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### The Silent Scream

Christine Roberts Gettys

*Hollins University*, [gettyscr@hollins.edu](mailto:gettyscr@hollins.edu)

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# THE SILENT SCREAM

By

Christine Roberts Gettys

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2004

Presented in

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the degree of Master of Arts in Liberal Studies  
in Social Sciences

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Director of Essay: Lorraine Lange

Lorraine Lange, Ed.D.

Department: Education

## Dedication

This work project is dedicated to *The Screamers* – all those who speak in silence to themselves, caught in *Unutterable*, seeking Elusive and live to talk about it; (and, to those who don't) – *these*, I pray come to be understood *not for the causality of circumstance*; but the *compassion* they, like all of us, deserve (Pain does not discriminate, Suffering does not take sides – they both pervade and perpetuate Ambiance's disruption, leaving marks on individual and collective psyches). To those who have ever felt Need, recoiled, and met Shell-Shock's electrocution (*even for a second – for any reason*), I offer a hand extended and a heart that beats with you: I cannot know the dynamics pressing down upon another; for though I may sense another's struggle, sympathize, empathize with it – life itself is a joint venture; but a singular experience. Ever present in the act of this writing exists *the nexus between holding on and letting go, rising and falling*, and the need for *an agent of capacitation* to absorb *the known and unknown*, as is the problem of the human condition -- my deepest hope, my central aim is to provide more than narrative; instead the lessons stemming from it: *The Silent Scream* is my story, but its threads are the fabric of many.

For my son and Tiger, my daughter, and Twenty-six Cents, my husband and the pets—each who gave me a reason more significant than myself to continue onward—I say thank you: May you always find oxygen and have eyes to see the mirror of souls—knowing first your own, as they reflect the ones I know better than all others as *good* and *holy* and *worthwhile*.

To More and Less, Bigger Than and Divine Appointments -- every moment Never Could meets Stand Tall in the day or darkness, seeking Rest --*The Silent Scream acknowledges* your chime: the *incantation* of souls sees One's Born Catching Up & The One's Time Caught Off Guard – Eternal Perspective is *Unutterable Reprieve*. May you (and every sibling, parent, and caregiver

giving more than giving can provide) find affinity in respite's due: may my words bridge *angst* and *triumph*, offering *peace through reconciliation*. To Healers, Teachers, my students, mentors, friends, and the Incidental Stranger who taught me and shared humanity -- your examples brought me *closer* when Too Far needed to walk my way (lest I become roadkill in the act of enduring); To the *Stick By'ers*' – those who stayed, those who went beyond comfort's reach, and those whose memories mine contain, may you *all* feel the reverberation Grace proffers in Mercy's name – may Certainty be yours.

## Acknowledgments

To Lorraine Lange, whom I first watched from afar as she led Roanoke County Schools (Superintendent), your reassurance (with a nod and a smile), knowing you saw further, helped me find flight, pace, and learn priorities. Thank you for your leadership, requiring me to see the best in myself, and kindness as my MALS thesis advisor at Hollins University. I would not be here without your patience and faith in me. To Ed Lynch, Thank you for helping me best, Dante: I appreciate the chances you gave me to stand in the fire. Hearing you call me “courageous” humbled me; your respect and our association strengthened me. To Cathy Koon, I did it! Your influence matters. Your genuine interest in my outcome lifted me higher. To Klaus Phillips, Caren Diefenderfer, and William Petty (in memoriam) (Hollins University & Oregon State University) – your influence remains.

To my spiritual giants (you know who you are), I am better for your examples of faiths. To Lester Caudill, to know you view me as a scholar is to have “arrived.” My gratitude to you for your faith in me. To my Debbie’s: (Debra Caudill, Deborah Luther, and Deborah Seagraves), your encouragement and support mean the world to me, thank you. To Jared Woolstenhulme, Linda Wallace, and Cathy Bagwell, thank you for giving me confidence. Your presence throughout this journey was indispensable. Finally, my deepest thanks to my daughter Sarah for inspiring me; my son Joshua and husband Jim for believing in me. Your love keeps me striving: you are my heart, each and together.

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## Introduction

“I shall pass this way but once. Any good, therefore, I can do or any kindness I can show [ . . . ] Let me do it now. Let me not defer nor neglect it, for I shall not pass this way again.”

—Ralph Waldo Emerson "

Born prematurely with Cerebral Palsy, I also struggled with complex childhood trauma. The need to find a competing narrative strong enough to make sense out of pain, the need for communication and compassion, strategies to navigate exhaustion and complex interpersonal difficulties and isolation -- I needed all of these and more. I found a few, but what became evident as *The Silent Scream* took shape was how difficult the narrative was to shape in the first place. I spent months just wading through the junk memories, which were actual re-living moments. Despite the massive amounts of counseling already received on these issues – they still had rent space, and I was unpacking. Fortunately, I knew when to rest and recognized the need to regroup.

The following pages will demonstrate capability (skill) and capacity (fuel) using various vignettes across time. The first is polished, but in some cases, it drops off, perhaps. In the second instance, it should be easy to see where I have either tried to adopt a different narrative voice (e.g., a child’s voice) or where I use italics and make no corrections for punctuation. While I can clean those up, I believe a very didactic aim is being achieved by leaving them. The shifting timelines, voice, and less polished parts show how pressure impacts construction. The reader can see 1) where trauma intersects, or an individual has regressed and/or just slides into a conversational tone; and 2) physical difficulties a person with Cerebral Palsy may encounter, significantly when spasticity or dystonia impairs the ability to relax, control muscles or sustain pace. (Again, I am not saying

these cannot be cleaned up); I am saying only that the title of my memoir is *The Silent Scream* for a reason, and as I've neared its completion and rewritten the introduction and conclusion, it seems it may be more suitable to allow such uniqueness to stay situated. This said, let me be specific: the following pages: 1) show vignettes across time as a young child, born prematurely and diagnosed with Cerebral Palsy, takes in the world around her; 2) learns to gain power as an adult; 3) uses the skills she has to raise a family, gain an education, and provide for them; and 4) my assessment of lived experience. I found myself writing and rewriting until the composition books were filled and sick of me. However, I wasn't rewriting narratives or journal writings but trying to protect them. I was trying to write a narrative different than I knew -- to sanitize the information.

Compassion, insight, and means to forgive shortcomings – (to do less would have been to combust; the magnitude of my circumstance had no room to overthink): my dark satire and Shakespearean dramas leaned into one element of life that gave me power: my capacity to learn.



# The Silent Scream

## Part 1: Hidden Childhood (Broken)

### The Short Bus (1969-1971)

I started school riding a short yellow thing I was the only person on. I had some contraption with headgear that looked stupid. How would I know it looked ridiculous? I was too young, remember? No, not really. I remember that helmet, and I started with a hard one and ended up with a soft one, but either way, it sucked. Then again, so did face planting, and I needed help to walk.

### Traveling to California (1975)

– three thousand miles in the way-back seat counting license plates, looking for Bob’s Big Boy & Dairy Queen – I laughed to think Bob & “his queen” co-piloted the wood-paneled Ford LTD station wagon, not to mention how my three sisters and I scanned the freeway for glimpses of buttocks shaped Golden Arches; and “going potty” meant “Hold it” (twenty more miles), and required trying not to identify with the color yellow – it was a trip (puns intended). Dusty, our retriever mutt, my only distraction from the recoil *Come Hither* oversized mock of Ronald McDonald -- with his red blubber lips and enormous clown shoes. Her wagging tail and vitality to relieve herself were matched only by arthritic decrepitude – *both* seared into my psyche. I lost my appetite. With companionate forlornness, as she was hustled back into the steel trap, a window cracked, draped by frothy slobber markings: *her quest for air* – accentuating an understanding of my own gasping asphyxiation. The only redeeming quality: my scarcely touched burger complimented the Big Mac my father wolfed down; so hungry he was, stretching the dollar, feeding his family. “Two all-beef patties, special sauce, lettuce, cheese, onions, pickles on a sesame seed bun.” (Averting tears) I knew rattling off the McDonald’s jingle might

help stave off anger, but tears welled up. My mother's expression was nearly raging. Guilt? of my noticing? Acting on discomfiture? "Happy" Meal was oxymoronic (I understood literary devices before I could name them.) I could not bear the sadness: Dusty's eyes -- pleading, she **strove**, pushing her head through the window crack, begging . . . forget liberation. *She has the right to be free*, if not for the act of it: *Semper Fi* – the double entendre ever incapable of righting. I knew if dogs were "Man's Best Friend" with this kind of treatment, I'd settle . . . for being the enemy.

My shame over Dusty predicament was heightened, thinking of Bozo the Clown (the top-rated Saturday morning child's television show character) and Ronnie as doppelgängers: creepy. I tried to maintain posture in a white swivel chair but could not. I slid off. My foot landed and squirted! -- the ketchup was all over beneath my white shoe. **Sit! Still!** – (*treated like Dusty*) Truthfully, (*it was a ketchup pack*), I'd have wanted my kid to sit still, too, so I could clean it; however, the issue of the swivel chair (rather than a booth or some other option deemed suitable for a kid with CP) – therein, lies another problem.

They had to get Dusty across the country, but that doesn't mean I didn't feel her sadness at every moment. Lucky for me, I tore a piece of burger. I would give it to her later . . . (or sooner.)

### **Treacherous (1975- 1978)**

. . . treacherous? I wrote teacherous; I missed the "r" (spelled wrong). I would learn. I was "Smarty-Pants: praise-punished – pray-prey. I would sort those out, too (eventually). I pondered "toad" – ugly, a jumper: What was croak? I knew pupils popped, but I wondered about my report card: Pupil: "Christine" – my name! – *it looked perfectly* printed straight on the line. *I knew I was great*. I saw the P = Pass and E = Excellent, but only two S's =Satisfactory, and no

U's = Unsatisfactory. I was good. Smile faces! Sticker stars! I liked school. It was fun! I was learning! – and good.

In September, I discovered narrow rhymed with harrow: The bus driver told *The Legend of Bus Number Twelve* decades later. The chug-a-tug sound turned to grind as brakes burned up rubber. The stench and black billow. The Holy Smoke ride—The slide and lurch slamming, as kids screamed, flew from the back: it just happened. Fitting three into two-seater spaces was awe-inspiring. Gaining the right front side seat meant slamming into a railing or carousel bar. I was glad when the kids squashed beside me. I used them as body blockers -- no matter if they thought I had cooties – name-calling, a small price to pay compared to my lack of posture control, as were the daily paper airplanes to the back of my head. In truth, no one had a concept of the danger when the substitute driver, racing went even faster -- “off schedule” shut everyone up. The curve round the lake: I understood rhyme and didn't dare look. The fact that driving through the ammunition depot soon after signified safety, crossing from the military base into Fallbrook, spoke volumes. The morning after the movie *The Day After* came out made us uber aware of the nature of disintegration. Bunker drills . . . lockdowns of the future; by the time Pat Benatar came out with Hell is for Children, Billie Holliday (God Bless the Children) seemed like child's play – I was used to radioactivity, bombings, and discrimination. “*Shi kata gai Nai*” (*Farewell to Manzanar*). “*It can't be helped.*” -- a misnomer of youth grinding grooves in the LP of my brain, replaying across time– my transfixion.

### **Landscape & Location (1975 - 1976 Est)**

Switching to lay off my side, I took in the mid-afternoon sun – the cliffs with sharp rock and the vistas, ever eroding and capable of mudslides. I could not help the flash as my mind conjured a similarity between the artificial lake and an image of John the Baptist, entering and

emerging from the edges. Whether Jesus was dunked or drowned, I could not quite figure out, but I knew dark blue meant deep, and the center was empty. Imagining no presence gagged my consciousness, so I stopped looking for him. The bends toward our faux paradise plopped into nowhere. I hated being told we moved from Jersey **to be near the hospital** -- (They left out the part where we lived by Grandma & Grandpa.)

### **Plaster of Paris & Tarleton's (1977-1978 Est)**

I had no idea what "I have had it" meant. Whatever it was, it was about me. Always (to mostly always) – at least; but, sure enough, I was the only one who stumbled, jumped, or didn't run, *that's why!* Go Figure. It took over a half-century, and I get it! The Tarleton 100's: *I have had it* meant *I am done*. I got the brunt -- now and then, one of my sisters, but it diverted to me, even when it was their turn. It turned into "Don't you look at me that way." Yep! It was about me. I didn't want them to get it anyway.

Most days, I couldn't reach my feet. There was no way when these heavy white chalk tubes weighed me down. I went to the bathroom, but the bowl under my butt hurt. It wasn't a bowl. It was a plastic thing that broke with sharp edges. I kept having to return to the hospital for a catheter (I wondered what that was – I saw the word cat in it, but there weren't cats at the hospital.) Why are people always touching me—down *there*? These were cylinder things. I see the irony in serial casting: serial killers are more like it. Seriously, it messes with a kid to be in a wheelchair out of school or back and deal with this stuff.

### **The Fuchsia Bathing Suit (1979)**

Okay, so we're going to start right here. I'm pissed. It's my memoir. I can say it. Let me repeat (this is a stream of consciousness, right?) – I'm angry! I just realized . . . I've got these memories returning as I write. I'm happy I've processed most; but tell me: in what world does

anyone think a grown man ought to be putting on a little girl's two-piece string fuchsia bikini with flowers on it – let alone when she just hit puberty and is budding away? Dear God. I will tell you. None. Unless supervised, a lady in a room, or whatever you want, I do not care who they are! (supervised) -- *Hello, Scars – that feels better. What about the Whirlpool bath?* I wonder about the unnecessary bubbles. Why did *two* men have to help put Mr. Bubble in? – rip, rip --Away! (I can't tell precisely what literary device I'm trying to deploy there.) Now -- *that's* interesting. ***Daddy was deployed***; he wasn't around. Mom often sang *Tie a Yellow Ribbon Round The Old Oak Tree* and *Leaving on a Jet Plane* – (I knew all the words.)

### **Appearance & Officer's Wife (1977 Est)**

Panic. The doorbell. The first guest. "Too late," said a voice in my head. Where was my sister? She jetted. I saw her blonde head fly past the window. Wait! Get me! She was gone. I looked up. I felt the yank on my hair. I was blocking to pushing and shoving . . . I stared. (Not again.) Don't say a word. (Kleenex wad) Open!" (The cigarette) Open! (Stun-gunned) -- I don't quite remember which came next. Gagging, no sound, needed air. I fell back. Another red ember: seared -- for good measure. My inside forearm and wrist. Shut up! Damn *you!* Don't say a word. Duct tape -- swiped. My fate was now sealed -- ***no one would hear***. The excellent daughter's outside watching her sister; Out! Let me out! (Outside together? Wrong.) The officers' wives began to arrive. I saw high heels through the bottom door crack. Slumped in a hump, no room to roll. Muscle spasms – (Please, let me die!) He will be a general someday, said the wife. No one knew. It got darker. The closet was small. I was nine, ten . . . who knows. Who cared? I waited and waited, forgetting the rest. The next place? The next place? My mind split in two. Chrissy, the child: nobody knew.

Appearances mattered. I did not fit. The beach babes and me – the Tote-Her-Along. It wasn't all bad. Sometimes it was lovely. When I did the chores. I vacuumed well and folded the towels. Who cared about the fingerprints I'd left on the wall? I had to hold on as I pushed back and forth. The rugs looked *so* good. She called it "therapy." Saturday came. Chores: bathroom sinks and toilets. I felt before hearing: Get the spray! Who has been touching the wall (not again!)? See what you've done! (I tried not to slink.) Nothing to hold. Marks on the wall! They were my height. I took the spray. It dripped down the wall. I did too. A heap. I'd later know it as fetal. For now, eleven felt lethal.

### **Snail Theory (1976-1977 Est)**

Bored? (she was *bored*) – this sister, entranced with horror movies, had collected an array of snails. (She, *too*, *knew* amebae came from *recesses*); and how they aggregated toward coolness. On this day, she excitedly pulled my hobbling self down the sloping drive with her; as I thought of Jack & Jill, my hatred for nursery rhymes: the gutter – (she caressed as if speaking to the shell in her hand.) Unceremoniously, I plopped; then fell backward, hitting my head. Unfazed, she seemed ambivalent to my pain, as I reached out for help to be pulled up. Her glare was icy. I went to fetal hoist Rolley-Polley-Olley, using my go-to side-roll to force air into my ribcage and spasticity as leverage to jitter-jolt-propel myself upward. She seemed enthralled by the curvature of the shell *she was petting*. I looked down. Before processing her, I watched as she pulled out a Ziplock bag and put the shell inside. Why did she bring me *here*? (Couldn't we have added it to the rest of our beach collection?) It was a worm with rabbit ears protruding. (*Oh!*) She picked another from the gutter. Sewage of yard waste forced run-off to a trickle. She fingered, coaxing it, toward her array of perversity. I watched as they jitter-jolted, owning the *in-and-out slam bam!* – back receding -- the (inside-out), *separating a bit from themselves* – it was:

*Too Much.* She pointed, oohing and awing; as I watched, aching with the injustice of innards forced into the sunlight. (Cajoled with a cackle) – *No!* I reached for what she saw coming from the water. I had to protect it! *How?* – (I had *no* idea.) The goo latched on. I sensed fear . . . held back squelching, being tortured by the sucking tentacles of this dually frail personification of myself – bloodletting! No. Snails did not bleed, apparently – (my heart, on the other hand, did.) Before I could think about it, a harem had gathered. She scooped up shells, dropping them into the baggy. (*At least . . . they were safe, and she stopped scaring us!*) I was taken off guard when she reached out, offering this time to upload me into her graces. (*Lucky! So lucky! Good fortune, at last!*) Uncharacteristically chatty and praise-worthy, she told me to hold the baggie and ran into the house. Shiver-quiver returned, but I balanced. She had a paper bag. (*Bologna and cheese?*) Too soon, I felt the hollow of emptiness. She shook the bag open, asking for the snails. (*Foreboding upon me*), I took her hand as she said, “C’mon, let’s go.” – she stopped every few feet, picking up snails from the gutter when she saw them; they piled on each other as they tried to escape. Satisfied, she zipped the bag. We got to the corner. This time, she guided *my slide into me* – the landing was nothing . . . until I saw the brown bag. She double-checked the seal, confident and satisfied; she cackled with green glee. (*Suffocation!*) – “*No, No, No. No*” – Why couldn’t I breathe? Asphyxiation? (Suddenly, *hypoxia* flashed – vocabulary of my birth – gothic!) I touch-tasted, heard, saw, and bore **snail theory** long before it registered. Near the stop sign and curving sidewalk, I rolled toward the grass. I saw her jump up. She was waving her hands. She leaped. Excited, waving furiously, she threw a line drive at the car – I am sure she timed it. *Los Padres:* The driver didn’t know. I did. **Crunch!** Her brown bag . . . *her pets* – the tires – she **killed them**. She left them. Splat! Dead. She precisely knew her power. I burrowed,

felt sick, wished for underground: *antenna honed toward eternal waning*. . . The eighties are bearing down like a freight train.

### **The Groaning Years (1979-1984)**

(May-June 1979)

I waded out. Whitewash pushed and pulled; sediment encased. I dove through the swell: Buoyance, my friend. Wait. The Big One will come. I time it, let myself float. Churn to froth wraps of Curling's embrace . . . The salted sea knows me. No questions. *Braces and Walking* -- be damned! Excise! *No more. I want peace*. The world is perfect . . . out on the edge. Watch the crash! The Jetty! Dare to hold. Claim it! (I remember the day) --the swell. Grey with blue and green; a storm rolling in. The rip-tide familiar: *Sucked in*. Power, by any other name: Sea Work-of-Art . . . then, there is me: swimming parallel to the shore: 'Stop! Tread! -- Dive ... I was ... *out beyond the breakers*.

(1980-1984)

A dirt road with potholes: reptiles and mud-blasted earth and boulders. I'd slide, skin a knee, then crawl to a slope and push myself up. Late for physical therapy meant trouble. I'd usually make it, but getting home was the worst. Tired already, the soldier girl chanted cadence: "Left, right, left; right left," as she focused with might. Bracing. Almost there. Father's Road is nearly as long as a football field. Uphill. A car stopped. *Don't talk to strangers*. Dusk is setting in. Still, homework to do -- (*this would go on for years*): **be near the hospital** rang in her ears.

### **Jerry Lewis and MDA (1979)**

Seventh grade was a blur and a buzz. I did a bowl-a-thon for Jerry's kids and gathered dollars in firefighter boots; I focused on others, *thinking* I was too much. They said so. I owed them for keeping me; "it might be better if I died when I was born," she said. I found a way



forward. They seemed to accept (at first) how I fought for life. How could they not? Since I was four, she wanted me to watch *The Jerry Lewis Telethon*. By now, twenty-one hours was nothing; and I knew all the words to *The Impossible Dream* and *My Way*; and I wanted to help his kids. I didn't understand why he called adults kids, but few were on. I tried hard, and I got good grades: National Merit Scholar. God did miracles, but I didn't need them. I was not dying.

### **Obedience (1978-1980)**

I did precisely what honor and duty commanded and the sit-ups. My sister did her three reps of ten in five minutes; I got to six, and the drill instructor made me stay. Horseradish sat on the dinner table next to the butter. It was my turn. Thirty was too much. A whole spoonful, no water, and my little sister had a friend over. I couldn't cry or spit it out. Oliver North was on television. At least he stopped watching me. My mother stared. My other sister asked what I did wrong. Obedience. Soldier girl. *Yes, Ma'am. No, Sir. Yes, Ma'am.* I don't remember what I answered. I just gave. Whatever I had to. Dishes. Therapy. The glasses. Just don't break . . . Knee crouch. The sink and counter are wet. *Dusty. My Dusty.* I don't dare. I do, anyway. It's a giant chunk. My meatloaf: *I own leftovers.* Dessert? Chips-Ahoy. As they guzzled milk and soda, I gave Dusty mashed potatoes. No one saw – *this* time.

Twister cables – an idiot name for something supposed to help me! – somewhere in time, I lost track. I was looking good. “No Pain. No Gain.” I must wear them at night now. Saddle shoes and bobby socks – another Bobby? Great. I found it funny that instead of hamburgers, it was socks, but they had to be rolled down perfectly. I couldn't cross one knee over the other, so I had to have perfect bobby socks with my ankles together. I got yelled at because boys and girls could not let boys see up skirts. What boys? -- so I wore pants, but they wanted skirts – idiots.

Muscular Dystrophy became a synonym for pain and injustice, and I'd spend my life trying to get rid of it. It meant dying way too soon. I went to Camp Cuyamaca from the time I was thirteen until twenty-three. I couldn't push a wheelchair, but I could make people laugh. I could sit by the fire. Ideally, I could do arts and crafts, listen, and be *me and a friend*. I didn't have to pretend to be strong. I could watch the deer in the meadow at dawn and whittle manzanita wood – it was my place because it was theirs, too. I changed and grew up. I escaped and became Chrissy, the Crusader; helping others gave me some purpose and power. I noticed reactions changed if I explained my limp, but kids still mocked me – they didn't get it. I worked at a Chinese fast-food place when I was fourteen and went to help MDA camp in the summer for a few weeks. I went door to door for kids and wheelchairs. The more I went, the better. We wanted me gone, or my work of me. All my money had to go to college.

### **The Chef & Pink Cup (1978-1979 Est)**

Teachers rewarded and looked for my strengths, mainly in English, History, and home economics. I was a great cook because having me stand and make chili or meatloaf was more therapy, and I could bring it home since Ms. Edwards helped. I got to sit down and let Greg help. She was glad. She always saw me leaning hard against the counter. I got a good grade. I measured flour precisely and knew how not to burn the cookies. There were lots of us. It was push-around there, so we went, and I sat down first.

Since I got a good grade, making dinner became my new (practice keeping my legs straight) chore. It was Thursday. Fish is Friday. He wanted tuna sandwiches *every Friday*. I made chili. I knew horseradish didn't match. My mom was setting the table. He pushed my sister toward the seat by his chair. I grabbed the plastic cups and moved them. She gets pink. I played *Switch* with my younger sister. She was nine. My mother noticed. He was playing with rabbit

ears, trying to get Cronkite. I pointed. My sister was frozen. My mom shoved a massive bowl of chili in front of him; my older sister was twelve and across from me; she dropped her napkin on the floor by him. The youngest was six. He scanned the table. “God is great. God is Good. Now, we thank you for the food. Amen.” I had put the horseradish inside my sweater. I had put it behind me in a “roll” for “good posture.” – (I never could sit up all straight; my mother felt better that I looked straighter with something behind me on the straw-woven straight-back chair.) My sister knew. She stared a lot. My father said, “Who made the chili?” I was sweating. I had given myself the least, mostly sauce, to ensure he got enough meat. He took a bite. I saw my sister. “What are *you* doing over *there*?” I had shifted, saying, “I want to see the news better.” He turned as if news *must* be heard. Then, he asked for the horseradish. My mother said, “We’re out of it.” I said, “Chili’s hot.” His look told me to shut up. I chicken-stared a bull down. (*He knew it. He knew it.*) My older sister had the sense of a cover-up. She dropped and began looking for her napkin. “Keep your napkin on your lap and be a lady! They said it simultaneously, locked in the “These are your kids look.” The commercial ended. He messed around looking for Dan Rather. The rabbit ears are always messed up. By then, his irritation seemed to play out on the rabbit ears. “I told you we need to get a color tube one from Sears,” he glared at my mother. Nobody cared about the chili. My littlest sister started reaching for her sippy cup. Way too much was going on – (years later, I’d understand the word *undercurrent*.) My sister said, “I’ve got Social Studies to do. I remember that because it was the first time in a long time that I had loved the snail sister. She looked at Mom. She had figured it out. Mom *knew*, too. She said, “Eat five more bites.” Then, help rinse the dishes first. She was going to eat, rinse, and do homework! – I’d *let* her beat me at Ms. America next time (she always won); I probably said Darla would play Ms. America. She said, “YOU can be the judge!” (The deal was sealed. She’d win. I’d make

sure Darla won “The Interview” part, but my sister won the bathing suit, and they’d come super close on dresses. I’d ask Carla’s sister to judge (they lived across the street) – she’d do it. Darla would *need* to win some time.) – it killed me. I didn’t want to fake her, but they were both prettiest. Maybe I’d ask a tricky interview question.

### **Painted Horses & Ms. America (1978-1979 Est)**

Pink cup sister said I’ll do a bath first. Father said, “Just help your mother.” He pointed to her and the little one, saying, “Make sure you brush your teeth.” I do not know how it went down now. I know something from television had him demanding silence. I was moved a little and panicked. The horseradish was showing. I began to move out of my seat, trying to perch as I stopped for silence and the need to cover it. My mother noticed. My sister grabbed the sweater. She was behind me now. He was looking at the television. I couldn’t stay in my slip-off chair. I let out a gasp-yell. I was falling. He turned. The next thing I knew, my wrist felt a vice grip. He yanked me like I was a monkey hanging. He must have caught me halfway down or pulled me halfway up. My next memory was of my mother with an apron. She was doing the dishes with my sister. She looked soft and stern, her eyes saying something, but I figured not being mad was good enough. She said, “Go do your homework.” He let go. My sister said, “I’ll help you with Social Studies.” -- (we both knew I did not need help in Mr. Jones's class.) I took extra time getting in bed. I had no homework. I was waiting for Sister #3 to get out of the bathroom. Guarding. I didn’t know what to do when she came past my room. We couldn’t talk about horseradish. I just got in bed. I was exhausted. I was scared. Everyone knew. They always knew. I had no secrets. I had all the secrets. It was better for me to get in trouble. I would be in trouble for exercises anyway or not walking straight -- for something about my appearance. She got me a blanket. I recognized it as my old “baby one” – we all kept our baby blankets; but had crochet

covers on our bed. She said, “You, *my* sister; an indication she was claiming favorites over her two big sisters for the night. Social studies sister came in from the hallway. She had her favorite plastic horses. She said, “You can have the painted one.” I don’t know what I said or did, but it’s exhausting to tell the story. She did say, we both had to call her “Best Sister” to play the Three Musketeers after school. I never got picked for that because I couldn’t run with swords. Well, and we knew the pink cup trick. He started making us keep seats and kept #3 by him, but I can never know what else went on about a lot of stuff. I kept my word and played Ms. America, and I remember losing every time because I wouldn’t wear bathing suits, even with Barbie and Ken’s talent show. I hate Barbie & Ken & Ms. America. If I even see horseradish, I get sick. Painted horses are not my favorite, and I don’t care much for chili anymore, but I will make chicken chili, not beef. I think Sister #1 has won a beauty pageant; her beautiful daughter won many of them. The other daughter always does fashion make-up and Tik-Tok. I like that they like each other from what the pictures say. I wish we all did no make-up day. I want no make-up.

Pimples and makeup didn’t quite work, so I got good at spirals, planting my feet, and anything that brought honor to the Marines. Patriotism. The Marine Corps Hymn. Honor veterans always and thank God for freedom and liberty – that was hard. I couldn’t figure out the difference. I had the freedom to play outside, but I couldn’t use it. Does that mean I was not at liberty to play? Was I just stuck because I could not go out, but I didn’t want to embarrass Sister #1? Boys liked her now. If she had to bring me, they would think I was stupid and words rhyming with “hard” – those were awful days. She was beautiful, but I had zits. We had to go to the doctor to get rid of them.

She had to be Ms. America now. It was her superpower, but it wasn’t. When they got mad, or he got gross, we would hear about milk duds and twisting someone’s – it bleeds my

heart, and I can't breathe well typing this, but it needs off me. I'm glad God forgives me, but I'm not sure I know what I'm forgiving. Doesn't forgiveness require the person confessing sin? This is a big subject, and as an adult, I have developed ideas, but I don't analyze this kind of stuff. There's no good in remembering. So, how about blanket forgiveness? People do wrong. They are human. Humans do wrong. So, I'll forgive humans, so I don't have to hate them. Heck, I've tried to reconcile with humans for things I don't need reconciling for; at this point, the best thought is "remembering is not always positive, and I don't want to make my siblings have to remember because I don't know what it is they need to forget. When the remembering starts, I know it's better if you have someone like Debbie, my LMFT. Then, she can tell you if you need perspective or if sometimes people are assholes. I don't want to be an asshole.

### **Major surgery and trauma (April 1980)**

Bilateral derotational osteotomy, translated: "best left alone" – this was the worst experience of my life. I missed most of eighth grade, and I had a homebound teacher I hated who was lousy and spent most of her time talking to my mother. PTSD.

I could do anything with my brain except block out fear. I wanted to know what I'd done wrong, planning and anticipating when I'd set someone off. Writing the memoir and painting myself as an angel would be disingenuous. Let's say I was terrible 70% of the time. I'm joking. I was a pretty good kid. I was the soldier girl, the respectful one, and I tried to stay out of everyone's way, but I did cry and got him upset. I was supposed to be stalwart and brave and not make them feel bad; that's how I interpret it. I remember vividly saying, "At least when they go to sleep, it goes away for them, but there is no break for me.

*Disneyland*

*So, it was stupid and mean to think I would call Shanna to come over and put me on the bedpan when you went to Disneyland. Do you believe a 17-year-old was going to do it? It's no wonder I peed all over my cast and had to go back to the hospital, or maybe that's not why I went back to the hospital. I stunk either way, so I hope you guys had a great time.*

*Mickey Mouse, is it a good thing that I like Donald Duck? Remember how I was holding him with that first surgery that you took a picture of me with the one when I was two, and I had on these airplane casts then, too? So now I've ultimately had my say, and I'm not going to act adult and write something else because, like I said, it's my journey, and this is the way PTSD works. People talk in regressed form, so it's helpful to show that I do not have a fit here; by the way, I am an adult now. Things were fine; however, there is a reason for a stream of consciousness, and I believe it's to protect you. Maybe that's why Hemingway did it so often. We'll look for the periods later. I had plenty of those in those days. Yep, what a way to start, and I thought Miss Schmidt's class was doing well. Period checks needed to be corrected. PE was bad, but not so much.*

### *The Trapeze*

*I got to my little brother. Well, I was his babysitter. He stayed on top of my body cast. All I had was a shirt and a sheet, and he swung on the triangle. Yeah, I think they called that a trapeze. He must have felt like a monkey. Either way, I was scared to death but hugged him a lot. Here is my baby.*

### *The Journal:*

*My journal and poetry belong to me, and I do not have to say goodnight things about my mother. Even though you tell me that I can't expect other people to understand what I am going*

*through because they've never been through it, I can tell you to leave my room. And yes, we started periods. Who thinks it's OK for my little sister to clean me up?*

*The Float:*

*I'll tell you another reality: Don't send a kid to an eighth-grade graduation in a spica cast on a gurney and let people tie balloons on their toes. I'm glad my friends welcomed me, but I'm not the float. I did not know what to do, and it ruined my graduation.*

### **The Rant (2018-2021)**

I feel spasms, cannot roll in bed, and sometimes can't breathe when my chest is in my throat. I have done "global improvement" every single time I see a therapist or go to the hospital. It isn't brilliant. If I couldn't put on my shoes before, why are we focused on making sure I dress alone when, with help, I am done in ten minutes? Who wins when putting on my clothes and shoes takes forty-five minutes? Time yourself. Pick a pair of pants, underwear, and socks with shoes; now, take them off and pretend you hate them so you can choose something else. Now, put on your clothes with two-pound weights on your ankles and wrists (you can take them off to put arms in your sleeves, but make sure they are back on when you button your shirt or pull your jacket down in the back. When you are ready for bed, make sure you have twenty-pound weights before you swing your legs onto the bed – I won't even begin to explain what sharing a bed is like; it's enough to say people like privacy and hate selfish assholes; and I'm only referring to how much space is on the bed. Dogs welcome—people by appointment and interview. If I don't like you on a particular day, enjoy your favorite activity and give me space. I'll do the same for you. The End. (It takes a specific person to help someone when they need help; it takes a tender person to share your personal space in any environment). I have learned over time that we are most capable when we see ourselves as beings who deserve gentleness and compassion. The



problem is that intimacy requires trust, and when you cannot communicate, no matter who you are, because you are “appropriating and changing what you might otherwise find acceptable to minimize push back, keep a relationship, or need the relationship (whether it’s private or with an employer; or any number of settings) – you are playing Ms. America or pink cup, and it becomes more difficult if you must win; if there is no way you can trade up. The best thing to do is not expose yourself to bulls, but life is not that simple – so, perhaps, it’s just to be able to recognize and try not to be the bull – the analogy is confusing. I’m not going to sort it out here. (I’ve said before that this is didactic; perhaps learning about bulls is worth consideration.)

### **Braces and camp (1978, 1980s)**

I tried to anticipate what I had done wrong in advance. It proved useless. Who needed that? My parents did – a scapegoat. We spent years serial casting me, braces, and twister cables, and I had enough of sneaking a hanger down my cast to chase mosquitos. By turning twenty, I rode western to hold on to the saddle. English was girly -- I skipped the girl part, even the child, but that was a problem: I did not quite get it. Guys were creeps; they didn’t have what it took to go the distance with me. . . (uh, well . . . I take that back . . . kind of) – I know now, some stuff went way out of bounds, but they were “protectors,” and I was too young, I’m not going to go there; except to say, complex post-traumatic stress doesn’t get diagnosed by accident; and stick around decades. I wouldn't say I like hospitals now.

By high school, I lost interest in explaining my condition. I just asked, *What’s your issue?* Taken off-guard, most people became indifferent; a couple of friends stayed – people tried to pay me to do their homework; I joked and said, “No thanks, I’ve got brain damage.” With me getting good grades, suddenly, my Cerebral Palsy was more of a dilemma for kids. School social life was troubling. Our parents wanted us girls to act like ladies but look like beach babes – Bo

Derek, Farah Fawcett. My friends laughed and thought it was weird that we had to wear makeup by eleven or twelve as soon as “milk duds” showed up and menstruation – what an odd word. I was supposed to walk and not embarrass anyone. Entice and recruit suitors, a boyfriend – so wrong. “Can’t you *act* like your sisters?” *was rich!* Which one? I was the only one with golden blonde hair. My grandmother said my looks were timeless. She compensated for my discomfort over not being the same as the platinum-blonde California stunners, as Grandpa called them. I always wondered if I was adopted. I couldn’t think about the implications of different. When they said cerebral, I just cast it off brain damage. I knew it went with the brain, but I was “bright,” so it didn't make sense. “Gifted” was even more confusing. Nothing felt like a gift. One thing was sure: I made them sad; she wished I was at work, and he was gone. Next, my dad took way too much interest in our bra size. One day, my sister walked past, and he made some weird comments. I watched her blush. She seemed nervous. I couldn't get through the doorway; I had never seen that look, but I knew it was creepy. He called boobs Milk-Duds. Embarrassing.

(1982-1983 Est)

I am trying to remember exactly what I did when I met Cathy. Still, she’s got this sophisticated power walk mixed with a laugh you can’t help but laugh along with -- She’s a Give-A-Damn’er who watches *Bad Mom’s Christmas*, eats ice cream on waffles with chocolate fudge and whipped cream, and best of all . . . she puts up with me. She talks about fun stuff and makes me lighten up – and my kid thinks she is excellent; she likes to travel and beaches, good drinks, and good food, but mostly, she’s chill and honest – (she even has tact!) – which is good; “cause sometimes I miss that part just a smidgen.” I can’t remember who introduced us, but we became close friends. She was the first one who taught me to drive. Yep, I was supposed to do it. I'd taken some driver's education in school, but you know, having cerebral palsy and stuff, who

would think I could handle the break and the accelerator? It wasn't hard. I just needed someone to believe in me and give me a chance. Everyone was driving, and I learned how to drive.

Simple. Today, I use hand controls now. Anyway, here's Cathy; she's got this VW bug, and we're working at the Orient Express, and my parents aren't taking me to get my license, so we decided to do it instead. It's straightforward. The only problem was when the driver's license showed up in the mail; I forgot it would do that. My old man saw it before I did. Oh, that was good, not so much, but I had my license, and nothing like a big W; had it!

### **The Orator Student (1985)**

The mid-nineteen eighties were, let's say, tumultuous. I was seventeen to twenty-two. I found heaven and blew up hell. My first year of college was in 1985. I received offers from many schools. I was an orator: Get out of my way. Nationals with my first shot out the gate. "Trauma care needed in rural areas" – starting with six-year-old Timmy flipping his bike, bleeding out on a two-lane highway lane highway-- straight-forward. Timmy's six-year-old guts on highway: a no-brainer of a persuasive speech. Why no one? Georgetown and Fresno State but ended up at SDSU. Forensics Team. I had run the circuits for years as a "male" team; for Fallbrook High, I had been riding a city bus to join El Camino by my senior year. Persuasive speaking: I made it, and the coaches knew me. It bored me a bit; entering Persuasion knew me. I'd made the closest, and full-ride tuition didn't add up to room and board, so I guess I made it to submissions. Nationals and persuasive speaking that was a rush, but it wasn't a surprise I knew how to talk. That's something serious, though, however. I could not get around the hilly campus, and in those days, they didn't have much for disability services. I would get aids and classes I could attend, and the others were too far away or down steep hills. The best class was a Brit teaching Marxism: Political Science. When I realized I couldn't get to the class, he gave me a

thick book that said to give him fifty pages within 48 hours. We planned to meet at the lunch cafeteria. I knew he didn't think I would finish it, but my interest and gratitude for the opportunity made it enjoyable. We became friends after that. I got an A in class; that was the only time I showed up. Imagine that it's exciting how policy can shift around if someone's looking to see if you know how.

From then on, I became an advocate for accessibility services, but the most important aspect was not that each school had the services; rather, that the will to provide accommodation existed. The biggest problem was a lack of familiarity with the conditions and the expectation that I, as a student, would know which modalities might help. To the extent I may not have been exposed to an option, I didn't know what was needed – this is a gap occupational and vocational staff should address better going forward. Learning is disrupted when appropriate aid is not procured. I would not be where I am without teachers who understood that pacing was essential to my outcome. A person can't write, think, or do when their world's blowing up – an explosion.

## **PART 2: Young Adult (Enough)**

### **Associates Degree (1989-1992)**

The late eighties found me working a steady job, coming into my own, and returning to college at Palomar in San Marcos, CA, for an Associate of Arts in Liberal Science. Over and over, I picked schools where I could plan for a teaching career, but the advice I received needed to include licensure. It was simply that “Liberal Studies” was the degree for teaching, and if you could get some good grades and extra courses in a specific subject, most people would be set. Not so for me. My grades were perfect. I became engaged. The children would be following.

### **Best and worst of days (1993, 1996, 1985)**

These were the best days. These were the leaving days. My children were born—the most incredible gifts. My parents had been out of the picture for almost a decade. I took a bag to work and stayed in the one place I knew – the back rooms at the hospital, until I had enough money. She said my sisters resented the time he spent with me, and didn’t I know I belonged in an institution? I owed her. I was causing stress. I said, “I’ll relieve it—I’ll leave.” She said, “You will do nothing without my permission.” “Watch.”—my head hit the stove as Tarleton made its last mark. He was now in the arch of the kitchen door. “You’re just as guilty.” “You didn’t stop her.” I felt a shoe in my ribs. I heard, “GOD DAMN YOU.”

My children never knew them. I tried a few times. My children were born at the hospital. I had married an “enlisted” marine. We did not fit into the officer’s quarters. There's so much to say. I’ll skip it. My new life as a mother was waiting.

## **PART 3: Motherhood (Calling the Shots)**

### **Virginia (2004 -2006)**

Deciding to come to Virginia had been a shock, but it was essential; Oregon held too many difficulties for my husband. Without the details, which are frankly his to divulge, I am safe to say: public record indicates VA compensation for mental concerns, a protective order with J&D Court, as well as complete custody to me, and no visitation without my discretion until eighteen. It was the right call. I will always advocate for safe spaces and people who give each of us more significant fuel and skill to see the paths before us.

### **Damage Control/Progress (2002-2004)**

The kids are on time. The kids were four and six, and when the ex-hubs, on more than one occasion, had difficulties with his mental health concerns and aggression. We have just begun the transition: an adjustment period moving from Eugene to Roanoke. I was 34. I had no idea how to deal with a volatile husband. I had just found the biological father and reunited kids with the biological mother and the skill it took to learn about reactive attachment disorder and childhood depression, and be driving a GMC Suburban diesel, looking in the rearview when a thirteen-year-old says, Aunt Chrissy, I was harmed (using more graphic terms). Two of my own, three taken in, and a husband who has problems, not to mention a father-in-law needing quadruple bypass the week I give birth to, and a mother-in-law who has end-stage liver disease. I wouldn't believe it if I hadn't been the core caregiver. 9/11 had occurred in the thick of it. These were my 'promise years'.

All the surgeries, castings, and bracing had paid off – physically, I was walking. Psychologically, I was compartmentalizing, and I was using all my knowledge (educational and lived experience) to rally help for my entire family and advance my education in the wee hours of the night. I didn't realize how tired I was—I just finished the job. I was excited to see Josh

begin talking; he'd been born with an Apgar score of 1. It came as a shock when, as soon as the boys departed, my body got weaker. I had my first cervical spine surgery around 11/2002. Pretty straight-forward. I was gut-punched when BCBS ordered me a power wheelchair.

(2004)

Sent the kids to Portland or Camp Roanoke or a weekend sleepover with a trusted friend. They had enough to deal with, and their dad had gotten them used to coming by the hospital when I had surgery for ten-minute drop-in-ins: "Fix yourself." "Call us. . . when you're better." His approach wasn't the best. If I had it to do over, I'd want them to learn compassion differently. Were it not for my two Cathy and Becky, the nine surgeries and sepsis might've done me in, but they were good at Starbucks, sneaking the dog in and holding a nemesis bag – I was lucky; no -- point blank blessed. It was agony missing the kids, but it was a required trade-off. All toll, twelve hospitalizations between 2006-2017; the outpatient therapy was tedious. It wears me out to mention it.

I needed to stay bread-producing, even with my disability retirement. I was trying to be able to work between two jobs and volunteering, and the fewer surgeries they saw up close and personal, the better. Understandably, work provides dignity and stability if one can maintain pace; otherwise, it stops and starts to promulgate a disintegrating sense of self.

Addressing such an issue creates a better likelihood of success if a guaranteed livable wage and a specific knowledge of stable housing are involved. I watched it happening in real-time. Repeatedly, one must examine the factors dynamically changing and place them against cohort time, age, and perception changes. Another person might rewrite every page I list here; the story would change depending on whether the person had direct or indirect knowledge. The only way to get at the truth is to have the critical analysis capacity to entertain and weigh

multiple facts. Still, I can confidently say that trained professionals guiding me through the same information across decades helped me make the best decisions for my family. The Silent Scream would appear to be about barriers that held me back. The reality is that screams go on generationally. Without sustained cognitive behavioral therapy and learning via my coursework at Oregon State and Hollins to critique and balance information, I would not have had the tools to meet the situations we faced or the means to move life forward. No elements under the sun provide better-coping mechanisms than learning. Love cannot do it because it is unaware of what compromise looks like, and unless compromise becomes engrained, ongoing problems exist. The world is not black and white.

#### **OSU/Hollins (2002-2009 Est, 2016)**

Assisting my ex-husband was formidable; it is hard to admit a mental health concern: the Veterans Administration qualified him based on percentage, and I found myself getting school at Oregon State online, only to need to move to Virginia, where I believed I'd have support from my aunt. I enrolled in the MAT program at Hollins. I graduated as commencement speaker and guest of John and Annie Glenn, only to find that my husband had gone out the window with some military gear and needed to be hospitalized. We got to Virginia. The house we had rented through a property management company was a fraud. The house was a dump with no stove running water. As the years passed, I took a job at Social Security, worked on my MAT program, and switched to a MALS degree. I continued to deal with specific concerns on many levels; what came before the decision was a real shock.

#### **Social Security (2004-2008)**

When the Department of Vocational Rehab recruiter called, he had just negotiated a career position with a guaranteed (GS 09) pay grade with a guaranteed (GS-11) increase over the



next two years. He took claims from the Social Security Administration. With credits for prior civil service years earlier, a husband out of work, a first and third grader -- a certain \$74K with comp time, benefits, and a personal aide to assist – I had to take it. Firing on all cylinders, I thrived and produced quality work. My bachelor's degree had paid off. I was given the cases that needed approval yesterday, certainly no later than tomorrow: terminally ill, low birth weight babies, Office of Inspector General fraud reports; the rollout of Medicare Part D; pulled overtime during Hurricane Katrina when half the office resituated, sending people south. I loved making a difference – quite the policy wonk, I was in my element. My familiarity with medical systems and terminology complemented my command of language. The freight train hit without warning. I retired early – Oct 28, 2008: little did I know the flood would follow.

#### **Mental Health/ Protector (2009 - 2010)**

Sixteen years: It was incredible to face the fact that it was over. I could not believe the way it went down. I planned his budget, and we decided how to tell the kids. The following week, I took a claim; the woman was distraught. She gave vivid details. I redirected, handing the call over to my assistant with about ten minutes left. She could add the medications. I called my doctor, asked for time off, and spent the next ten days in behavioral health. Thank God for small favors. No, *this* one was big. Trauma at twelve . . . rocket launch back to the eighties. C-PTSD: what was that? Branding. My mind was spinning. The spica cast. The fight. The man/men – perpetrators. With CP, I could not escape, so my mind protected me for four decades. Now, it rolled out bit by bit, perhaps jolted because Sarah was the age I had been. I stood my ground.

#### **Gaining Confidence (2011 - 2014)**

It had been a raw, long road back; after the years, tender hearts need not know – **ever**. Sarah was home from college tooling around with Josh, who was proud to show her off, glad to

be a junior in high school with a bit of confidence and some success of his own. They knew we all needed their scholarships within a few minutes of talking. She managed the lines, and he cashiered, flipping to the bagger if she needed to open another register. I'd gotten used to hanging out at Starbucks after school, doing my schoolwork, or following up on SkillsUSA and Presidential Volunteer Service projects and the lesson plans. My mentor, Skip, was happy to let me prepare so he'd have time for his graduate work. The Criminal Justice classes were easy, and the kids did well. Josh's friends would call me Momma Roberts by mistake, and we all smelt bad the morning the dog got into a chase with the skunk (Oh, my poor Josh!) -- on his way out the door. His first suit presentation was that day when they raced around the house, and he struggled to get Spices back in. I was teaching a lesson on The Innocence Project and workforce readiness skills, and he was giving a speech; instead, I had to continue and call a friend to help him clean up. We were both mortified.

Life was a lot of work, but we were all proud to show off to Mr. Boone and celebrate successes as the kids spent time at Kroger, packing away some cash. I coordinated student leadership activities (unifying Kroger's support of MDA's *Shamrock's for Dystrophy* campaign and SWVA's Feeding America *Peanut Butter Drive* with my lifelong passion: saving kids. My own finally hung around like Besties again, and I had never been as happy as the days of our joyous ones. She was through the hippie stage (*Thank God!*) Between skateboards and boys, acting out, threatening to run away, choosing tardies (forging my name), crip-splaining her absences, *and* having to troll (before parents knew trolling), I thought I would never find a cadence with Sarah. Wrecking the car (more than once) was a gift compared to surviving grown men in Kansas & Ohio – the heartbreak ache we shared (for entirely different reasons) as prey and prayer spun cyclonic: MySpace; need of space, and Divine intervention inverting seventeen

like a tailspin dive back to the two-sies, caught on the wing of Grace with Mercy—the wingman – it was epic. *I'm an adult; you can't stop me!* —Code. The Double Dawg Dare Me. I jockeyed for leverage, blocking doorways and opening them the same. Immensely proud, fierce independence, excruciating need – my baby so recognizable, yet so herself – I could not help analyzing my Pooh, Simba, Little Bear, and the Hogwarts in my Hermione. Yes. Sarah fit Hermione . . . to a tee. She seemed comfortable with The Slithering? which made me shiver, reflecting. (Gandolf?) *Father* in Eminence? – Wait!\_(Had we?) -- evolved? Struck by the profundity, I didn't bother with exploring. It was The Ring and Mordor we both sought . . . (Or so my fable goes.) Whether I was Mr. Frodo, she Sam, or the reverse was . . . circumstantial (to a point.) In the years to come, respect would become “evidence of the hoped-for; seen first, by believing” (Corinthians, 7:9). We would switch places now and again, but one thing was sure: we had each other's backs. I swore to myself that I wasn't dating anyone or even imagining it – I was the mom who got Father's Day cards.

Allowing Semper Fi to whistle Dixie differed from Faith laying down arms in our Civil War battles. I summoned Gung Ho, Get Tough, The Marine's Daughter, and whatever muscle memory knew of Mary. I WOULD – be The Mother (*Madonna*): Miracles demanded consecration. To love unconditionally -- *this* mother would leave no one behind. I had no idea how, but we'd all be educated. I knew failure to strive was a failure to thrive, so Strive coerced Doubt into silence. Headed to Dominion University the following year and a ninth-grader, bullying had been terrible for both Sarah & Josh. Given that they were taking hits from every angle (not the least of which had to do with me) and Josh's speech impediment, and that Daddy had found online love interests way too soon, who were too young and/or too competitive, she was crushed. Don't Tell Me No Three was nothing compared to Sassy Seventeen and Almost

Eighteen Now. Between “Live with Zan!”, a cast of boyfriends, and tie-dye stains in the tub when Kristi came over, she had kept me -- zipping. She was mini-me in many ways, especially in her bravado, mixed with a bit too quick candor borne of defensiveness. Secretly, I knew she was more intelligent. I would never have gotten fives on AP Calculus and Chemistry.

The night she had an Ayn Rand paper to finish at midnight and asked for help, I knew instantly she had not read it. She was beside herself, wanting me to write it, essentially. The fit turned to desolation. I went in for the save, coaxing her through it. She looked at me and forlornly told me I was crappy as an English teacher; then, a week later came in grinning. She’d taken a half-grade cut for the tardy but got an A minus. She let me read it grudgingly. “I told you I’m a better writer, Miss English!” Our eyes met as she waited, shifting a tad, waiting to see if I’d be angry. (The depth of searching between us was out of this world.) I said, “I love you.” (The mutual respect was sealed), as I whispered . . . “You’re right, Dear.” She came of age that day: Defiance found slumber, and I slept well for the first time in years – pulling double duty on the backside of Daddy’s angst had been a ride.

### **Divorce/Full Custody (2010 – 2011)**

Weeks rolled to months into years; mothers and daughters, sons to mothers – an odd kind of push-pull as time shapes the chorus, but one truth was certain: I summoned Gung Ho, Get Tough, The Marine’s Daughter, and whatever muscle memory knew of Mary. How? I was unsure, but I vowed to be The Mother (*Madonna*): *Miracles* -- demanded consecration. **To love unconditionally** -- *this* mother swore to leave no one behind. I had no idea how, but we would become educated. My children would find upward leverage. C knew failure to strive was the failure to thrive, so Strive coerced Doubt into Silence. Sarah was off to Old Dominion University the following year. (Bullying was taking its toll; they wouldn’t say at first, but soon they did; she

down the steps, he for his speech; jokes about reduced lunch and me: I couldn't stop it altogether) -- few actions were taken. It felt like "Don't ask, don't tell" – They needed to manage some independently, and they did well.

### **Sessions (2016-2024)**

Debbie, my counselor, reminded me of unreasonable fears long ago of my paralyzing fear of raising kids. I know I was freaked. I did not want them to be without their mother. Why would they? It's ridiculous to think they would be taken away from me. Why did I think someone would deem me incapable of meeting their needs? I knew what losing felt like, and I wouldn't change it. Soldier Girl – it was my job to come up short. Faulty Thinking! Crap! Such Crap! He knew my Achilles heel and was intimidated by my earning power, but more than that, he knew I would do anything to protect them.

Many sessions went by before I understood behavior objectively at all. Debbie said people were toxic and abusive. Knowing that should have made me feel better. At first, it scared me. Naming a problem or person meant dealing with it. I learned to ground myself. I focused on reminding myself of my strengths, but it was unnerving. The takeaway is that to gain agency, I must see myself honestly and own myself, not others, and I do not have to excuse wrong behavior. It provides me great joy to have spent sixteen years learning cognitive behavioral therapy and imparting the value of **consistent counseling** and good fit partnership. To my children and those I can influence, if there were one gift I wish I could offer the world, it would be that they each have counselors they trust and learn to treat mental health as straightforwardly as a skinned knee.

In all walks of medicine, I have serious concerns about the industrialization and corporatization of healthcare as it is going . . . there will be no treatment. In the days of yore,

relationships were solidified by one-on-one familiarity with providers – that is dying fast. If society does not find a way to treat holistically and engage with moral maturity, restoring personal care choices, the results will be dire. I have experienced contraction, including something as evident as polypharmacy:

### **Supply Chains (2021-2022 Est)**

People are used to nurses running through scripts, asking what medications one takes. Much less frequently do they assess contraindications or drug interruption. This was unbelievable to me when I had a physician who prescribed my meds move to a different state. No doctor wanted me as a patient. I was too complex. Finally, we found someone and moved to a different state. I got a call that the doctor changed his mind. What occurred next is beyond the pale: supply chains dried up. My medication was backlogged and was not to arrive for another week. The pandemic was in full swing. I could not reach any provider who “knew” me as an established patient. Urgent Care and Emergency said they couldn’t help because I needed the doctor who “knew” me to write a new script for a different pharmacy. Still, a new pharmacy wouldn’t fill the script for a “new” patient without verifying with the established physician, and they had their supply problems and quota ratios. I had twenty-four hours max to fix the problem—all dead ends. I began looking up dosing equivalents. For all my medical knowledge, this task was over-the-top. Way risky. I had no choice; I looked at my remaining meds, and I began to titrate myself. People are told to take Narcan if they overdose; nobody explains withdrawal. I was two days in. I wheeled outside the hotel we were staying in. Drank water and prayed. Three weeks later, I began to feel more human, if you could call wiped out human. I played with the grand dogs less enthusiastically, but I managed. I can’t say when it happened, just that it did. It has been two years; this month, I celebrate. According to one of my doctor's

notes, “less than 2% of patients on this amount ever get off” the medicine I’d been on for over ten years. I was free – the 75mcg patch (every 48 hours) was no more – fentanyl was over.

### **Acceptance (April 2020)**

It’s the superficial aspects of life that sometimes are the most complicated. I used to complain about them. There are nightmare scenarios: *A) Enough! No! It not. . . My truth matters: I pee in towels, behind tinted windows, when time is too short. Please don’t ask me for the details. Try it yourself. What does it mean to lose control? To lose the means to . . . to fight to hold on? (It’s not about urine) It’s about the stripping down, the trickle to gush, the profound undoing, the Self one can’t find, having nowhere to hide, and the literal hating to say, “I need help.” Its body turning soul inside out, acting as if just fine – is okay; it’s showing up late. It’s living. It’s striving. Self-reliance be damned. Once is more than they do in “I Can.”*

### **Cooper & Caring & Coping (Spring 2009 and 2024):**

Puke. The cat upchucked his breakfast. Bright orangish-yellow – chunks. I grabbed the blanket – *just in time*. Lifted Cooper, poor guy. I strategically tried to move the blanket from under Cooper’s cat carrier. Hubs, a four-hour drive, three pets – *what a load*. (Already). At least the sun was shining. Hubs was eating a banana, intently concentrating, savoring, and content to have his first snack – such a kid. At seventy, he still needed to stop at Wawa every hour. It drove me crazy. (“Pick your battles,” I told myself. Radical acceptance!) – *(I sucked at it; Oh well.)*

I’d ride the wave and roll with the tide: *No choice*. I took a deep breath, cast a sidelong glance, and noticed the orange triangle on the instrument panel: *Maintenance Needed*. Great! What next? *Damn!* (Air?) I needed air. Oxygen! *Dear God, Help!* (I felt cursed by irony.) Hubs cracked a window, tossing the banana peel on the dash without saying a word. *(Clueless!)* He reached for the radio dial -- *Sirius XM*: (Seriously?) (Breathe.) To speak or hold my tongue? --

when *need* is involved: count to ten. “Better to be grateful,” I told myself. He'd help clean the mess. (*My mind wandered to water*): A seagull persevered and sat on the pier's worn wooden railing. Stronger. Surer. (I petted the cat.)

Sarah and Zan had conspired to save a litter. He appeared out of Sarah's pocket. I'd driven on a wild goose chase, “looking for the home” to return him. When we got there, the tenants wouldn't open the door. Who knew if it was the original owner or if the girls had snowed me and led me to a fake address? It was sketchy. We weren't staying. I came out of Ukrops with my bags to find her on the roof of my van. Sitting with crossed legs, happy, she shouted, “Hey, Momma! We got a name: “Mini Cooper” (after the latest fad car.). Do you want to buy one for me? She laughed; typical. She knew I'd been fuming over the cat, but a bite-sized car? -- *her* laughter, taunting one-upmanship seemed to say what we both knew – *this* time, Mom wins! Who was I kidding? She had me wrapped. It was hard to be serious. She lit up the sky. My smart whippersnapper: (She would need this quick wit.) She just grinned. “Get off the roof. Get in. I will drive.” She handed Zan Cooper, jumped, caught him, and as they poured back into the back, I heard: *A van? -- not the worst, I guess.* My mind roared, laughing. I glanced in the rear-view mirror before staring straight ahead, willing myself to maintain my Mom's Serious Face . . . and keep from bursting aloud.

### **Compassion/Bonds (2024)**

A friend: it was my turn to give. This salt-of-the-earth kind guy, freshly retired, a bit worse for wear, has never shown fear, but he calls me: Prostate cancer, he says. What does one say? (*Hey, I ought to know*) -- *with fourteen stays in twenty years*, but I do not. It is different each time, and no two people are the same. I do not have a right to claim another's pain, and comparison is selfish (at least to me): shared affinity is not the same as digging inside oneself



and growing capacity. In all our lives, moments come demanding responses; moments that require capacity – it must be by design. Once you step in and out, you sense a change. It is strength through vulnerability—the clear midnight sky. Life flashes forward and back. You do whatever you can. My experience appreciates the impact advocates/loved ones make getting through paperwork, hospital stays, and an extra hand around to help take in what’s happening. There are so many times I handled surgeries and hospital stays alone. I’ll be there to ensure someone else has extra help. I was glad this time. It was late the night after surgery, and he wasn’t feeling well. I grabbed the closest container. He barfed. After several go rounds, he didn’t look as yellow. It was tricky cleaning up. It was not conducive to my wheelchair, but I figured it out, and he was appreciative.

Again, my knowledge and experience were assets, and so was my ability to address needs. More importantly, I recognized the value of continuous learning and plodded forward with my goal to complete this project. I have slowly come *to value education as an agent of traction that binds an individual to themselves; therapy creates a place of certainty in one’s life. No matter what has transpired, I have returned to the same goal – to use education to lift myself and others higher.*

## **PART 4: Navigator (Leading the Way)**

The medical system in the United States is broken, and problems are getting worse. This is my perspective – but I imagine you could ask a million people and end up with some key points of consensus. I am examining the last twenty years. I would not be here without education and the means to advocate for myself. The blessing of *this* memoir is that it shares lived experiences and makes it worthwhile as a reference for a dynamic work application to self-compassion, but it also demonstrates the means to get beyond the darkness and live a life based on well-being; traditional medicine has less.

The provider-patient relationship has fallen prey to a system that reduces individuals to billing codes. The individual body part is managed to an extent, and then the person is sent with the prescription or referral or neither and waits five months for the referral, which cancels out the appointment that was just done. It is a vicious cycle. In the meantime, providers make choices. One certainty: healthcare is different from wellness, and wellness is not well-being.

## **PART 5: Spirituality (Surrender)**

### **Make It Matter (2021-2022)**

I had turned off my Zoom video feed so colleagues wouldn't notice me in bed. Occasionally, I'd throw a blazer over my pajamas and hide that I was declining or not well that day, covering pillows with a dark blanket and trying to sit up when it was my turn to talk. When the theme was announced for the following year, "Make It Matter," -- I broke down in tears, forcing myself to sit on the edge. I'd been in a hotel for nearly two years after modifications on our home failed. The pandemic made it impossible to find suitable housing – housing stock didn't mean mobility-impaired. If it did, it was coded: senior housing meant "active" (can get around), "independent" (55+ who want amenities), and "62+ continuing care retirement" (with lists for the best places or requiring an enormous buy-in costs.) Apartments didn't even pretend to want me and weren't touring anyway, which was a nightmare. I thought of my kids, Jerry's kids -- all that had brought me to that day. I knew how to help them, but help wasn't reaching me. I thought I knew how to navigate the best and worst situations, but nothing can help when *Closed* and *Keep Your Distance* signs litter the landscape. Plenty of lesser exclusions dot every path known to man. The question is: Who does the opening?

### **Solid Ground/Faith (2024)**

Circumstance catapults people into situations. Intent creates and/or brokers opportunities. We all need oxygen to breathe, emergency preparedness, and a backup plan, and crews with new supplies can keep spacecraft going for a while; without them, its orbit will become shaky, descent will occur, and it breaks or explodes. People aren't all that different. Put under too much pressure, with environments shaky, they burn up and *combust*. *It's not so hard to see*. What allows me to sustain? Faith. A perverse beauty exists in knowing one cannot sustain life on

one's own: it's the certainty that Vulnerability Requires Surrender. Once one must find a higher power, summoning it is easy. Enduring mortality isn't easy, but if we see ourselves as immortal, we know all can be made whole and see others more efficiently as our Heavenly Father sees his children. To live in isolation and handle trials alone is not sustainable, so bearing one another's burdens must be an aim.

Time and talent are gifts. We all have them. Harnessing them requires discernment. Listening to the still, small voice inside until it beats like a drum is the only way I know the only way to hear it when sirens go off all over the place. Had I lacked the concept of A Benevolent One, a vast eternity wouldn't have held me. It still wouldn't. Knowing there exists one eternal existence allows me to separate my mortal self from my immortal one. I can promise you this: I was never broken. I needed healing. The human condition cannot be cured, but there is an answer: Atonement. We must believe in a love so great; its manifestation blows our mind, not pain so deep we lose it – faith is nothing more – that is my belief; and whether another person believes as I do, doesn't concern me; only that I speak to the truth I know and allow them the same.

Born at twenty-five weeks gestation, breech, pulled out by forceps, weighing three pounds, given Baptism & Last Rites within minutes of birth, I was named Christine meaning anointed); my parents waited, Science & God took over. What transpired in the interim and since matters little, except to say it made me more perfectly aware and more capable of loving others and myself, seeing people as beings worthy of compassion.

To have faith, I needed to know safety; to maintain it, I needed to trust, but I needed a strong support system to venture out and test the world around me. None of these would have happened except for the knowledge that both constructs first make connections to dually an

outlet for pain, physical and emotional, but it is not a quick fix. My *experience* is by order of one; shared for perspective, but it is valuable because it indicates the possible and the reality of life living with catastrophic illness (defined operationally by me): a lifelong condition impacting more than one body system that interferes with activities of daily living; require assistance for basic self-care tasks. Cerebral Palsy is a movement disorder; it affects people differently. My mental health difficulties are situational but rooted in childhood trauma. The beauty found in writing *Silent Scream* is that I found a center. I had to rely on forces larger than my own and trust my spirituality to move me forward. I had to forgive situations to write about and work through the implications. I am grateful for the eternal perspective that sees beyond the moment.

## **Conclusion (Arrival)**

An education for someone like me may not be worth the time because I will be in and out of the workforce. I say the need to navigate life, engage in systems, and organize priorities – these are out-flow and the air, allowing an individual to, frankly, negotiate life itself. Education Saves Lives because what is gained remains useful across the lifespan – this should be a core aim. More than any other intervention, the learning process gave me a way to reconcile difficulties and move forward. I saw myself within the pages, came alive in the act of engagement, and placed the circumstance of moving forward above the circumstance that would threaten to hold me back -- to value myself, not just the people around me. If there is a parting salvo, The Silent Scream brought fulfillment and made me rely on the power I could harness to be calm and kind to myself. For all the birthing and spasms, sharing a memoir has helped me see that I am worth care. We are not our conditions; instead, they are the clothing we wear, and if we can tolerate them, they will cease to restrain us because that within us will always take precedence over our adornments. May you always find purpose and commit to continued learning in all people. We are all made better when we believe in possibility over stagnation.

## **Epilogue**

The water rolled upon the jetty. Filled with adrenaline, I forced a walker across the sand; I had not seen those waters in thirty years. We had driven 2500 miles to Las Vegas for the American Association Cerebral Palsy & Developmental Medicine Annual Conference. “Making It Matter” meant one more destination. This day in Oceanside, I saw a sailboat; I envisioned sisters, brothers, and father as they scattered the ashes of the excellent mother they had, whom I had not known since I was young. I said goodbye, glancing back; I knew it was goodbye to The Marine. He would not see me, though I had tried. He played “I Will Always Love You” (Dolly

Parton), said, “Listen!” and hung-up years ago. Bittersweet Memories... no, I was out beyond the breaker, floating with the tide. I kept going, the impossible happening, chanting Catholic hymns. I got to the water and felt gutted sitting on the walker, needing air, as it hit me – the Pacific Breeze. The beach was empty. I saw the child walking, falling. She disappeared. I looked over at my husband and had no idea how we would get me back. I waited. Soldier Girl, saying goodbye – to a lifetime, paying respect, though none would be proffered, except self-respect: the elusive she had yearned for during her Silent Scream. She stood, nodded to the blue-green, and waited – for the curl. One last dive. She felt it. As she turned, five people surrounded her and carried her, though she insisted her feet stay on the sand, barely as hoisted. *Goodbye, Silent Scream*”

*(Sis #3 sent a message: “Sorry. He said when he looks at a military wall, he knows it should read, “General.” It says, Lt. Colonel, because of you. He had to **be near the hospital**, so he did take deployment.”) . . . Goodbye, goodbye . . . she went . . . **beyond the breakers.***