "you can't fight city hall" contributed to a sense of non-confrontational inaction. There was also speculation that some residents simply did not care enough about the issue, or that they would pay more attention to the issue if they were personally affected. It may

be argued that remaining “neutral” was a way of taking a side without inviting unwanted attention, and that doing nothing had its own implication of passive action. In this case, the decision of most residents to remain uninvolved benefitted Whirlpool, which to date has not offered a proactive response to the contamination issue.

### *Individualization of Responsibility*

In the course of discussion, many residents determined that the responsibility for mediating exposure to chemicals existed at the individual and family levels. The theme of individualization of responsibility within the narratives of Clyde residents collides with the concept of protecting existing paradigms when genetics and lifestyle variables are attributed to the cause of cancer. Even to the point of controlling one’s exposure to hazards, the concept of self-monitoring as a strategy for self-protection becomes commensurate to good citizenship.<sup>17</sup> The onus of good citizenship then shifts to the individual with the expectation that they make informed decisions about their exposure to risk.<sup>18</sup> This evolution now includes the concept of self-monitoring.<sup>19</sup> Consequently, where self-protection becomes an obligation of good citizenship and protection of self is no longer in the hands of previously relied upon institutions, accepted avenues of resolution become obsolete. This collision of evolving paradigms has made no small contribution to the confusion and dissension within the town of Clyde. Conflicting tenets such as these are reflected in some of the narratives presented earlier in this chapter, particularly in the quotes of residents who claimed “responsible living”<sup>20</sup> as being the reason why they or their family did not get sick. Furthermore, the narratives indicate that the management of household health is constructed as a caregiving responsibility at the family level, despite the uncontrollability of toxic threat within their midst.

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<sup>17</sup> Miller, Peter and Nikolas S. Rose. 2008. *Governing the Present: Administering Economic, Social and Personal Life*. Cambridge: Polity Press. See also O’Malley, Pat. 2004. *Risk, Uncertainty and Government*. London: GlassHouse and Scott, D.N. 2007. “Risk as a Technique of Governance in an Era of Biotechnological Innovation: Implications for Democratic Citizenship and Strategies of Resistance.” Pp. 23-56 in *Risk and Trust: Including or Excluding Citizens?*, edited by the Law Commission of Canada. Black Point, N.S.: Fernwood Pub.

<sup>18</sup> Haggerty, Kevin. 2003. “From Risk to Precaution: The Rationalities of Personal Crime Prevention.” Pp.193-215 in *Risk & Morality*, edited by R.V. Ericson and A. Doyle. Toronto: University of Toronto Press.

<sup>19</sup> Rose, N. 1999. *Powers of Freedom: Reframing Political Thought*. Cambridge: Cambridge University Press.

<sup>20</sup> Osborne, T., Robin Bunton, and Alan R. Petersen. 1997. “Of Health and Statecraft.” Pp. 173-188 in *Foucault, Health and Medicine*. New York: Routledge.

### *Risk, Trust, and Responsibility*

Along with the narratives that emphasize residents' frustration with governmental processes outlined in the previous chapter, narratives presented here highlight other characteristics of the risk society—the intrinsic connection between risk and trust, as well as risk and responsibility.

Those most impacted questioned government agencies' resistance to testing all sites for possible contamination, expressing frustration that nobody was taking them seriously. "We can't test every dump site that people tell us about," the on-scene coordinator for the EPA told one resident who was worried about a dumping ground next to Whirlpool Park. One family recounted instances where they attempted to contact state-level politicians, including Governor John Kasich, but received no response. They stated that Governor Kasich expressed concern around election time, even requesting to talk to the family's ill son on the phone, but stopped short when it came to doing anything meaningful. Others felt that, had the contamination been validated by the ODH or EPA representatives, then perhaps skeptical members of the community would view the concerned residents' complaints as being more legitimate. Complex, conflicting, and delayed distribution of information from government agencies added to residents' frustration with their lack of recourse.

The issues in Clyde initiated a cycle of mistrust between affected families and the government agencies involved. The families, feeling as if they were being intentionally misdirected, expressed doubt in public officials' actual knowledge and abilities to address their problems, and questioned the truthfulness of the EPA and Whirlpool's findings. Some suspected that the EPA and ODH were not aggressively investigating the cause of illness because Whirlpool was "paying them off." It is difficult to understand why the discovery of nine feet of toxic PCB sludge at the former Whirlpool Park would be regarded as a non-conclusive event. Considered as a whole, although the narratives contain contradictions, these conflicting viewpoints indicate that Clyde is a risk community whose residents are grappling with an evolving paradigm in a town that is on the cusp of change. Some residents appear to respond to the issue of the cancer cluster through the parameters of what Beck's first modernity, believing that science, government agencies, and the corporation Whirlpool would provide the safety and protection that they expected. Yet others, albeit a small number, were challenging the corporation and questioning the effectiveness of those institutions to effectively manage and respond to risk of toxic exposure.

While significant environmental and human health dilemmas dominated the public dispute over the cancer cluster in Clyde, it is important to recognize that social, economic, and political consequences of those issues were also at stake. As Beck would observe, what emerges in the risk society is the political potential of catastrophes.<sup>21</sup>

Interviews with residents in present-day Clyde indicated a more complicated but similarly inharmonious community compared to the fictional town of Winesburg. The conflict that residents face is deeper than the isolation and hopelessness reflected in Anderson's short stories. Regardless of where residents stand as to the cause of the cancer cluster within the community, those impacted experience continuing relative levels of distress and turmoil. No one has stepped in to find answers or correct the problem, nor has anyone been held accountable. Residents have been left with few resources to solve the problem on their own and consequently their versions of truth, community, and hope have been degraded. People who expected to live out their lives in a safe community are facing a catastrophe wherein children are dying, neighbors mistrust each other, government is questioned, residents are financially burdened, and the community is fearful of the future. Arguably, the "truths" that some people in Clyde embrace contribute to the problem of child and adult cancer remaining unresolved. As diverse as my interviews were, however, there was a common thread among them—people's definition of their place in their world was changing.

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<sup>21</sup> Beck, Ulrich. 1992. *Risk Society: Towards a New Modernity*. London: Sage.

## CHAPTER 5

### THE FAMILIES

“My name is Sierra. I am 11 years old, and I have had to watch both my brother and sister be sick from leukemia for years as they went through treatments.” She seemed remarkably small as she stood alongside her father in the large gymnasium holding the microphone as she spoke to rows of adults who sat dispersed among the bleachers. The first public informational session held by the lawyers since the filing of the lawsuit happened to be on a rainy Memorial Day. Despite the poor community turnout for the public meeting, Sierra made her plea for community support. “You do not want this to happen to your family.”

I first interviewed Sierra’s dad Dave Hisey at his home in June 2013. In 1996 he moved from Indiana to Clyde, where he met his wife Donna, and married her shortly thereafter. He recalled the positive first impression he had of Clyde as a family-friendly place where he would want to raise kids. He described himself as a fun and loving parent with a life that revolved around his family. This was evident to me as I observed him interact playfully with his daughter Sierra, who interrupted the interview to request permission to go to Twistee Treat, the local ice cream shop, to meet a friend.

Dave spoke candidly with me as he shared stories that, taken together, illustrated the anxiety, emotional, and financial difficulties that accompanied the tremendous burden that disease had placed on his family. In February 2006, the Hisey’s daughter Tyler was diagnosed with AML Leukemia and underwent seven months of chemotherapy at Saint Vincent’s Hospital in Toledo. When Tyler was diagnosed, Dave and his wife Donna made the decision to make efforts to keep the other two children’s lives as normal as possible. As such, it was decided that Donna would stay with Tyler at the hospital, while Dave would stay with their other two children at their home in Clyde to continue “regular” lives that were centered on homework and sports. Like most parents of children with cancer,<sup>1</sup> Dave and Donna wanted to take an active part in the treatment-related care of their daughter. Donna spent nearly all of the seven months that Tyler was in the hospital at her side, while the time away from home brought emotional stress to their family. In reflecting on the various dynamics of marital stress in the face of a child’s diagnosis,

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<sup>1</sup> Pyke-Grimm KA, L. Degner, A. Small, and B. Mueller. 1999. “Preferences for Participation in Treatment Decision Making and Information Needs of Parents of Children with Cancer: A Pilot Study.” *Journal of Pediatric Oncology Nursing* 16:13-24.

Dave explained, “it does gnaw away at you with just all the different little things that you wouldn’t really think about.”

It was during the summer of 2008, when Dave and his wife were coaching their son Tanner’s baseball team, that Tanner began complaining about his arm hurting. He had some blue marks, and was tired. They did not think much of it, but they did have a couple of blood tests done which came back negative. After his third practice of Peewee football in the late summer, Tanner came home and complained, “Dad, I’m always so...I’m really hurt.” Dave recounted how he affirmed that what his son was experiencing was normal. “It’s just growing pains, Buddy. You’re just working hard with practice. All the guys are with you on that. Push yourself, work hard.” They took Tanner to the hospital, where a lump on his neck was discovered, removed, and determined to be cancerous. The unimaginable had happened again. Two years after his sister’s diagnosis of AML Leukemia, Tanner was diagnosed with ALL T-cell Leukemia at the age of 10. He underwent four years of chemotherapy. Dave recalled how the diagnoses of his children disrupted the expectations they had about their lives. “We were just thinking that life was just starting, you know? Not thinking about kids’ lives ending,” he explained. Similar expressions of shock were echoed as families independently and collectively recalled the smallest of details surrounding the traumatic discovery of their loved one’s cancer.

### *Parental Loss of Control*

The shock of diagnosis was also accompanied with uncertainty regarding the outcomes for their children. The fear of potential fatality associated with childhood cancer is traumatic for parents.<sup>2</sup> Many in Clyde described having to quickly adjust to a “new normal” as interactions with the medical community became a predominant feature their lives. The bureaucratic aspects of managing illness also included having to travel outside of town for treatments. Childhood cancer involves a myriad array of stressful events<sup>3</sup> that affect parents in grievous ways, one of which includes the loss of control during a child’s cancer treatment, which has been found to be a salient risk factor for later posttraumatic stress symptoms in mothers.<sup>4</sup> In reflecting on the course

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<sup>2</sup> American Psychiatric Association. 2013. *Diagnostic and Statistical Manual of Mental Disorders (Fifth ed.)*. Arlington, VA: American Psychiatric Publishing.

<sup>3</sup> McGrath P. 2002. “Beginning Treatment for Childhood Acute Lymphoblastic Leukemia: Insights from the Parents’ Perspective.” *Oncology Nursing Forum* 29:988-996.

<sup>4</sup> Norberg, Annika Lindahl. And Krister K. Boman. 2013. *Psycho-Oncology* 22(2):324-329.



of their children's cancer, some parents wondered if they could have controlled any circumstances which would have made a difference.

Parental reactions included feelings of anger, despair, and a sense of responsibility associated with their children's cancer. Dave lamented his initial lack of response to his son's complaints about not feeling well. Alexa's mom Wendy reflected on her own years of swimming at Whirlpool Park and wondered if her daughter's cancer was something she had "passed on to her," expressing suspicion that chemical risks resided within her own maternal body. This suggests the influence of discourses that emphasize risk avoidance and personal accountability. As discussed in the previous chapter, women's bodies become sites that bear and transfer risk, and their actions and choices become central to mediating risk.<sup>5</sup> Guilt seemed to be compounded by the fact that families did not know what had initiated the cancer. This sense of helplessness challenged one of the primary roles of parenthood—that of being able to protect their children.

Loss of control extended beyond the inability to control disease or its consequences. While levels of concern about the safety of their environment varied among participants, impacted residents were more likely to question the safety of everything around them. Some parents questioned their children's prior activities, searching their memories for possible links to exposure. There was heightened anxiety related to the source of contamination and the resulting inability of parents to protect their children in the face of the unknown. Edelstein observes that in contaminated communities adverse outcomes may be attributed to toxic exposure even if there is no way to prove the relationship,<sup>6</sup> and this happened to Clyde residents who began to question previous illnesses within their families. Furthermore, exposure to toxins is "psychologically burdened with legitimate expectations of the worst outcomes."<sup>7</sup>

Studies have shown that in efforts to reassert parental control, parents reshape their role by focusing on the child's physical and emotional needs<sup>8</sup> and by fulfilling tasks that promote feelings of positive contribution to their circumstances.<sup>9</sup> Gender differences have been found to

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<sup>5</sup> Armstrong, Elizabeth M. 2003. "Conceiving Risk, Bearing Responsibility: Fetal Alcohol Syndrome and the Diagnosis of Moral Disorder. Baltimore: John Hopkins University Press. See also Lupton, Deborah. 2011. "The Best Thing for the Baby"; Mothers' Concepts and Experiences Related to Promoting their Infants' Health and Development." *Health, Risk, & Society* 13:637-651. See also Waggoner, Miranda. 2013. Motherhood Preconceived: The Emergence of the Preconception Health and Health Care Initiative. *Journal of Health Politics, Policy and Law* 38:345-71.

<sup>6</sup> Edelstein, Michael R. 2004. *Contaminated Communities: Coping with Residential Toxic Exposure*. Boulder, CO: Westview.  
<sup>7</sup> Ibid:18.

<sup>8</sup> Varni JW, OJ Sahler, ER Katz, RK Mulhern, DR Copeland, RB Noll, S Phipps, MJ Dolgin & K Roghmann. 1999. "Maternal Problem Solving Therapy in Pediatric Cancer." *Journal of Psychosocial Oncology* 16:41-71.

<sup>9</sup> Durbin M. 1997. "From Both Sides Now: A Parent-physician's View of Parent-doctor Relationships During Pediatric Cancer Treatment." *Pediatrics* 100:263-267.

exist in the act of “being there” for sick children, with mothers tending to focus on involvement in the life of their child and fathers tending to advocate and support the child in more practical ways.<sup>10</sup>

### *Making Lifestyle Changes*

Because the “facts” of toxic disaster are often unclear, the “perception” of the disaster becomes central to its consequential effects.<sup>11</sup> In addition to challenging people’s paradigms, environmental contaminants affect lifestyle choices wherein people’s way of living, relationships, pattern of activities, and places needed to sustain these activities alter to accommodate a changing reality.<sup>12</sup>

Residents expressed trying to protect themselves from suspected toxins in their homes even though they did not know the exact source of contamination. They described the strategic moves they made to protect their families by, for example, having their ponds and wells tested even before the involvement of the EPA and Health Department, changing their well water to city water, or installing water filtration systems in their homes. Some students at the high school brought bottled water to school to avoid drinking water from the fountain. Families also bought bottled drinking water for their homes to avoid possible well water contamination, put air purifiers in their bedrooms, or made changes in their food choices. Bubba’s sister reflected on how their family’s experience with cancer changed the way that she lived:

I also feel like the concern for getting cancer and the concern to get healthier has really affected my husband and I. We buy all organic, local produce and meat, we buy organic milk, we drink filtered water, we don’t use water bottles, we use the reusable stuff, we don’t use paper plates. We’ve just completely changed our lifestyle in the way that we eat and the things that we do because of that concern. We want to take all of the precaution that we can to make sure that we’re doing everything that we can to not get sick. I think that’s really hit home for us.

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<sup>10</sup> Kars, M. C., M.S. Duijnstee, A. Pool, J.J. Van Delden and M.H. Grypdonck. 2008. “Being There: Parenting the Child with Acute Lymphoblastic Leukaemia.” *Journal of Clinical Nursing* 17:1553–1562.

<sup>11</sup> Ibid.

<sup>12</sup> Ibid.

Through attempting to minimize their exposure to risk by modifying consumer choices, some residents became what Scott refers to as “citizen-consumers”<sup>13</sup> who negotiate their exposure to risk through product selection, and manage chemical risk exposure through tasks such as grocery shopping. However, with the perception by some that toxins and hazards could potentially be present anywhere, concern was voiced about the pervasive sense of losing control over health and lifestyles. “You can be bombarded with things and you can try to be as safe as you can be in a lot of areas, but you just can’t get away from everything,” Wendy explained. There were also financial limits to protecting oneself and one’s family, and the price of products such as water filtration systems was often cost prohibitive.

Additional concerns were voiced about the safety of their homes, gardens, and the actual soil they lived on. “I’m afraid to dig anything in the soil...you know, plant flowers.” They expressed regret about losing the ability to have what other people take for granted. There was a level of caution now attached to her daily activities. Concerns about toxic exposure were evident. One Whirlpool employee, Erika, expressed having heightened concerns about occupational hazards and often thought about toxin exposure while working:

I always thought about it ‘cause once in a while I work up in the department that my girlfriend worked in and I would work overtime. They would clean these things out, and there’s all this junk dripping on ya, and they want you to wear these white paper suits and boots and it was hard getting around in ‘em because they were real small, so a lot of times none of us wear the boots and it wasn’t mandatory, they just said so you don’t get your feet all wet because you walk through all these chemicals and stuff, and they’re dripping on ya. And they’re dripping on your mouth, and your hair, and sometimes I’m thinking, why am I doing this?’ It’s probably why my friend got sick, and that’s before the cancer cluster really was brought out or anything. I was doing this and now I’m thinking, ‘why did I ever go in those departments? Why wasn’t I thinking more about what would go through my skin?’ So sometimes, yeah, you’re sitting in there and you’re working away and you’re

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<sup>13</sup> Scott, D.N. 2007. “Risk as a Technique of Governance in an Era of Biotechnological Innovation: Implications for Democratic Citizenship and Strategies of Resistance.” Pp. 23-56 in *Risk and Trust: Including or Excluding Citizens?*, edited by the Law Commission of Canada. Black Point, N.S.: Fernwood Pub.

bored, the factory's monotonous and you think, 'okay, what am I breathing in here?' There's a total mist at the department next to mine. When you look over there, it's like a mist--a vapor, all day, everyday... They won't let it go out in the air so they've supposedly pumped it back in through a filter into the plant right where we're working. So sometimes it makes you wonder 'What am I breathing in?'

Those in close proximity to Whirlpool Park were also concerned about PCB run-off in their well water. Karen, a mother of two children with developmental delays and cognitive disorders, lamented the fact that their family memories were now tainted with suspicions of toxin exposure. In reflecting upon the park, Karen recalled:

It was just, it was great. I mean people used to envy us because we lived so close to Whirlpool Park—because it was so convenient. It would be so crowded in the summertime so we'd wait until just about dinnertime because we always ate early. My [mother-in-law] always had supper on the table when her husband came in 'cause he farmed, so they had a specific amount of time for him to eat and get back out in the field. So then I just kinda carried that on, and we'd already have our supper ate and we'd go over there by the time everybody was leaving to go home and eat and then it wouldn't be crowded at all [laughs]. It's too bad that your memories are being, you know, tarnished. Because now it's like when I think about when I had my son's birthday party over there, and all my nieces and nephews were over there in the creek gathering up the frogs...I mean you just think, I don't know—were we safe or weren't we?

### *Social, Emotional, and Physical Impact of Cancer on Children*

Children encounter unique challenges during treatment for cancer, whether the results are successful or unsuccessful, and they also experience difficulties as cancer survivors. Because serious side effects do not occur as readily in children as they do in adults, children may be given greater doses of chemotherapy and radiation over shorter periods of time.<sup>14</sup> Cancer and the side

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<sup>14</sup> National Cancer Institute: PDQ® Pediatric Supportive Care. Bethesda, MD: National Cancer Institute. Date last modified November 13, 2015. Retrieved January 30, 2015 (<http://www.cancer.gov/types/childhood-cancers/pediatric-care-pdq>)

effects of treatments for the disease can often impact children more negatively than adults because of the harmful effects on developing organs. Side effects may occur immediately or appear years later, and may also affect a child's growth or cause a second cancer to form. Children may also respond differently to drugs that control symptoms in adults.<sup>15</sup>

The initial days of medical intervention during which the child is often in the hospital are usually the most stressful for the child and the family. Family members adopt different methods of coping, and some parents and children resort to counseling and medication to deal with issues of depression related to cancer. Apprehension about receiving medical care and being away from their familiar home environment is common. Some studies have shown that this anxiety typically decreases over time, and that most children treated for cancer, as well as children who are long-term survivors of cancer, have few serious psychological problems.<sup>16</sup> In general, children may experience high self-worth, good behavioral conduct, and improved mental health and social behavior upon cancer treatment completion.<sup>17</sup> However, leukemia, lymphoma, or a cancer or treatment that affects the central nervous system—the most common cancers affecting children in Clyde and the surrounding area—are often cited as exceptions in that those particular diseases and their treatments increase the risk of social, emotional, or behavioral problems in children.<sup>18</sup>

Contrary to literature that shows no differences in measures of social isolation between children with cancer compared with other healthy children,<sup>19</sup> parents perceived changes in their children's social relationships. Alexa's father Warren Brown, for example, remembered observing the moment his daughter realized that she was different from other children, and that she would be different from then on:

Alexa used to go over to the neighbor's house and jump on their trampoline with the other girls. I remember. This was after she got out of the hospital, after her surgery, after learning to walk and talk again, and keep in mind Alexa's gait was never the same ever again. She could never have walked normally again I don't

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<sup>15</sup> Ibid.

<sup>16</sup> Sawyer, Michael, Georgia Antoniou, Ian Toogood, Michael Rise, and Peter Baghurst. "Childhood Cancer: A 4-Year Prospective Study of the Psychological Adjustment of Children and Parents." *Journal of Pediatric Hematology/Oncology* 22(3):214-220.

<sup>17</sup> Bessel, A.G. 2001. "Children Surviving Cancer: Psychosocial Adjustment, Quality of Life, and School Experiences." *Exceptional Children* 67(3):345-359.

<sup>18</sup> Ibid.

<sup>19</sup> Noll, RB, S. LeRoy, WM Bukowski, FA Rogosch, and R. Kulkarni. 1991. "Peer Relationships and Adjustment in Children with Cancer." *Journal of Pediatric Psychology* 16(3):307-26.

think. Maybe over time, had she had more time, she would have strengthened those muscles and become a little more agile, but she stood at the dining room window and looked across the street at the girls jumping on the trampoline. And that's when it hit me that [pause] she knew she would never be the same again, she knew there were something different that would always be different that... just from her body language, from the look from her face, I was struck with the fact that it's never gonna be the same for her. [...]

Dave Hisey reflected on how his children missed out on physical, social, and cognitive development, as well as things that would have been important to them in the course of a normal childhood. Dave's children were experiencing changing relationships at school, in part because of the challenges of absenteeism. In studies on peer relationships and adjustment, children with cancer have lower satisfaction with athletic competence than their peers.<sup>20</sup> Dave described the physical changes his son was experiencing due to treatments, citing on how his classmates were "sprouting above him, and he missed out on all the social things through junior high." Falling behind in school was also stressful for Dave's son. Often times, when his son was home from the hospital, he would not be feeling well and would lie on the couch for two or three weeks, which further delayed his ability to catch up with school-work, and would result in his having a large amount of homework when he finally started feeling better.

Another symptom of anxiety appears in the form of sleep disorders in affected children.<sup>21</sup> Dave described his son's experience as follows:

He, he always wants to be around someone, sleep with somebody because he doesn't want to be alone by himself, and that's gotten so much worse over this. And, you know, he's gonna be 15 and I feel bad for him about that, you know? But on the other hand then you want him to be close to you so you end up caving because you don't know what next week's gonna bring.

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<sup>20</sup> Noll, Robert B., Maria A Gartstein, Kathryn Vannatta, Judy Correll, William M. Bukowski, and W. Hobart Davies. 1999. "Social, Emotional, and Behavioral Functioning of Children with Cancer." *Pediatrics* 103(1).

<sup>21</sup> Maurice-Stam, H., F.J. Oort, B.F. Last, P.P.T. Brons, H.N. Caron, & M.A. Grootenhuis. 2008. "Longitudinal Assessment of Health-related Quality of Life in Preschool Children with Non-CNS Cancer after the End of Successful Treatment." *Pediatric Blood and Cancer* 50:1047-1051.

Returning to school after treatment can provide a sense of normalcy, albeit in a slightly altered form, for children.<sup>22</sup> The perception of the school nurse Nancy was that parents of sick children wanted them to be in school as a way to normalize their children's lives—to “be at school and do what kids do at school.” Children with cancer often demonstrate an eagerness to go back to school after treatment,<sup>23</sup> but upon returning to school can face difficulties in psychosocial adjustment in the areas of scholastic competence, emotional stability, and social competence.<sup>24</sup>

It was also the school nurse's perception that affected children were initially more needy and insecure when they returned to school, and that they “had a lot of fear wondering if they were really cured.” Sometimes she identified psychosomatic illnesses among the impacted children and would redirect them to the guidance counselors.

All of the parents I interviewed felt that the schools were supportive and worked at creating accommodations for sick children. The nurse explained how radiation treatments to the head could cause traumatic brain injury, and how most of the kids diagnosed with cancer were on Individualized Education Plans (IEPs). Additionally, when children were absent for a long period of time they were put on an IEP so that they could be given all of the assistance that the school could provide.

Children that experience damage to motor skills<sup>25</sup> or even disfigurement from cancer treatments that require corrective surgeries and/or permanently altered their physical appearance, face monumental challenges as well. Survivors of pediatric cancers that result in physical impairment have been found to be less likely to have completed high school, ever worked a job, or ever been married.<sup>26</sup>

Families of children with cancer gained unanticipated insight into some of the specific problems associated with managing illness. Like an heirloom, passed on from one family to the

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<sup>22</sup> Bessell, Ann G. 2001. “Children Surviving Cancer: Psychosocial Adjustment, Quality of Life, and School Experiences.” *Exceptional Children* 67(3):345-359. See also McGrath, P., R. Suppiah, and M.A. Patton. 2005. “Re-entering Life: Pediatric Acute Myeloid Leukemia at One Year Post-treatment.” *Australian Journal of Holistic Nursing* 12:23-34.

<sup>23</sup> McGrath, P., R. Suppiah, and M.A. Patton. 2005. “Re-entering Life: Pediatric Acute Myeloid Leukemia at One Year Post-treatment.” *Australian Journal of Holistic Nursing* 12:23-34.

<sup>24</sup> Bessell, Ann G. 2001. “Children Surviving Cancer: Psychosocial Adjustment, Quality of Life, and School Experiences.” *Exceptional Children* 67(3):345-359.

<sup>25</sup> Maurice-Stam, H., F.J. Oort, B.F. Last, P.P.T. Brons, H.N. Caron, & M.A. Grootenhuis. 2008. “Longitudinal Assessment of Health-related Quality of Life in Preschool Children with Non-CNS Cancer after the End of Successful Treatment.” *Pediatric Blood and Cancer* 50:1047-1051.

<sup>26</sup> Punyko, Judith A., James G. Gurney, K. Scott Baker, Robert J. Hayashi, Melissa M. Hudson, Yan Liu, Leslie L. Robison, and Ann C. Mertens. 2006. “Physical Impairment and Social Adaptation in Adult Survivors of Childhood and Adolescent Rhabdomyosarcoma: A Report from the Childhood Cancer Survivors Study.” *Psycho-Oncology* 16(1):26-37.

next, they shared tips and tricks for helping their children cope. Dave recalled the thoughtfulness of a gift from another family:

Steve Keller—Kole Keller was his grandson—I can remember them coming out here and bringing a big basket in that hallway. They had this big basket, and it was just a big fluffy pillow pad. And you could put it on a twin size bed, and it just makes it more comfortable. We would have never thought about that, but somebody got that for them, they got it for us, ya know, then we got it for somebody else. But it just, you pick up little things that made life easier when we were there.

Dave discussed wanting to give his own sick children a proactive way of countering the negativity of their experiences, so he involved them in charitable acts. He recognized how having a computer temporarily helped kids escape from their sadness and the monotony of the hospital experience, and gave them an outlet to the outside world. Therefore, he and his kids started giving computers to other sick children.

When my kids were in the hospital, my boss bought Tyler a computer and we thought that was really neat because it let her be in the hospital and just, she didn't want to talk to anybody, she just, 'hmmm, mmmm'—that's how she would answer questions. She wouldn't communicate while she was frustrated, scared, sad. Then there's all the poking and the prodding. Ya know, nurses would be waking her up all night. Beeping. And, you know, chemo and stuff, so it was nice. It let her escape into that computer. She could put a movie in and just escape into that world and kinda forget about what she was in, and she could communicate with her friends if she wanted to. So then we did that for our son. And same thing, he went on it, in and out for three and a half years and it just let him escape, forget about the hell that he was in and just be engulfed in the movie world. You know, I'd spend the night with him up there, and I would come home and he and I would have Rocky Fest or whatever, and watch all the Rocky movies. It just let him escape. So we thought that might be something nice to do for other people.



There was a two-fold benefit to involving his children in acts of giving. On the one hand it gave a sense of empowerment to his children. In another way, he felt that it gave other sick children a sense of hope when they saw his children in remission, allowing them to see that they had a chance to be healthy again.

### *The Impact on Siblings*

James “Bubba” Andrews died on March 18, 2012 from Glioblastoma Multiforme at age 22. He was a popular “superstar” athlete in Clyde and was recognized for his athletic ability outside of Clyde as well. Bubba’s siblings described him as a protective caregiver who sometimes helped their single mother and stepped into a somewhat paternal role within their family in the absence of their father. “He was the Dad,” his siblings explained. As I sat with his family by the pool of his sister’s apartment complex, they fondly recalled how people throughout the state would refer to them with reference to Bubba. “I’ve always been “Bubba’s Mom”, and these are Little Bubba’s,” his mom laughed. His brother chimed in, “Little Bubba #7” was on the back of my hat the first year I played for the Merchants.” In reflecting on the diagnosis of their son and brother, Bubba’s family remembered the drama surrounding the discovery that Bubba was sick, recalling the meeting with his doctor, and the very moments they were told that Bubba had had a seizure and was in the hospital. “He was just so healthy, and just a normal kid. Never got the flu, never got a cold,” Bubba’s sister recalled. Bubba’s brothers added: “He was *more* than a normal kid. He was Superman.”

On the one hand, Bubba’s siblings described Bubba as initially being in denial about his diagnosis. Bubba’s sister recalled that Bubba had a “very good ability to zone out at doctor’s appointments and escape from reality by not paying attention to exactly what they were saying.” However, his family suspected that he privately struggled, but did not want his family to feel sorry for him. It was easy to deny Bubba’s condition for a while because he “looked normal.” His mom recalled rushing home from chemo treatments so that Bubba could go golfing or play in a softball game, and he would be concerned about not being home quickly enough. His sister, who had recently graduated from college, was scheduled to start working at a new job in a new city the week after he was diagnosed. “At the beginning, it wasn’t quite real,” she explained. As his tumor began to spread, however, his family confronted the reality that he would die, and the family supported Bubba as he grew more ill. When Bubba began chemo treatments in Columbus,

he lived with his sister who took him to his treatments and tried to be there for him in any way that he needed. He maintained the protective role he played in his family to his death, at times even helping his mother cope with her sadness. His mother reflected on how he gave strength back to her—how he helped her understand that she needed to appreciate the time that they had together, rather than anticipating the end.

The process of Bubba slipping away was painful and long for the family. Healthy siblings expressed that their own friends were initially very supportive. However, as their brother's disease progressed, their friends began to fall away because they did not know how to be supportive. Still, Bubba's siblings described how the relationships they had with each other since Bubba was diagnosed had solidified. "We have never been closer in our lives," they explained to me.

While they had different ways of staying connected to Bubba after his death, one brother described how he honored Bubba by emulating his diligence, his work ethic, and the same approach to life that Bubba had. All of his siblings described valuing life more, and having an overall increased appreciation for living. Bubba's sister expressed that she still struggles with feelings of anger over her brother's death. One of his brothers expressed feelings of survivor's guilt and compared himself to the type of person Bubba was, as if that were a factor in why some people get cancer. He reflected:

I always thought, why not me? Why him? He was always the best at everything. The best at sports, he was better in school [...] I just felt like the world would have been better off with him instead of me.

Siblings of children with cancer often experience the same conflicting feelings that parents do as they observe and experience changes within their family. Healthy siblings may understandably spend less time with parents who are otherwise engaged with the care of the sick child. Siblings of pediatric oncology patients sometimes exhibit stress responses to the illness experience themselves,<sup>27</sup> including difficulty sleeping and complaints of somatic symptoms.<sup>28</sup> While healthy siblings worry about their sick brother or sister, they might simultaneously perceive the

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<sup>27</sup> J.S. Murray. 2011. "Social Support for School-age Siblings of Children with Cancer: A Comparison between Parent and Sibling Perceptions." *Journal of Pediatric Oncology Nursing* 18:90-104.

<sup>28</sup> Havermans, S. and A. Zanelli. 1997. "Behavior Changes Exhibited by Siblings of Pediatric Oncology Patients: A Comparison between Maternal and Sibling Descriptions." *Journal of Pediatric Oncology Nursing* 14:3-14.

distribution of attention as being unequal, leading to feelings of resentment and exclusion. Yet, Dave Hisey noted the increased compassion and empathy that his daughter Sierra had developed for others. He described how the experience of having two sick siblings had prompted her to mature at an early age.

There was also concern present among healthy siblings that they would also become ill. Dave and Donna's daughter Sierra often wondered if she, too, would be impacted by leukemia like both of her siblings were. Bubba's sister stated: "It really really really messes with your head. You know, if it can happen to him, it can happen to any of us. And you just, *you never know.*"

While acknowledging the important role of family and friends in providing support, Dave Hisey noted that his children also seemed to have increased empathy for him and his wife, and they would often try to lift their parents' spirits if they detected sadness in them. Dave described the caregiving roles that his children assumed for their parents, as well as the respect the siblings developed for each other.

### *Choosing to Stay or Relocate*

To counter the disrupting situations their kids were in, Dave and his wife tried to maintain a positive home atmosphere for their sick children and retain a sense of normalcy.

Everything else has been taken away from them so we wanted to do everything we could to keep home because they're way in the hospital and when they come home we wanted them to come home to home because everything else was different. They pretty much grew apart from their friends because you don't have all that contact with them every day you know and even when you do get back to school, people treat them differently or they're different you know, they don't have hair, they're sick a lot and miss a lot of school. So the home thing was important to us.

The effort to maintain normalcy for their kids was in conflict with the conundrum surrounding whether or not to relocate. Affected families were often questioned as to why they did not simply move. In spite of the implied criticism of his parental ability to protect his kids, Dave explained that it was not easy to leave home. He and his family ultimately chose to stay in Clyde because

of their jobs, social ties, and to keep their children in the school system near friends and support systems. While he and his wife contemplated moving away, they did not definitively know what the source of the cancer was, and they wanted to minimize stress on their family. “You want to do everything to protect your kids, but at that point we didn’t really know what we were protecting our kids from,” he explained. The benefits of staying in the community were more important.

Wendy and others echoed his response. “Well, if you move 50 miles away, how can you know that *it* will be a safe place?” she said. Some acknowledged that if they were young and had a child, they would consider moving from Clyde, but ultimately they had no plans to leave. Strong family ties and the attachment to the community, particularly among older, long-time residents, made it difficult for many to move away from Clyde. “We were born and bred here. This is our home,” I heard over and over again. “Moving is unthinkable.” Bubba’s mother explained:

You love the people. Oh my god, they’re your family! They’re your best friends! Your *life* is here. It’s your life. Your life! It’s all you know. It’s all *I’ve* ever known[...] I had a reporter come up to me at a benefit and ask me, ‘Would you have raised your child anywhere other than Clyde?’ and I said, ‘Absolutely not.’ And they said, ‘Why, why would you keep you kids here? Why would you stay here?’ And I was like, ‘Look around this community, there’s not greater community in this world than Clyde Ohio. There’s not. The community is amazing.

Second generation family members or close friends who were impacted by disease were the most likely to leave. None of Bubba's siblings expressed the desire to live in or raise children in Clyde, potentially interrupting the established generational continuum of raising families in the community. Cody explained, “I feel like I’m breathing chemicals in, every single time I go back to Clyde. I just feel like I’m breathing in poison and killing myself every time I go back.” Another resident, Erika, spoke of her son:

When he got out of the Marine Corps, he moved to Cleveland to go to college and he doesn’t wanna raise kids in Clyde because of the cancer because three people in

the block [my husband] grew up in, three of the boys that grew up together died within like 3-5 years of each other of cancers.

Some younger families expressed the desire to move, but faced financial constraints and concerns that they would not be able to sell their house due to depressed property values, an issue Edelstein refers to as the “inversion of home.”<sup>29</sup> Karen felt stressed about the value of her property when, after contacting her bank to inquire about refinancing for a home equity loan, the bank suggested not starting the process of refinancing, implying that the property value may be lower. Michelle added:

I'm really concerned about living here now, but my husband and I can't afford two house payments. Nobody's gonna wanna buy this property now. And the refinancing company is requesting that we have soil testing done because of what's going on next door. And the soil testing is going to come out of our pocket. If they are requesting PCB testing, that could be 12-1500 dollars, and I don't have that to put forth. We just don't know what to do, but we're afraid to stay here. Are we gonna get sick? You know.

Although financially unable to relocate, Keith expressed wanting to keep his children from visiting for long periods of time:

With my car situation, I don't really have that good of a car, to go very far away [...] I have two young daughters, 13 and 14, from my previous marriage and [...] I'm much more conscious. One of my daughters wanted to come for six weeks this summer...I'm not gonna allow her to come. I don't want her there in that environment any more than she is. I'm sorry. I'm worried, I'm concerned, they still don't know what it is. People are still getting sick and dying and until that stops...I want to get out. I want to get out.

Participants also noted the culture of resentment towards the few families that chose to move out of Clyde. An example was cited of a family who dealt with their five-year old's diagnosis and

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<sup>29</sup> Edelstein, Michael R. 2004. *Contaminated Communities: Coping with Residential Toxic Exposure*. Boulder, CO: Westview.

death. This family had received financial assistance from the community in the form of fundraisers. While initially supported by many, when the family chose to move from Clyde while their son was sick, Travis, a family friend, recalled that some people turned against them and “badgered them with the question, ‘why did you move?’ ‘you left us, you left the town, you left the community, we supported you.’”

### *The Financial Burden of Health Care*

The management of chronic illness often requires households to make financial choices between health care and basic living expenses. The high cost of medical treatments and care are contributing factors related to economic hardship, which compromises patients’ care or self-care and has negative implications for risk reduction behaviors. This can result in compromised health outcomes and increased costs to the health system.<sup>30</sup> Ineligibility for government support, being on multiple medications, and not having paid employment were some factors mentioned by impacted residents that exacerbated the financial burden associated with their illness. Donald, an adult in remission from chronic myelogenous leukemia (CML), explained that when the economy changed, he couldn’t find a job that paid well, gave sick days, and provided insurance. He expressed concern that if potential employers knew about his condition, they would not hire him because it would make their insurance increase.<sup>31</sup> Because of his financial status, he was eligible for free medication that otherwise would cost \$3,500 per month. Each time his wife changed employers, she would have to have his medication pre-authorized. The prescribed medications for CML were expensive, typically costing between \$50 and \$80 after insurance. Both Donald and his wife were unemployed, without health insurance, and were having difficulty finding jobs. They also faced a financial barrier to prescribed medical tests because of their lack of insurance.

Concerns over job security were expressed by some who worked at Whirlpool, and who were confronting the possibility of choosing between the health or financial security of their families. Additionally, job security and longevity were impacted by the need for parents to take extended time from work while supporting their sick children. Concern about their financial futures added to their economic burden. One man stated:

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<sup>30</sup> Jeon, YH, B Essue, S Jan, R Wells, and JA Whitworth. 2009. “Economic Hardship Associated with Managing Chronic Illness: A Qualitative Inquiry.” *BMC Health Services Research* 9:182.

<sup>31</sup> Note that these interviews were conducted prior to the establishment of the Affordable Care Act.

I'm very nervous about one of us losing our jobs. [...] I mean, everything would be gone. We can't afford it on a less paying job. We can barely afford it now, especially over the years you get behind with charged things on credit cards, you know gas to go to the hospital, you start jackin' up credit card bills.

Among other factors, financial difficulties are more commonly seen among young or older patients who lack social support, have dependent children, and have low income or little savings.<sup>32</sup> To adjust to their financial struggles, participants described using their savings, relying on family and friends for financial help, and making changes to household spending. Consequently, many described a reduced lifestyle.

#### *Community Support & Community Criticism*

In the small town Clyde where everyone was “connected to each other,” it was difficult not to know somebody impacted by cancer. Fundraising efforts for affected families occurred regularly, as indicated in postings in the major local Clyde area newspaper, *The Clyde Enterprise*. References to 13 articles or advertisements for fundraisers or memorial events appeared in the paper between June 1, 2013 and June 1, 2014.<sup>33</sup> From chicken or spaghetti dinners to auctions and involvement of local churches, schools, and businesses, community fundraisers gave residents a way to be proactively involved and helped buffer the financial hardships that victims faced. The town became very efficient at hosting fundraisers, raising significant amounts of money for affected families. Those that did not have a lot to give often volunteered. Turn-out for these events was described as being high, with events sometimes even selling out. “Sometimes you want to get a ticket, but you have to wait for next one,” Betty said.

Bubba's family recalled that his fundraiser was particularly large. They estimated that 2,500 people attended it and raised \$60,000 for their family. “There were people showing up to volunteer that I have never even seen before,” Bubba's brother recalled. Even athletic teams from outside of the community came to show their support, and some even wore their own

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<sup>32</sup> Timmons, A. R. Gooberman-Hill, and L. Sharp. 2013. “It's at a Time in Your Life When You are Most Vulnerable: A Qualitative Exploration of the Financial Impact of a Cancer Diagnosis and Implications for Financial Protection in Health.” *PLOS One* 8(11)

<sup>33</sup> This number only reflects articles specific to cancer-related fundraising. Other articles were published that highlighted stories about residents with life-threatening illnesses that did not include notifications of fundraisers.

“Bubba’s Battle t-shirts.” In this regard, the family was extremely appreciative of the community’s support. They discussed how they still see people wearing the t-shirts and bracelets in honor of Bubba. Bubba’s mother discussed her own collection of t-shirts she had acquired from fundraising efforts:

I have two drawers of nothing but fundraising cancer t-shirts that I wear to work every day and I wear them proudly. “Bubba’s Battle,” “Taylor Tackle’s AML,” “Alicia’s Army,” “Scotty’s Smokehouse,” “Team-up for Tanner,” “Hugs for Alexa.” I wore Taylor’s to work on what happened to be the day she died.

Items, including food, for these events are often donated from companies around the area. The 2<sup>nd</sup> Annual 5K Run/Walk for Bubba held on April 27, 2014, for example, included a pancake breakfast for which Croghan Bank donated napkins, Gary’s Diner donated pancake mix, and Whirlpool donated sausage.<sup>34</sup>

On the one hand, the generosity and financial support offered by the community was discussed positively by participants and demonstrated their compassion for the impacted families. But recipients were also sensitive to judgment and criticism from within the community, which some perceived as having increased after the filing of the lawsuit. Dave felt pressure to keep his opinions about the cancer cluster to himself due to the reaction of his friends and the implied condemnation coming from the community regarding the legitimacy of his family’s financial need.

We have a pretty nice house but we built it ourselves. We did all the work ourselves and we worked hard. We have both worked the same job for 29 years, and I manage the grocery store. A lot of people think I own it, but I don’t, I just manage it for somebody. You have these fundraisers to help try to pay for bills and to keep life normal for the kids, and sometimes you feel like people are questioning why you need that. ‘You could sell your house.’ We heard that, you know. Well, everything else has been taken away from the kids, you know, their friends...so we were gonna do whatever we could to keep the house. And, you know, so you have these

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<sup>34</sup> Massman, Bradley. 2014. “Runner and Lion’s Club Show Support for Bubba.” *The Clyde Enterprise*. April 30, 2014.



fundraisers you help make the house payment 'cause your wife's off work for two and a half years through it all, and we get people looking at us. Before Tyler got sick we planted the pine trees out there and they were guaranteed. After Tyler got sick, our friends had a fish fry for us and the fire department raised some money. Right after that Perri's Plantation was out here replacing some of the trees that had died that they guaranteed and then some people were saying stuff about how we just had this fundraiser and 'they're out buying trees,' you know. So it's just... it's just uh , I feel it's very stressful.

He recalled another instance where he felt that critics were attaching his worthiness of receiving help to his income and how he spends his money:

We'd always go to Michigan for vacation and the kids would swim in a lake up there. That was our vacation every year, and you know, the kids really love swimming. So they couldn't swim because Tanner had this port in and there was worry of infection so we started talking about having a pool that if you chlorinate it yourself and don't let other people in, they can do that and it's something enjoyable...just family time, you know in the backyard, bonding. So we asked someone about that at Swim Rite Pools and then he calls me back a couple days later and says, 'Hey, I talked to a few of our lenders, and they can donate some of the stuff for a pool.' And I go, 'Oh, that, that's pretty cool.' Then they started talking about an in-ground pool, so we ended up getting an in-ground pool. We still had to pay some money, but we cashed in our 401k and paid for it that way. It's something for our family. I mean, at that point we were thinking, we want to spend as much time with them as we can. So you find yourself doing things like that for them but it looks bad to other people if you had a fundraiser. But you wanna create some memories, and you want to give them some fun while you can. It plays mind game with you because [...] But we did get a pool, and we paid for it, I did a lot of the work myself on it, paid buddies to help, you know, we poured the concrete ourselves.

Just as their children's friendships had changed, many adults experienced disruption among their own friendships. The division that occurred became more pronounced after the filing of the lawsuit.

### *Managing Ongoing Illness amid Concerns about the Future*

Because of possible late side effects, childhood cancer survivors need life-long follow-up care. Both Tyler and Tanner are in remission, but still have to deal with ongoing and long-term problems stemming from disease. Tanner, for example, takes growth hormone shots every night because he is in the first percentile in growth for children his age, a consequence of having radiation treatment on the pituitary gland. Other participants also stressed the point to me that the experience of illness—whether active or “cured”—affects one's daily life forever. It is not simply something that can be put away at the end of the day.

Donald, the currently unemployed 52-year-old who is in remission from CML, explained that the medication that he must take kills the fats in his bone marrow, resulting in strong flu-like symptoms every 2-3 weeks. Additionally, because his immune system is compromised, he is more vulnerable to more extreme illness, including bronchitis and pneumonia, than other people. Betty also discussed her daily concerns about her exposure to germs because her immune system is compromised by the removal of her spleen, which regulates infections.

The Hiseys, along with other families, were burdened by concerns about the future. A sense of foreboding infiltrated their everyday lives, along with an understanding that this issue would be protracted and chronic. Some projected that toxin exposure would affect the health of many more families in the future, including their own. “I worry every day. In the restaurant business, I see families every day and I wonder who's next,” Travis stated. Within this context, suspicions arose about even minor complaints that their kids could have cancer. “You take your kids or grandkids to the doctor for every little thing,” Erika explained. A cough from one of their children created stress for families as they constantly worried about their health and safety. Dave and his wife had to live with fear of the possibility that they would outlive their kids, and wonder who would take care of them if this happened. Despite the toll that cancer took on their daily lives, families still had to deal with the mundane aspects of existence, and they did not have the option to defer these responsibilities.

At some point, you get hardened to it because you realize life still has to go on [...] There are no right or wrong answers. You find yourself feeling bad for yourself one minute, then you get up, put your pants on the next day and the floor needs swept, you know, the food needs cooked, the yard needs mowed. I mean, life doesn't wait for you. But you just try to live life the best you can and try to do the right things. People might think you're not doing the right thing and you might not be, but I wish some of them could be more understanding of our situation.

Dave's decisions, like other parents, were motivated by advocacy for his family, and were rooted in his desire to promote stability amidst the chaos of his family's experience. The affected families in the Clyde cancer cluster remained cohesive in this aspect. Their struggles with the unknowable did not alter the integrity of their families. The impact of cancer on their lives put them on the perimeter of a traditional experience of family within the community. As the sphere of responsible parenthood expanded within this cultural context, wherein the source of toxicity was unknown and accountability was impossible to achieve, families without financial resources, time, and stability were pushed further to the margins of what was considered normal. Families were most immediately concerned with managing their everyday lives, and were grounded in the needs of their loved ones. The imperative for self-protection created serious psychosocial and practical conflicts as they adapted to the impacts of cancer on their families and in their community.

## CHAPTER 6

### CONCLUSION

Given the rise of environmental hazards worldwide, an understanding of agency and accountability is an increasingly important area of research. My dissertation has addressed this topic through the specific case study of the disease cluster community of Clyde, Ohio. Through an analysis of in-depth interviews, government reports and media files, and participant observation, I have demonstrated how individualization of risk is evident at both a macro-level and in the narratives describing everyday life in a cancer cluster community. I examined how the consequences of risk propel changes in individual and collective identity within the context of undetermined sources of toxicity.

In the first analytical chapter, chapter three, I investigated where the locus of power resided in the risk community of Clyde. I examined how government regulatory agencies determine what constitutes a “risk,” a “cause,” and a “consequence.” I traced the history and development of chemicals as products of industrialization, addressed their introduction into consumer society, and documented the laissez-faire regulation of chemicals in the U.S. I examined the potential harm resulting from lax regulatory standards, as well as the impossibility of calculating the consequences of “manufactured uncertainty” as related to the proliferation of unregulated chemicals.

The susceptibility of women and children to the adverse effects of toxic exposure is accompanied by an increase in literature directed towards women as predominant risk managers within their families. The emphasis on self-protection from health risks in the media and public health organizations is illustrative of how risk is individualized within these larger institutions.

Chapter four explored how risk cannot be considered in and of itself. Through an examination of the range of community responses to contamination in Clyde, I showed how perceptions of risk were influenced by an assortment of local conditions that determined disparities in community response. Through residents’ acknowledgment of or denial of toxic exposure, I showed how change was imposed on identity, how beliefs in existing systems dissolved, and how perceptions of risk influenced individual and collective responses to anecdotally evident yet scientifically undetermined threat.

Chapter five examined the psychosocial effects of contamination in Clyde, where risk and awareness of risk have penetrated the dialog of everyday life. It also documented the burdens associated with the management of illness, particularly in the family management of a child's illness.

For those directly impacted by disease, protecting their families from the risk of toxic exposure became a common facet of everyday life. The themes of *personal responsibility* and *self-protection*—from discovery of the cancer cluster, to residents assuming the burden of proof of contamination, to residents protecting themselves from suspected toxins—informed each of the analytical chapters in this dissertation.

This concluding chapter culminates in a more complete understanding of issues explored in previous chapters by offering a framework called “risk community adaptation theory,” which describes a process by which the community of Clyde, threatened by catastrophe and risk, changed to accommodate risk, rather than to substantially alter it. It is characterized by heightened public risk consciousness, inadequate response to initial encounters with risk, and an awareness of the ongoing threat of risk. In this chapter, I also address questions regarding social justice in the risk society, wherein legal procedures are largely ineffective in the pursuit of identifying the source of risk, assessing accountability, or preventing the emergence of future environmental endangerment.

### *The Enigma of Loving an Abuser*

I sat with Wendy in the breakfast room of the Red Roof Inn, the hotel where I stayed during my first visit to Clyde. It turned out to be a foolish meeting spot since the hotel sat adjacent to the Whirlpool factory plant. At times, Wendy spoke in whispers and looked around the room to see if anyone was nearby to hear her when she talked about Whirlpool. “The thing about Whirlpool...,” she whispered. “We don’t want to close Whirlpool. We just want them to do things that are right.” She talked about her daughter Alexa and the impact her journey had on their family. In talking about her community, she helped me understand that people in Clyde would not want to hear the word “contaminated” used to describe their town, which led to a discussion about stigmatization. Then she said:

You want to protect something that's your own whether or not you have...Okay, just an example of... and I have no idea why this example is coming to me, like if...Okay, say that you were a wife who was beaten by her husband. Sometimes you'll defend him to the end and don't want to admit that he is what he is even though you know what he is... But you don't want other people to know that something's wrong.

I knew at the time that this was an interesting comment, but I did not quite know what made it so. Other participants would make similar analogies to aggression, such as “We’re like a kicked dog.” Literatures that examine reasons why victims of abuse do not leave reveal similarities when considering the collective community inaction among residents in Clyde. Both internal factors and structural constraints have been identified for victims of abuse, including the presence of a perceived threat to one’s physical or psychological survival, the presence of perceived small acts of kindness from the abuser to the victim, and the perceived inability to escape the situation. Circumstantial reasons for staying also include external constraints on the victim’s ability to leave, including economic dependence or lack of occupational skills.<sup>1</sup>

In considering qualities of victimhood, similarities exist among all forms of survivorship that are evident in the identity of people who choose to either remove themselves from a dangerous or threatening situation, or, as in the case of the Clyde lawsuit plaintiffs, who choose to assert their right to protection from harm. What are the options for people involved in unjust distributions of harm, and how are personal and collective identities altered as a result of self-protective action? The subsequent redefinition of survivor identity involves participants in either singular or collective restructuring of previously understood life expectations. The question arises as to how we then continue our lives without certainty and without assurances of safety.

### *Adapting to Cancer as a Way of Life*

Although the identity of the broader Clyde community changed, it was not in ways that addressed the original problem of risk, eliminated the presence of risk, or protected the community from future catastrophe. In the case of Clyde, people have adapted to the

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<sup>1</sup> Anderson, Deborah K. and Daniel G. Saunders. 2003. “Leaving an Abusive Partner: An Empirical Review of Predictors, the Process of Leaving, and Psychological Well-Being.” *Trauma, Violence, and Abuse* 4(2):163-191.

consequences of contamination even as the cancer cluster persists. Inevitably, Clyde would have evolved in spite of the cancer cluster, but because of the attention drawn to the issue, changes to the town's identity have been more immediate. The most apparent indication of this is detectable in the perception of the town as a cancer cluster community. Cancer fundraisers, which have become commonplace and continue to be regularly attended, are the most obvious indicators of this. In a sense, they have redefined what it means to be a part of the community. Some would argue that they have even drawn residents closer, providing a measure of unity within this divided town. People take pride in the outpouring of compassion and participation, perceiving those things as normal responses to the emotional impact of a cancer diagnosis. Barb explained proudly that "there is a lot of good support for the sports, but we have just as much or more for the fundraisers." In this sense, fundraisers, like school sports, have themselves become social events on the weekends. Some residents describe these appeals for funds, which occur nearly every weekend, as being unique identifiers of community affiliation. As Carl explained, "It's like if ya haven't been to a fundraiser or don't have a wristband, then you're not in *our* community." Memorial fundraisers occur annually, and no longer need a description of who they represent because their histories are well-known and have been absorbed by the community. Fundraising efforts have seeped into the physical environment of the community as well. Solicitation for support funds continue community-wide, appearing in a variety of locations including the Speedway gas station, restaurants, bars, fairs, sporting events, and even the cafeteria at the high school. Cancer awareness stickers adorn cars. Cancer centers and radiation treatment facilities that are peppered throughout the town, including a Cleveland Clinic Cancer Center adjacent to Whirlpool, have been described as being simultaneously "weird but convenient."

The local schools have also participated in a system that has evolved in the community in response to the cancer cluster with nurses actively engaged in the care and reintegration of sick children. On an individual level, parents, physicians, and school nurses have become more vigilant to signs of illness. Nurses offer guidance to other students so that they know how to treat an ill child returning to school and how to limit germs, and they prepare students for the fact that sick children coming back to school might look different, but still need friends. Every school year, elementary students have "cancer week" and each day of the week they wear a different colored ribbon representing a different type of cancer. Children are being socialized to accept cancer as a normal part of life as they are themselves initiated into the culture of community by

wearing hats to school to support kids, donating hair, and wearing ribbons. It is apparent that the new collective identity of Clyde has evolved by giving cancer a deeper meaning, and has broadened the significance of what it means to be a Clyde resident. The message remains that Clyde is a supportive and giving community.

A dissenting faction of the Clyde community emerged after repeated unsuccessful attempts to get the help they needed through traditional means of recourse failed. These impacted families continue to live under the assumption that there is, in fact, great risk present, and that no one entity will ever be identified as liable. Choices are being made to become proactive in their encounters with risk. Other than choosing to leave Clyde, which few have opted to do, this faction of the community has shifted to a more cautionary model of living. Furthermore, families who lost children may have had their traditional perception of the community altered by the fact that they were not universally supported. While still engaging with and living under the umbrella of the broader community, this faction of the community shared a certain inchoate sense of group identity, distancing itself from one of the core ideologies of the broader community—that of seeing Clyde as a harmless, idyllic place.

### *Risk Community Adaptation Theory*

In this section, I offer an outline of a theoretical framework aimed towards describing the processes through which Clyde, threatened by catastrophe and risk, has changed to accommodate risk, rather than substantially alter it. It positions risk as an element of both social structure and cultural representation, and involves the interplay between these two factors. This framework locates Clyde on the cusp of change in Beck's view of paradigm shifts, but is informed by a broader range of theoretical ideas that highlight the complementary relationship between structure and agency with regard to community processes. It also helps us understand how factions of residents are reconstituted through marginalization within their communities.

At first glance, the system of power at play in the story of Clyde seems to be purely economic. And while economic power is perhaps the most dominantly operating system, I identify four intersecting *systems of power that place constraint on the community's culture and*



*ideologies*,<sup>2</sup> and that play out on both the macro-level and in everyday experiences. These systems of power worked to hamper a collective sense of community subpolitics.

### Organized Irresponsibility

Industry and government exist on one level, which mutually interact to define, interpret, and manage risk. The inadequacy of government in protecting a community's health, however, is inevitable given the already outmoded systems through which risk levels are determined. Also, as science and business have assumed greater positions of power in decision-making, local, state, and federal-level interventions have eroded. The mutual interdependence of these institutions (industry and government) may also be viewed as a larger version of the interdependence that exists between Clyde and Whirlpool. When economic determinations drive the conversation, the human consequences of any affiliated activity related to unequal distributions of wealth or power (such as expansion, profit, taxation) become secondary concerns. Although resultant personal tragedies attract public attention to catastrophic events, they are largely unproductive as motivators of meaningful change. Existing power structures resist acting to retroactively repair harm and eventually cannot do so because problems become so far removed from their scope of management. Rather, they operate within a distortion of order which confuses and misdirects attempts at modification or redress. The term "organized irresponsibility" implies intentionality, although it is arguable that at some point the dysfunctional elements of unregulated, human-created hazard assume a "life of their own" which is, in fact, no longer subject to intervention or control. Response to these outcomes appears, rather, in coordinated efforts to deflect responsibility, with both industry and government "tossing the ball" to one another as they attempt to avoid accountability for cause or reparation.

### Economic Power

Instances occur wherein profit-motivated definitions (and redefinitions) of risk are imposed by the very institutions that created the problems in the first place. This illustrates the complexity involved in risk assessment. Rather than a utopian enterprise which enhances human health and happiness, science is more frequently used in the unregulated pursuit of economic gain at the

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<sup>2</sup> This idea borrows from Williams' (1973) interpretation of Marx's idea of "base." Williams proposes that we interpret "bases as placing constraints on the superstructure, rather than being the causal force in cultural outcomes. See Raymond Williams. 1973. "Base and Superstructure in Marxist Cultural Theory." *New Left Review* (82).

expense of a consumer society. In examining the distribution of economic power in Clyde, we see social structures at work that keep the community economically dependent, and consequently less likely to engage in activities that would threaten the existing arrangement. Financial dependence on the Whirlpool Corporation had a direct impact on the community response to risks that many suspected were generated by that same corporation.

Financial concerns were a major determinant of residents' actions or inactions, as seen in their complacency with maintaining the status quo and in their fear of standing up to Whirlpool. Thus, the economic distribution of power not only positioned groups differently within the community, but also shaped their resistance, or lack thereof.

A percentage of human casualty is the seeming consequence of living within a risk society. It is not simply that human casualties occur, but that they are now considered as probable and acceptable in the pursuit of strategic economic advancement. Residents of Clyde did not anticipate that their community would be environmentally degraded or that members of the community would become ill, and most do not recognize or accept this as their payment for participation in an economic system through which they also benefit.

The ramifications of problems faced by the Clyde community are expansive in that workable solutions for protection from environmental hazards are in direct conflict with the threat of personal financial disaster. How does one select from presented disasters? Does one decide to move away from contamination, or to lose their job? It is largely supposed that Whirlpool at first presented itself as a promoter of financial good within the Clyde community, and, indeed, interacted as such, at least superficially, for many years. The community's "adoption" of Whirlpool into its identity initially operated in a mutually beneficial manner, both financially and socially, but ultimately enhanced the corporation's power as Clyde's population became more economically dependent upon what is still considered by many as a positive exchange.

Acceptance of a regulating entity, in this case Whirlpool, was dependent to some degree upon the belief that the power entrusted to them would work to further the interests of all involved. Yet, as Whirlpool's financial integration into the Clyde community became more entrenched, and perhaps because of the resulting complacency on the corporation's part, decisions were made that threatened the least powerful members of the arrangement. It is certain that profit-based corporations such as Whirlpool are understandably motivated by a financial

agenda, but the question arises in Clyde as to what degree of imposed damage is acceptable in the company's enterprise of profitability. The economic power structure between Clyde and Whirlpool arguably changed when non-public courses of action, such as the dumping of toxic waste or building a community park over contaminated soil, were imposed upon the community without their knowledge or consent. Whirlpool changed the equation by assuming a power to which they were not ethically entitled.

In one sense, the existing status of Whirlpool within the community remains unchanged. Due to the undetermined, exact source of contamination, the distribution of blame has been so dispersed as to render the corporation inculpable, and has facilitated their escape from financial responsibility for compensation. Additionally, the corporation's access to legal representation far outweighs the financial resources of plaintiffs.

### Stigmatization

Stigmatization presents in two ways in Clyde. First, the community experienced a sense of external stigmatization by being identified as a cancer cluster town. The perceived threat to community character included not only its economic identity, but more importantly its self-perception as an unspoiled rural American community. This was a recurring theme among interviewees whose inherent pride of place was threatened by the taint of cancer cluster classification. It was apparent that the perception of outsiders mattered to residents, that there existed a sense of exclusivity in the town's quiet, unblemished wholesomeness. The community operated smoothly and residents were connected through their high level of satisfaction with the existing coherent framework, which had been successfully spinning for decades. When negative media attention was directed at Clyde, the challenge to the integrity of the town created defensiveness and a detectable sense of loss. Adaptation to the changing identity of Clyde continues to be met with reluctance, and has, perhaps, been one of the strongest barriers to a unified response to the contamination issue.

The second manner in which stigmatization operated within the town was as a divisive method used to censure voices threatening the status quo. Criticism of Whirlpool's complicity in the environmental contamination of Clyde was often met with reproach and condemnation. It was as if a threat to Whirlpool were a threat to the existing character of the town. Grumblings and rumors circulated about lawsuit participants, whose motives and methods were

questioned. While the experience of having a child with cancer placed people on the perimeter of normative parenting to begin with, the larger community contributed to affected families' sense of isolation initially through lack of support, and ultimately by not aggressively dealing with the problem of risk. As the once cohesive community splintered, it could be argued that dissenting voices were marginalized to legitimize the broader community's inaction.

### Individualization

Where collective identities, such as race, gender, or social class were once the determinants of action, risk theory asserts that life in the risk society is progressively self-directed. This can be seen most evidently in a situation such as that presented in Clyde, where traditional avenues of recourse to address harm have failed to achieve an outcome of safety. The consequential individualizing logics that influence the perception of risk contribute to its normalization as the tasks of managing risk become more personally determined and are woven into daily life. Risk is further legitimized by its integration into social dialogue through media and public health policies that promote the concepts of deterrence and avoidance of harm as matters of individual preventive choice. In the case of Clyde, care-giving, family decision-making, and even consumer selections became acts of individualization as affected residents considered their own courses of response to contamination. Measures taken (such as the purchase of bottled water, water filtration systems, etc.) not only empowered residents, but qualified their personal investment in the outcome by strategically redirecting responsibility of outcome to the individual. As a result, perceptions of risk influence the experience and response to risk, while at the same time obscuring and legitimizing the operation of other systems of power.

### *Risk Community Adaptation beyond Clyde*

In applying this theoretical framework to the case of Clyde, several overlapping conditions emerge: an economic dependence on an industry within a town that employs a large portion of residents, a strong community affiliation with the company, education level, expectations of democracy, rurality and appreciation of identity of a small town middle-American town, industrial contamination, and the gradual awakening of community awareness of risk.

Conducting field research of other locations of contaminated communities is an efficient way of determining how applicable the theoretical framework presented in this chapter would be

to other locations throughout the U.S., as encountering the range of community response to contamination requires spending time within a community and gaining trust from its residents. Media portrayals of cancer clusters usually fail to capture or portray the social dynamics of the impacted community. Regional news coverage of Clyde, for example, tended to victimize community members in a manner which favored the plaintiffs, but did not capture the broader sentiments felt by residents who believed that Whirlpool was not responsible for the cancer cluster.

Many communities have parallel experiences with their town's emergence as a cancer cluster. An unusually comprehensive *Houston Press* investigation in Somerville, Texas provides an opportunity to examine a community faced with conditions very similar to those of Clyde. Somerville, a town of approximately 1,400 people,<sup>3</sup> is home to a large wood-treatment facility that locals call the "tie plant," once the nation's largest producer of railroad cross-ties.<sup>4</sup> In the late 1990s, its residents began noticing high rates of birth defects and cancers of the brain and stomach within the community. Environmental scientists identified extremely high levels of cancer-causing chemicals in the dust of Somerville homes and school buildings. As reported by the *Houston Press*, residents were contracting stomach cancer at a rate as much as 40 to 60 times the national average.<sup>5</sup> Ronald Supak, who worked for the tie plant for 28 years and whose son was born with a birth defect, stated: "My friends are all dying from cancer; I'm waiting for my turn."<sup>6</sup>

In response to resident concerns, the Texas Department of Public Health Services conducted epidemiological studies, but did not find that the incidence of cancer was significantly different than the national average. However, these studies depended on death certificates, which can be inaccurate. Additionally, the studies did not include residents who moved away or died in hospitals outside of Burleson County, which has no hospital.

Some impacted residents sued the local company, alleging that the company sprayed toxic pesticides throughout the facility, burned creosote-treated wood in boiler stacks at night to avoid complaints from townspeople, destroyed company documents, and failed to provide

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<sup>3</sup> U.S. Census Bureau, American Factfinder. "Geographic Identifiers: 2010 Demographic Profile Data: Somerville City, TX. Retrieved March 18, 2016.

<sup>4</sup> Spivak, Todd. 2007. "Toxic Town: Cancer and Birth Defects in Somerville." *Houston Press*. Retrieved March 18, 2016. (<http://www.houstonpress.com/news/toxic-town-cancer-and-birth-defects-in-somerville-6575305>)

<sup>5</sup> Ibid.

<sup>6</sup> Ibid.

employees with proper safety equipment. Several employees recounted receiving instructions from company managers to conduct these harmful practices, noting that their jobs depended on fulfilling these requests, and that “respecting authority” was a value with which they were raised. Residents described working at the plant as a “family tradition.” The tie plant even “provided families with metal barrels that once contained pesticides to use as makeshift barbecues.”<sup>7</sup> This suggests not only deceit, but it illustrates how deeply the company was integrated into the community.

The theme of individualization is also present in the story of Somerville. Former managers and city officials downplayed the cancer problem in Somerville, and placed responsibility for protection from industrial contaminants on the plant workers. In response to the class-action lawsuit, one company spokesman stated: “It is our position that there is no reliable scientific evidence to support their claims.”<sup>8</sup> A former mayor and longtime tie plant worker (who also had cancer) was quoted saying, “It’s their responsibility.”<sup>9</sup> When interviewed by the *Houston Press*, he stated, “There’s cancer everywhere, and it’s not just in Somerville.”<sup>10</sup>

Those involved with raising awareness about the health risks in Somerville reported strong backlash from the broader community. They were approached by other residents who told them, ‘You need to leave this alone; the railroad built this town.’<sup>11</sup> Some residents, even those impacted by disease, reported having mixed feelings about leaving. “People here are friendly [...] Somerville is a nice town, actually. This isn’t a place we’re dying to get out of.”<sup>12</sup>

What can be gleaned from this media account is that, like the town of Clyde, Somersville’s response to contamination and community-wide illness was constrained by its economic dependence on the tie plant, by a chain of neglect and incompetence, and by the individualization of responsibility. Also similar to the Clyde community’s experience was a desire to protect the town’s identity from the stigmatization of being labeled a “cancer cluster”.

While other cases may not have conditions identical to those of Clyde and Somersville, the systems of power outlined in this chapter present to varying degrees in other communities impacted by industrial contamination. The current lead contamination crisis in Flint, Michigan

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<sup>7</sup> Ibid.

<sup>8</sup> Ibid.

<sup>9</sup> Ibid.

<sup>10</sup> Ibid.

<sup>11</sup> Ibid.

<sup>12</sup> Ibid.

strongly reflects how the systems of organized irresponsibility and economic power work to disenfranchise communities. Like Clyde, Flint is located in what is considered the rustbelt and was once the location of the largest General Motors plant. Flint began to decline in the 1980s when GM downsized. In this case, the re-sourcing of the city's water supply was initiated as a cost-saving measure as the city's water source was diverted from Lake Huron to the heavily polluted Flint River. This move ultimately corroded the city's older pipe delivery system and leached lead into the sinks and showers of a city of approximately 100,000 people, with children emerging as the most vulnerable victims of the contamination.

Public officials were instrumental in changing the water system to save money that affected water quality. Flint's mayor, U.S. EPA officials, and emergency managers repeatedly told concerned residents that the water was fine, and to this date two years later, there has been no assertive intervention to correct the problem.

Important differences exist between Clyde and Flint, however, in that the source of toxicity has been definitively identified in Flint. Compared with Clyde, the problem affects a greater number of people, is more immediately recognized as a crisis, has received enormous public attention, and awakened perceptions of the presence of lead in the water of other communities. Additionally, it is a disaster that has impacted the whole community.

The financially-driven catastrophe in Flint was imposed upon a predominantly low-income Black community,<sup>13</sup> and it is probable that this situation would not have occurred in an upper-income white community. City officials operated under the assumption that the population of Flint had no political power, lobbyists, or resources to fight back. The arrogance involved in this case is evidenced by the presumption that city officials could get away with malfeasance because of the social determinants of community it was imposed upon. It was not until someone with a "pedigree", in this case a pediatrician who recognized a rising trend in lead levels among Flint's children, raised the alarm that attention was brought to the situation.

Race played a more insidious role in the decision-making process in Flint than it did in the community of Clyde, and continues to be a significant determinant of health consequences there. Flint residents' experiences with and responses to contamination were reflective of pre-existing low expectations that government would respond to problems in communities of color to begin with. Sociologist Robert Bullard's work illustrates that communities of color are more

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<sup>13</sup> The median income is less than \$25,000, which is approximately half the state average.

likely than whites to confront polluting industries and less likely to receive media recognition or government support.<sup>14</sup> While whiteness in Clyde was experienced as privilege, and residents there who claimed “American-ness” expressed shock that institutions of government had failed them, such unequivocal levels of trust in Flint’s government were likely absent to begin with. Institutionalized racism facilitated the cycle of deception, and even now, in spite of overwhelming evidence, media attention, and national outrage, the problem persists as actions to determine accountability for the water crisis stall. In addition to being a significant determinant of the health outcomes and expectations for resolution, race also impacts response to disaster. Celene Krause argues that activists of color view community contamination as part of a longer history of racial injustice, and ultimately see themselves as connected to the racial justice movement.<sup>15</sup>

### *Implications for Justice*

In many ways, impacted families’ actions to resolve contamination were shaped and limited by the very forces they sought to challenge—science and unknowable risk. This faction of the community took an active position of advocacy for safety and health, networking to share information and support, attempting to garner community backing, and eventually filing the lawsuit. In so doing, they engaged in what Beck would describe as subpolitics. Comprised mostly of families directly impacted by cancer, and of those living with a heightened public risk consciousness, this faction of the Clyde community was forced by the consequences of manufactured hazards into a position of social and political reflection. In the model of subpolitics that developed in Clyde, as traditional avenues of the existing political system failed, families chose a more direct form of action to address the issues of contamination.

While the ultimate benefit of supolitical involvement would allow public engagement in the initial decision-making processes that would control or prevent catastrophic outcomes in the first place, this direct re-structuring of top-down politics was not the primary goal of the lawsuit participants. Although a small-scale, local movement that engaged in alternative means through which their objective of accountability could be achieved, the weakness of this shift toward subpolitics in Clyde was conspicuous in that the objectives of the lawsuit were less driven as an

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<sup>14</sup> Bullard, Robert. 2000. *Dumping in Dixie: Race, Class, and Environmental Quality*. Boulder: Westview.

<sup>15</sup> Krause, Celene. 1994. “Women of Color on the Frontline.” In Robert D. Bullard, ed., *Unequal Protection: Environmental Justice and Communities of Color*, pp. 256-271. San Francisco: Sierra Club.



action to enact political change than that they were directed at the impossible task of identifying a singular culprit for the toxic burden and holding them liable. Unsuccessful legal efforts to hold Whirlpool accountable indicated that meaningful change would not be immediate and might not ever be achievable through the legal system.

Responses to risk in Clyde have been accepted and integrated as the new norm. Supportive activities that empower residents by allowing them to feel that they are doing something helpful and proactive, in a more subtle way, provide a venue through which small town values are preserved. Yet these community responses fall short in that they divert attention from other forms of activism and dilute efforts to find the proper determinations that would lead to cleaning up the contamination and making the town safe again. A discernible air of defeatism is attached to the general acceptance of circumstances which demonstrates how we have not adequately learned how to successfully maneuver in a risk society. People are waiting for leadership to intervene and tell them how to cope with the results of risk society, but leadership fails in the face of the increasingly undefinable nature of risk.

What happens to our ability to pursue justice in the risk society? Beck promotes a vision of a “culture of uncertainty”:<sup>16</sup>

[...] readiness to openly talk about the approach to risk, the willingness to acknowledge the difference between quantitative risks and non-quantitative uncertainty; the willingness to negotiate between different rationalities, rather than to engage in mutual denunciation; the willingness to erect modern taboos on rational grounds; and, last but not least, a recognition of the central importance of demonstrating the collective will to act responsibly and accountably with regard to the losses that will always occur despite every precaution.

If we were to look at Clyde as a measure of where we stand on this point, we can see that Beck’s vision has not yet materialized. It is probable that this will not occur unless there is, as Mythen

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<sup>16</sup> Yates, Joshua. 2001. “An Interview with Ulrich Beck on Fear and Risk Society.” *The Hedgehog Review*.

argues, “a sizeable swing in public values and a sustained effort to sacrifice short-term for long-term gains.”<sup>17</sup>

Questions surrounding how to deal with the scientific uncertainty of regulating in the face of potentially harmful chemicals, how to use hard and soft sciences without subverting them, and ultimately about the governance of uncertainty itself are yet to be resolved. However, some degree of scientific uncertainty with regard to the prevention and management of toxins and their health consequences must inevitably be made. Furthermore, the inclusion of all voices in such determinations is important to the success of risk governance.

Although benefits may not be immediately visible, momentum works in favor of the families fighting for justice, as they have a more ethically legitimate argument. It is reasonable to assume that change will inevitably occur as more cancer cases and an increase in public risk consciousness leads to the networking of solutions, interventions, and a larger response to issues of contamination. Eventually, older generations will be replaced by the new, who grew up with a different reality and who consequently will not place as much value in the old identity of Clyde.

When explaining to me that two journalists from Toledo were going to write a book about the cancer cluster, Wendy said, “I wonder how are they are going to end the book because it just doesn’t end.” As long as economic dependency between Clyde and Whirlpool exists, and the financial health of the community is intertwined with the success of the corporation, it is unlikely that changes in the existing dilemma will occur in the foreseeable future. However, there is hope that at some point Clyde might yet emerge as a cleaner, more strident and vital community. Justice can manifest when resistance to systems of power by subpolitical groups is asserted and they are given voice in the process. The human community’s quest for safety, opportunity, and connectedness will not disappear in the face of risk, regardless of its overwhelming complexity, and will inevitably influence the course of human action in the uncertain future.

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<sup>17</sup> Mythen, Gabe. 2005. “From ‘Goods’ to ‘Bads’? Revisiting the Political Economy of Risk.” *Sociological Research Online* 10 (3). Retrieved February 5, 2015 (<http://www.socresonline.org.uk/10/3/mythen.html>).

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## APPENDIX A

### METHODS

Methods used in this research included ethnographic fieldwork conducted in Clyde and Green-Springs, Ohio, both of which lie within the boundaries of the identified cancer cluster. Fieldwork was conducted from March 2013 to August 2013, coinciding with the filing of the class action lawsuit against Whirlpool in March, and an increase in local and regional attention to the cancer cluster. Community tension was high during this time, which provided a unique opportunity to explore community dynamics in light of these events.

#### *Entry into the field*

I visited the community of Clyde and conducted my first interview with Alexa Brown's mother Wendy several months before the bulk of my fieldwork was conducted. Talking with a knowledgeable insider for my first interview helped me design a project that was meaningful for me as a student, and truly representative of the predicament faced by members of this community. Wendy's insight into the nature of the town was invaluable in terms of helping me make informed decisions about my research approach.

The regional media accounts I relied upon for information in preparation for entering the field were not particularly helpful in that they did not capture the sentiment of the larger community that stood behind Whirlpool in the face of the lawsuit. Additionally, in light of a growing body of literature on the rise of popular epidemiology, I entered the field with expectations of a more proactive and also a more collaborative engagement between the government agencies and residents. I would learn, though, that citizen/government collaboration had not occurred in Clyde. My initial experiences influenced my decision to broaden my scope of study from the psychosocial effects of contamination to include the wide range of community responses to their identification as a cancer cluster town and its implications.

My search for a temporary place to live in Clyde was initially hampered by the fact that there were not many units available that did not require a year-long lease. After meeting with a landlord to view a small apartment near town, however, she invited me to rent a room in her basement no longer occupied by one of her children. I was able to establish a rapport with most residents, and believe that my experiences in the demographically similar town of Mantua, Ohio,

where I grew up, were helpful. Although power dynamics in the interviewer/participant relationship can be complex when different social positions are present, I suspect that my own background, especially related to experiences of class and race, helped to break down barriers.

Additionally, my concern and advocacy for residents' well-being was genuine, which I think was evident in my interactions with them. In addition to being receptive, for example, I engaged in activities to establish rapport. For example, I exchanged a series of short letters with a woman who lived alone and expressed feeling estranged from her family. The Brown family invited me to see their home and to see Alexa's room, kept just as she left it before she died. They invited me to view the butterfly garden they maintained in her honor.

I first noted evidence of residents' emerging trust in me when I attended the 'No One Fights Alone' community picnic held by the lawyers. I arrived early and sat by myself at a table under the pavilion. Alexa's father Warren came over and sat by me, then I was gradually surrounded by five other townspeople who I had interviewed. He also warmly introduced me to a few other residents.

### *Data Sources*

Thirty semi-structured open-ended interviews were conducted with residents located within or proximate to the identified boundaries of the cancer cluster. The sample of affected residents highlights key impact variables, including age, length of residence, and distance of homes from the suspected pollution source.

To supplement interview data, information was collected through newspapers, local meetings, government reports, and public community archival documents. Analysis of documents about the case, including government health reports and articles written by journalists or other reporters in the field, were used to construct a detailed chronology of events for the community, as well as opposing views. Detailed fieldnotes from participant observation within the community helped to capture participants' experiences in their "everyday lives".<sup>1</sup> I spent time observing and writing fieldnotes at various locations throughout the community, including Gary's Diner, the historical society, the public library, Legend's Pub & Grille, Biajo Fontana

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<sup>1</sup> Taylor, Stephen J. and Robert Bogdan. 1998. *Introduction to Qualitative Research Methods*. NY:Wiley.

Italian Eatery, Our Town's Brewin' coffee house, Wendy's, an informational public meeting held by the lawyers, and the 'No One Fights Alone' community picnic.

### *Data Collection, Analysis, and Writing*

About one-half of my interview contacts were made at a public meeting held by the lawyers in June 2013. This gave me the opportunity to introduce myself and my research to community members. I distributed flyers about my project with my contact information, and I collected attendees' contact information. Additional contacts were made at the 'No One Fights Alone' community picnic.

Interview questions were developed from researching mostly qualitative studies on social processes related to community discovery of contamination experience and its consequential effects. Each interview guide consisted of approximately 15 questions designed to capture narratives around the topics of the contamination experience, illness experience, coping, conceptualizations of health and illness, community identity, social relations, and connections to place.

Most interviews took place in the participant's homes, or in another private location, without the presence of other people. Other locations included the Red Roof Inn, one participant's place of employment located outside of Clyde, Columbus, Ohio, and the McPherson Cemetery (at the request of the participant). Prior to each interview, I explained the interview process. I used a semi-structured guide to organize the interviews, but sometimes deviated from the questions, depending on the nature of the interview. The nature of semi-structured interviewing allowed participants to tell their stories at their own pace, in their own ways, and within their own time frames. Interviews ranged in length from forty minutes to two hours, with most lasting about one hour.

Analytic techniques included active listening, which required concentration on what the participant was saying, differentiating between the participant's "inner voice" versus his or her "public voice," and simultaneously being aware of the "process as well as the substance."<sup>2</sup> Open-ended questions as opposed to leading questions were asked to elicit more genuine information.

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<sup>2</sup> Seidman, I.E. 2006. *Interviewing as Qualitative Research. A Guide for Researchers in Education and the Social Sciences*. New York: Teachers College Press.

Digital recordings of the interviews were recorded, transcribed, and analyzed in ATLAS.ti, a qualitative data analysis program. Open and focused coding contributed to the process of defining and locating the narratives within a basic social process<sup>3</sup> and finding common themes among participants' responses. Analysis was also accounted for in the form of memos—analytical and theoretical notes related to what I was observing in the narratives. This also allowed for comparisons between narratives, categories, and concepts.<sup>4</sup>

Applying a grounded-theory approach, I chose themes that recurred within the transcripts. Themes were also selected based on their significance to participants in the field. After the main themes were selected, I returned to the data with the objective of refining connections. Thematic patterns were then identified and explained, and interconnections between themes were considered.

I initially stayed “close” to the data as a means of staying true to participants' meanings and to prevent my own bias from influencing the process of writing.<sup>5</sup> By paying close attention to emotions, I was able to discern what was most important to participants.<sup>6</sup> I explained “how members use terms in specific interactional situations and how involved parties differentially understand and evaluate them.”<sup>7</sup> I also paid attention to participants' explanations and theories—their own understanding of what caused something to happen, such as illness or toxic contamination. I noted differences between members' theories and how members actually classified events.<sup>8</sup>

An additional analytical technique was to thoroughly re-read my interview transcripts and fieldnotes after data collection, which allowed me to gain new insights, and recognize patterns.<sup>9</sup> Finally, analysis involved linking local events to social forces. One way in which I approached this was to identify the ways in which members themselves made local connections to broader social forces.<sup>10</sup> I also expanded my analysis to focus on institutions that were affiliated with the setting, including the Ohio Department of Health and the EPA. This process contributed to

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<sup>3</sup> Charmaz, Kathy. 2002. “Qualitative Interviewing and Grounded Theory Analysis,” pp. 675-694 in *Handbook of Interview Research*, edited by Dans J.F. Gubrium and J.A. Holstein. Thousand Oaks, CA: Sage.

<sup>4</sup> Ibid.

<sup>5</sup> Emerson, R, R. Fretz, and L. Shaw. 1995. *Writing Ethnographic Fieldnotes*. University of Chicago Press.

<sup>6</sup> DeVault, Marjorie. 1999. *Liberating Method: Feminism and Social Research*. Philadelphia: Temple University Press.

<sup>7</sup> Ibid:108.

<sup>8</sup> Ibid:128.

<sup>9</sup> Emerson, R, R. Fretz, and L. Shaw. 1995. *Writing Ethnographic Fieldnotes*. University of Chicago Press.

<sup>10</sup> Ibid.

identifying barriers to collaboration, including lack of access to information and inadequate communication.

With regard to writing, I planned to address the “problematic lived experiences of ordinary people available to the reader” by employing narrative techniques associated with performative writing.<sup>11</sup> I aimed to “show” rather than “tell”, to embrace the audience, and to contextualize the narrative with my own personal reflections.<sup>12</sup> Also in line with the tenets of interpretive interactionism,<sup>13</sup> my goal was to produce a narrative that serves as a platform for critiquing public health and scholarly discourses which emphasize lifestyle variables as the primary sources of disease, as well as the scientific limitations of conveying the level of threat posed by carcinogens to communities.

DeVault reminds us that writing itself “constructs and controls meanings and interpretation.”<sup>14</sup> Editing decisions about excerpts from the interviews were based on a number of criteria, including length, relevance, readability, comprehensibility, and anonymity of informants.<sup>15</sup> Editing decisions were also made to preserve members’ meanings while at the same time drawing attention to specific moments that helped illustrate the story I was trying to tell. Additionally, some chapters were shared with participants to elicit their feedback on the accuracy of information included.

### *Ethical Considerations*

All participants were treated in accordance to the ethical guidelines of the University of Illinois Institutional Review Board. Participants were given a written consent form that outlined potential risks. I explained this form and told the participants that they could stop the interview at any point and did not have to answer questions that made them uncomfortable. To ensure confidentiality, all participants were given fictitious names unless participants indicated that they agreed to have his or her full name and other identifiable information used alongside comments or quotes in the final dissertation, other publications, or conference presentations. Participants were informed that the recorded interviews would be destroyed after they were transcribed, and any records linking them to their code name would be kept in a secure location separate from the

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<sup>11</sup> Denzin, Norman K. 2001. *Interpretive Interactionism*. Thousand Oaks: Sage.

<sup>12</sup> Ibid. See also Madison, Soyini. 2012. *Critical Ethnography: Method, Ethics and Performance*. Thousand Oaks: Sage.

<sup>13</sup> Denzin, Norman K. 2001. *Interpretive Interactionism*. Thousand Oaks: Sage.

<sup>14</sup> DeVault, Marjorie. 1999. Pp. 79 in *Liberating Method: Feminism and Social Research*. Philadelphia: Temple University Press.

<sup>15</sup> Emerson, R, R. Fretz, and L. Shaw. 1995. *Writing Ethnographic Fieldnotes*. University of Chicago Press.



transcripts. Additionally, all transcriptions were assigned a number written on the cover of the interview to protect the identity of the informant. The audio files and transcripts were stored on Illinois Box. Approval from the University of Illinois Institutional Review Board was received prior to data collection.

Ethical and methodological considerations were kept in mind when interviewing participants who were ill or who had a child with illness.<sup>16</sup> I approached the interviews with a mindfulness of the participant's state of being, and anticipated that calling on ill participants or parents of affected children to reflect on their conditions would likely be an emotional endeavor.

### *Limitations*

While the most common approach for in-depth interview studies is to study small homogenous samples, racially specific claims are more difficult to make when no racially comparative groups are included in the sample.<sup>17</sup> In choosing as my study site a community where the population was 89.3% white,<sup>18</sup> there were limitations to exploring racial and ethnic variances in experience with regard to contamination and disease. The narratives of minority women are often most truly revealing of the unique dynamics of race, class, and gender.<sup>19</sup> The intersectionality of race, class, and gender makes the experiences of minority women qualitatively different than the experiences of white women. One way in which I tried to address this issue was to explore how whiteness shapes participants' experiences. By paying careful attention to participants' implicit and explicit references to race, I attempted to more actively investigate constructions of race and ethnicity and inequality.

Another limitation presented when I requested interviews from several factions of the community who did not respond to my request, including members of city council, school administration, government officials, and a representative of a regional nonprofit community advocacy organization. Furthermore, although I did get IRB approval and some parents' agreement to permit me to interview their children, attempts at follow-through were unsuccessful.

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<sup>16</sup> Morse, J. M. 2002. "Interviewing the Ill," in *Handbook of Interview Research*, edited by J. Gubrium and J. Holstein, pp. 317-330. Thousand Oaks, CA: Sage.

<sup>17</sup> Uttal, Lynet and Glorinda Holguin Cuádriz (1999). 1999. "Intersectionality and In-depth Interviews: Methodological Strategies." *Race, Gender, and Class* 6(3):156.

<sup>18</sup> U.S. Census Bureau, 2009-2013 5-Year American Community Survey: Clyde, Ohio. Retrieved March 23, 2016.

<sup>19</sup> DeVault, Marjorie. 1999. *Liberating Method: Feminism and Social Research*. Philadelphia: Temple University Press.

APPENDIX B  
FIGURES



**Figure 1:** Clyde Porcelain Steel fire, Clyde, Ohio, 1945<sup>1</sup>



**Figure 2:** Mural of Proposed Pool by Frank Hall, 1963.<sup>2</sup>

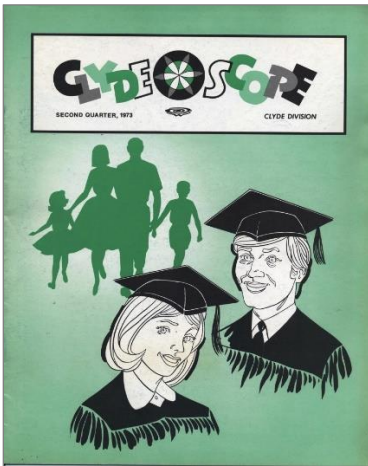
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<sup>1</sup> "Clyde Porcelain Steel Fire, Clyde, Ohio." 1945. Hale's Portrait Studio, Clyde, Ohio. *Thaddeus B. Hurd Digital Archive*. Clyde Public Library, 21 September 2010. Web. Accessed 21 May 2015.  
<http://www.ohiomemory.org/cdm/ref/collection/p15005coll19/id/1024>

<sup>2</sup> Hall, Frank. Proposed Pool for Whirlpool Park. 1963. Clyde Historical Museum. Clyde, Ohio.



**Figure 3:** An Undated Photo of Whirlpool Park<sup>3</sup>

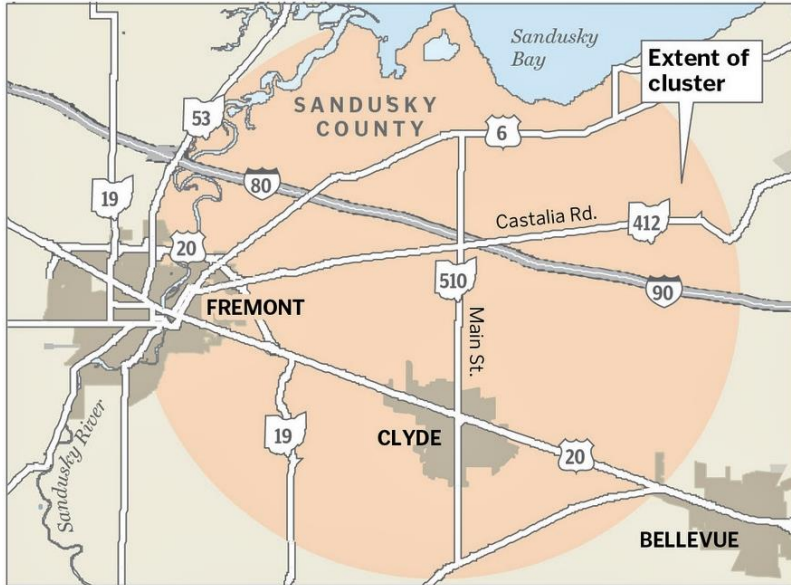


**Figure 4:** 1973 *Clyde-O-Scope* Newsletter<sup>4</sup>

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<sup>3</sup> We Miss Whirlpool Park. (n.d.). In *Facebook* [Group page]. Retrieved May 25, 2015, from <https://www.facebook.com/photo.php?fbid=1522661313620&set=o.120902597953632&type=3&theater>

<sup>4</sup> *Clyde-O-Scope*, Second Quarter 1973. Communications Section of the Industrial Relations Division, Whirlpool Corporation.



**Figure 5:** Map of Sandusky County Child Cancer Cluster<sup>5</sup>



**Figure 6:** Whirlpool Park, Green-Springs, Ohio, 2012. <sup>6</sup>

<sup>5</sup> "Map of Sandusky County Child Cancer Cluster." 2009. Sources: ESRI; TeleAtlas. The Plain Dealer. Retrieved May 25, 2015, from [http://www.cleveland.com/pdgraphics/index.ssf/2009/10/sandusky\\_county\\_cancer\\_cluster.html](http://www.cleveland.com/pdgraphics/index.ssf/2009/10/sandusky_county_cancer_cluster.html)

<sup>6</sup> "Whirlpool Park, Green-Springs, Ohio." 2012. The Toledo Blade. *ToledoBlade.com*. 14 November 2012. Web. Accessed 21 May 2015. <http://www.toledoblade.com/local/2012/11/14/Attorneys-Clyde-families-to-hold-news-conference-about-high-PCB-levels-at-former-playground.html>



Bureau of  
Environmental Health  
Health Assessment Section

"To protect and improve the health of all Ohioans"

# Benzaldehyde

Answers to Frequently Asked Health Questions

## What is benzaldehyde?

Benzaldehyde is a colorless, aromatic liquid that has a pleasant almond-like odor. It quickly evaporates (turns from a liquid to a gas) upon exposure to the air.

## How is benzaldehyde used?

Benzaldehyde is mainly used as a food and flavoring additive and can be found in many foods, including baked goods, frozen dairy, fruit juice, soft candy, gelatin pudding, non-alcoholic beverages, alcoholic beverages, hard candy, and chewing gum [Fenaroli, 2005].



Benzaldehyde is also used in dyes, fragrances (perfumes, deodorants, etc.), pharmaceuticals (drugs), personal care items (shave gels, moisturizing gels/creams, bath soaps, etc.), as artificial flavoring (cherry and almond flavors), and as an additive for one or more types of tobacco products. It is also used as a solvent for oils, resins, and cellulose fibers.



## Where do you find benzaldehyde in the environment?

Everywhere. Benzaldehyde is naturally found in almonds, apples, peaches, cherry and apricot kernels, and other *Prunus* species (fruits that have pits). Benzaldehyde can also be naturally found in essential oils including hyacinth, citronella, orris, cinnamon, sassafras, labdanum ("rock rose") and patchouli (type of mint) [Fenaroli, 2005]. Benzaldehyde has also been found in melon, grapes, tea and whisky [Leffingwell, 1998]. Benzaldehyde can also be found in combustion by-products in car and truck exhaust, wood fires and tobacco smoke.

A Swedish study of indoor dust detected benzaldehyde in 373 out of 389 homes. This suggests that the occurrence in the home would reflect its widespread use in household products. (Nilsson et al, 2005).



## What happens to benzaldehyde in the environment?

Benzaldehyde is not a persistent chemical, meaning it does not stay long in the environment. If released to the atmosphere, benzaldehyde is broken down quickly by the air and sunlight and has a half-life of about 30 hours. Benzaldehyde can be carried as dust particles in the air and can be removed by rain and fallout. If released to soil or water, it is expected to biodegrade [Hazardous Substance Data Bank – HSDB].

Figure 7: First Page of the Benzaldehyde Informational Flyer Released by Ohio Department of Health.<sup>7</sup>

<sup>7</sup> ODH. 2013. Benzaldehyde Fact Sheet. ODH, Health Assessment Section. May 2013.

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**NO ONE  
FIGHTS ALONE  
PICNIC**

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*Tuesday June 11th, 2013*

**COMMUNITY PARK IN CLYDE**

There are entrances to the park on  
*Race Street, South Street and Fair Street*

**6<sup>P</sup><sub>M</sub>** **HOT DOGS  
CHIPS &  
DRINKS**

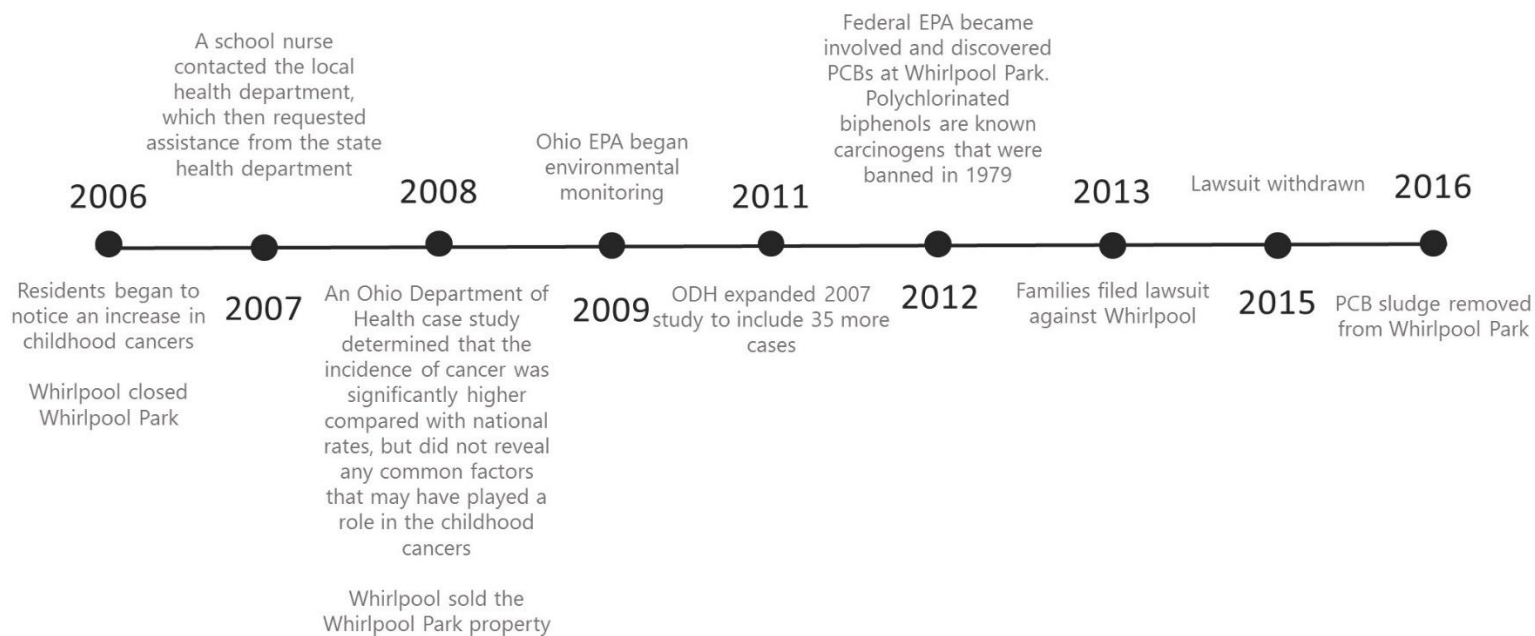
**THIS IS YOUR CHANCE TO MEET THE ATTORNEYS  
AND ASK ANY QUESTIONS YOU MAY HAVE.**

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**Figure 8:** 'No One Fights Alone' Picnic Flyer.

# TIMELINE

## Cancer Cluster Events



**Figure 9:** Timeline on Events Related to Cancer Cluster

APPENDIX C  
IRB APPROVED CONSENT FORMS  
**Informed Consent Form for Adult Participants**  
**Interview I**  
**University of Illinois**  
**Department of Sociology**

Laura Atkins  
(217) 418-1731  
Lbatkin2@illinois.edu

Dr. Assata Zerai  
(217) 333-7119  
Azerai@illinois.edu

I am a student at the University of Illinois, and I am conducting interviews for my research. I am studying the effects of residential toxic contamination among residents within the Clyde community.

During this study, you will be asked to answer some questions about your illness experience (if applicable), coping strategies, stress, your beliefs and values, and your experience of the events surrounding the disease cluster in Clyde and residential contamination. The interview is designed to be about an hour in length. However, please feel free to expand on the topics or talk about related ideas.

Risks to you are minimal and may include stress from answering questions related to your health and the health of your family. I do want you to know that your participation is completely voluntary. Also, if there are any questions you would rather not answer or that you do not feel comfortable answering, please say so and we will stop the interview or move on to the next question, whichever you prefer. And, if you decide you don't want to participate in the project after all, just let me know. I'll take care to delete any of our discussion and remove any record of your connection to my project.

Interviews will be audio recorded, which is necessary for participation. All the information will be kept confidential. I'll ask you to pick your own code name. I will use this name in the transcription of our interview and will delete the recording when I'm done transcribing it. Any records that I have linking you to your code name will be kept in a secure location separate from the transcripts. Only my faculty supervisors and myself will have access to this information. Upon completion of this project, all data will be destroyed or stored in a secure location.



### **Will my study-related information be kept confidential?**

Yes, but not always. In general, we will not tell anyone any information about you. When this research is discussed or published, no one will know that you were in the study. However, laws and university rules might require us to tell certain people about you. For example, your records from this research may be seen or copied by the following people or groups:

- Representatives of the university committee and office that reviews and approves research studies, the Institutional Review Board (IRB) and Office for Protection of Research Subjects ([http://illinois.edu/ds/detail?departmentId=illinois.eduNE344&search\\_type=all&skinId=0&sub=](http://illinois.edu/ds/detail?departmentId=illinois.eduNE344&search_type=all&skinId=0&sub=)) ;
- Other representatives of the state and university responsible for ethical, regulatory, or financial oversight of research;
- Federal government regulatory agencies such as the Office of Human Research Protections in the Department of Health and Human Services

**Participant's Agreement:**

I am aware that my participation in this interview is voluntary. I understand the intent and purpose of this research. If, for any reason, at any time, I wish to stop the interview, I may do so without having to give an explanation.

The researcher has reviewed the individual and social benefits and risks of this project with me. I am aware the data will be used in a Dissertation that will be publicly available at the University of Illinois at Urbana-Champaign. I have the right to review, comment on, and/or withdraw information prior to the Dissertation's submission. The data gathered in this study are confidential with respect to my personal identity unless I specify otherwise. I understand if I say anything that I believe may incriminate myself, the interviewer will immediately rewind the tape and record over the potentially incriminating information. The interviewer will then ask me if I would like to continue the interview.

If I have any questions about this study, I am free to contact the student researcher or the faculty adviser (contact information given above). If I have any questions about my rights as a research participant, I am free to contact the University of Illinois Institutional Review Board at [irb@illinois.edu](mailto:irb@illinois.edu) or 217-333-2670.

I have been offered a copy of this consent form that I may keep for my own reference.

I have read the above form and, with the understanding that I can withdraw at any time and for whatever reason, I consent to participate in today's interview.

Please check box to indicate that you understand that this interview discussion will be recorded.

\_\_\_\_\_  
Participant's signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Interviewer's signature

**Addendum to Informed Consent Form  
University of Illinois  
Department of Sociology**

**Authorization to Use or Disclose Identifiable Information**

**Project Title:** The Clyde Project: A Study of Coping with Contamination

Laura Atkins  
(217) 418-1731  
Lbatkin2@illinois.edu

Dr. Assata Zerai  
(217) 333-7119  
Azerai@illinois.edu

**What is the purpose of this form?**

This addendum to the consent form is to give you the opportunity to have your full name or your child's full name and other identifiable information, such as your job title, used alongside your quotes. Results may be published in the form of a dissertation, academic journals, the general media, and presented at conferences.

All other sections of the original consent form still apply. Please refer to it for any questions you might have.

**What happens if I do not sign this permission form?**

Please note that you do not have to sign this authorization. If you choose not to sign this permission form, any information you previously shared will be kept confidential, and a code name will be used rather than your real name alongside your quotes.

**What happens if I change my mind?**

Please note that you may change your mind and revoke (take back) this authorization at any time, except to the extent that it has already been acted upon.

**Consent of Participant:**

I understand all of the information on this addendum consent form. I have received complete answers for all of my questions. I understand that direct quotations from either my child’s interview or my interview may be attributed to my child or me in published reports, if I give permission below. If I have any questions about this study, I am free to contact the student researcher or the faculty adviser (contact information given above). If I have any questions about my rights as a research participant, I am free to contact the University of Illinois Institutional Review Board at irb@illinois.edu or 217-333-2670.

Please indicate whether you agree to have your full name and other identifiable information, such as your job title, used alongside your quotes in the form of a dissertation, academic journals, the general media, and presented at conferences.

- Yes (If you change your mind about this at any point, please let the researcher know)
- No

**Consent from Participant 18 years of age or older**

\_\_\_\_\_  
Participant's signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Interviewer's signature

*Once you sign this form, you will receive a copy of it to keep, and the research will keep another copy in your research record.*

**Please mail this signed and dated page back to us using the enclosed pre-paid envelope. Or you may scan and email it to Laura Atkins at Lbatkin2@illinois.edu. You need to return only this page.**