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# Moments of excess: Type 1 diabetes and the myth of control in adolescent fiction for girls

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# Moments of Excess:

## Type 1 Diabetes and the Myth of Control in Adolescent Fiction for Girls

by

Michelle E. LeGault

Thesis

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in
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Thesis Committee:
Amanda K. Allen, Ph.D., Chair
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# Dedication

This thesis is dedicated to Winifred K. LeGault, who was the inspiration for my quest to discover children's books with diabetic characters; and to the staff at Minneapolis Children's Hospital, who impressed upon me that there is no such thing as "good" or "bad" numbers. There are just numbers.

Thriving with T1D since 08-12-2014

# Acknowledgments

Many people supported me in my master’s journey and helped in the creation of this thesis. First and foremost, I would like to thank David, Winnie, and Alvin for uprooting their lives and moving across the ocean with me so that I could accept a graduate assistantship at Eastern Michigan University. You are my favorite people. Thank you to Kristi Gatchel for being one of my first points of contact at EMU and in the Children’s Literature Department. Thank you to the University Writing Center, most especially Kim Pavlock and Dr. Ann Blakeslee, for providing me with a graduate assistantship and a supportive community of writers. As an extrovert, it was challenging for me to complete my program in an asynchronous format, but the Writing Center provided me with a “home” at EMU. From my Children’s Literature cohort, I am indebted to Holly Greca for the many Fridays spent at Sweetwaters Cafe working on our theses, and to Alissa Johns for always being a willing reader, even when my work was “drafty.” Thank you to Dr. Christine Neufeld for offering a graduate-level literature course in disability studies after I expressed an interest in an independent study. The insight I gained from the disability theories we studied in our Tuesday night sessions dramatically changed the course of the chapters in this thesis. Thank you to my second reader, Dr. Annette Wannamaker, whose classes provided me with an important foundational knowledge of children’s literature. Lastly, but most of all, thank you to my thesis chair, Dr. Amanda Allen. Thank you to Dr. Allen for continually pushing me to think in terms of arguments, for asking probing questions, for stuffing my head full of difficult theories, for caring about the small things such as whether to use “on” or “in,” and for gently (but persistently) encouraging me to make outlines even when I continually resisted because “I don’t do outlines.”

# Abstract

This thesis is the first academic work to analyze the stories of the Type 1 diabetic teen girls of adolescent fiction. In novels for adolescent readers, these girls are often White, female, heterosexual, and middle class—resulting in a collective disability narrative that portrays an "every girl" and lacks cultural or political dimensions. This thesis explores the narratives of five fictional teen protagonists with Type 1 diabetes. They are: Stacey McGill from the Baby-Sitters Club series by Ann M. Martin, Rachel Deering in Lurlene McDaniel's *Will I Ever Dance Again?* (1982), Mackenzie "Zie" Clark in Sarah White's *Let Me List the Ways* (2018), Lucy Szabo in Pete Hautman's *Sweetblood* (2003), and Virginia "Dare" Chase in Sarah Glenn Marsh's *The Girls Are Never Gone* (2021). In these novels, diabetes is often made visible through moments of crisis—exemplifying what disability scholars David Mitchell and Sharon Snyder (2000) refer to as "disability as a material metaphor," and ultimately furthering what American author Jeffery Bennett (2019) refers to as diabetes' "crisis of signification."

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# Book List

This is a list of the books that are the focus of the chapters in this thesis. In order of publication:

| | |
|---|---|
| 1982 | *Will I Ever Dance Again?*<br>Lurlene McDaniel |
| 1986 | *Kristy's Great Idea* (The Baby-Sitters Club #1)<br>Ann M. Martin |
| 1986 | *The Truth About Stacey* (The Baby-Sitters Club #3)<br>Ann M. Martin |
| 1991 | *Stacey's Emergency* (The Baby-Sitters Club #43)<br>Ann M. Martin |
| 2003 | *Sweetblood*<br>Pete Hautman |
| 2018 | *Let Me List the Ways*<br>Sarah White |
| 2021 | *The Girls Are Never Gone*<br>Sarah Glenn Marsh |

# Introduction

Written records of cases of Type 1 diabetes date back to the first century A.D., yet the illness' presence within North American adolescent fiction appears to have been non-existent until the latter half of the twentieth century.[1] This absence may be partly due to the fact that until the discovery of insulin by two Canadian researchers in 1921, a diagnosis of Type 1 diabetes was a death sentence. Even though adolescents began using insulin in their diabetes treatment not long after this miraculous discovery, it would take about another five decades for their lives, forever altered by chronic illness, to be reflected in adolescent fiction.[2] The Disability Rights Movement of the 1970s, '80s, and '90s helped mainstream children with disabilities into "regular" school classrooms, creating an increased need for representations of disabilities within children's literature, including chronic illnesses. It was then that Type 1 diabetic characters finally began to appear in adolescent fiction. One of the first fiction books to be published with a diabetic adolescent character was John Branfiled's *Why Me?* in 1973.[3]

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[1] A note to readers: I want to draw your attention to the fact that there are differing opinions as to how Type 1 diabetes should be written. According to the Associated Press (AP) Style, the word "Type" is capitalized and the word "diabetes" is written in lowercase. This means that if you have previously read about diabetes in a newspaper or a magazine, you have likely seen it written like this: Type 1 diabetes. However, various medical associations dictate that the entire phrase "type 1 diabetes" be written in lowercase. In my research for this thesis, I have come across scholars who follow the AP Style guidelines as well as scholars who follow the medical guidelines for how to format "type 1 diabetes." As this thesis is for a degree in the humanities, however, and as it is my goal for this thesis to be accessible to readers with very little knowledge of diabetes, I have chosen to use a capital "T" when I write the phrases Type 1 or Type 1 diabetes. To me, this choice indicates two things: (1) Type 1 diabetes is a proper name that refers to a specific disease. (2) This thesis is written to call attention to a disease that is often overlooked or misunderstood by society—employing a capitalized "T" is a subtle method for visually drawing the reader's attention to mentions of diabetes in order to create a heightened sense of diabetes' visibility within the text.

[2] A quick note about the differences between the literary model of adolescence and the medical model. The American Library Association defines adolescence as 12-18 years of age ("Young Adult"). The American Academy of Pediatrics, on the other hand, defines this age as 11-21 years old, but also acknowledges that the upper age limit is somewhat arbitrary and can be modified on a case-by-case basis (Hardin 1).

[3] In the UK, Branfield's book was published under the title *Sugar Mouse*.

For nearly forty years, however, perhaps the most prolific literary example of a teenager with Type 1 diabetes has been an upper middle class White girl from suburbia with an extreme sugar aversion. Since 1986, *The Baby-Sitters Club* (BSC) by Ann M. Martin*,* a series of books about middle school girls who run their own babysitting club/business, has held a firm monopoly over diabetes representation in fiction with the inclusion of Anastasia "Stacey" McGill, their diabetic treasurer who has a keen fashion sense. While it is rare for juvenile characters with diabetes to recur, the core series of the BSC (published between 1986 and 2000) comprises 131 titles, twenty-one of which are narrated by Stacey.[4] In addition to the original titles, there are special titles and spin-offs that together form an expansive BSC universe.[5]

With every adaptation of the BSC series (film, TV, mystery books, graphic novels, and—most recently—a Netflix reboot), Stacey's dominance in the subgenre of Type 1 diabetes juvenile fiction is further cemented. In this thesis, my close examination of five fictional teen girls with Type 1 diabetes shows how, in many ways, Stacey's White suburban, female, heterosexual character serves as a template for how diabetes in juvenile fiction is often portrayed. In order to show the broader trends within the subgenre of diabetes literature for adolescents, I have selected titles which span the past four decades—from the height of the Disability Rights Movement in the 1980s, when many of the books on my list first started to appear—until the present day. In this thesis, I examine three books from the Baby-Sitter's Club

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[4] There are only three other recurring Type 1 protagonists that I have found to appear in fictional series for adolescents. All of these series are much smaller than the BSC, but they are worth noting because it is rare for characters with Type 1 to recur at all. A 4-book series by Rob Buyea, follows the story of a middle school friend group and their favorite teacher, Mr. Terupt. One of the students, Danielle, is diagnosed with Type 1 in the third book: *Saving Mr. Terupt (2015)* and she appears again in the final book, *Goodbye, Mr. Terupt* (2020). Another recurring adolescent character with diabetes is Josh, an elite hockey player, who is featured in a two-book mini series by Lorna Schultz Nicholson. The two titles are: *Roughing* (2004) and *Interference* (2004). The third series with a recurring Type 1 protagonist is a pair of sci-fi fantasy novels written by Carlos Herdnandez. The series features a young Cuban magician, Sal Vidón and comprises two titles: *Sal and Gabi Break the Universe* (2019) and *Sal and Gabi Fix the Universe* (2020).

[5] For a complete list of the BSC titles narrated by Stacey, see Appendix A of this thesis.

series: *Kristy's Great Idea* (1986), *The Truth About Stacey* (1986), and *Stacey's Emergency* (1991), as well as four other texts with Type 1 protagonists. Those other texts are: Lurlene McDaniel's *Will I Ever Dance Again?* (1982), Sarah White's *Let Me List the Ways* (2018), Pete Hautman's *Sweetblood* (2003), and Sarah Glenn Marsh's *The Girls Are Never Gone* (2021).[6] My analysis of the portrayal of Type 1 diabetes within these texts demonstrates that although the girls' stories reflect a complex relationship between diagnosis and identity formation, their persistence in establishing the straight, White female as the "every girl" of diabetes fiction critically limits the ability to represent diabetes culture. As disability narratives, these texts often focus on the emotional struggle of illness acceptance, rather than the cultural or political ramifications of life with a chronic illness. Furthermore, as a collective group, these stories often perpetuate a myth of control where "good" behavior always results in favorable diabetes outcomes and "bad" behavior always results in dangerous consequences.

**Type 1 Diabetes: Defined**

As this thesis explores fictional portrayals of Type 1 diabetes (T1D), it is important for the reader to have a basic understanding of what the condition is, and what it means to live with it. As the parent of a child with Type 1 (my daughter was diagnosed in 2014), I am acutely aware that many people know very little about diabetes. Some people, for example, think that my daughter developed Type 1 by eating too much sugar, or that she will some day "grow out of it." Both of these statements are false. In order to fully appreciate the research and theories presented in this thesis, please use this brief list as a starting point for familiarizing yourself with what

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[6] All of these books were written by women authors, with the exception of Pete Hautman, who wrote *Sweetblood.* Also, with the exception of *The Girls Are Never Gone*, which crosses over into paranormal fiction, all of the other titles would be considered realistic fiction. In the interest of recognizing patterns, I would also like to note that some of the authors have direct connections to Type 1 diabetes—Hautman was diagnosed with T1D in his thirties and McDaniel has a son who was diagnosed at a young age. However, the remaining authors appear to have learned about Type 1 through research rather than personal experience.

Type 1 diabetes is. (If you want to learn more beyond the bulleted list that follows, I highly recommend the Joslin Center and JDRF, two organizations dedicated to Type 1 research.) Before beginning my list of Type 1 hallmarks, I would also like to note that there are multiple types of diabetes, the most prevalent being Type 2. For the purpose of my research, I will focus on Type 1 diabetes, formerly known as juvenile diabetes (or sometimes referred to as insulin-dependent diabetes), which is recognized by the following characteristics and treatments:

A. T1D is thought to be caused by an autoimmune response, which destroys insulin-producing beta cells. Without beta cells, a person's body is unable to produce the insulin needed to metabolize carbohydrates. Without insulin, a person cannot survive.

B. T1D is managed with regular injections or infusions of insulin along with a healthy diet and regular exercise.

C. A unique feature of T1D management is the high level of autonomy that patients have in adjusting insulin doses—which must often be altered to account for illness, growth, activity levels, types of foods being eaten, etc. Frequent monitoring of blood glucose levels and adjustments to insulin doses are necessary to maintain optimal glycemic control in patients with T1D. Ironically, the insulin which sustains a person with T1D can also be fatal if given in excess. For this reason, insulin management is a relentless job which requires careful oversight 24/7.

D. Although T1D was documented as far back as the second century A.D. (Feudtner 4), the condition's exact cause remains a mystery. As such, there is currently no prevention or known cure for T1D. Once diagnosed, the patient must manage the condition for life.

E. T1D can appear at any age, but is most commonly diagnosed in young children—with one common peak being adolescence.

F. Sometimes, T1D is considered to be a physical disability, but not always. The United States Social Security Administration, for example, only offers disability benefits to people with T1D under certain circumstances. The U.S. National Park Service, however, offers a lifetime pass to anyone with a permanent disability, and T1D is an approved condition.[7]

Living with Type 1 diabetes is a unique experience that can be difficult to grasp for someone who is outside of the diabetes community. (I also concede limitations to my personal understanding, which come from being a caregiver and not a person with diabetes.) Even though a person living with Type 1 diabetes may face many of the same social or emotional challenges as a person living with another chronic condition (such as epilepsy), their daily challenges and concerns may look nothing alike. As noted author and library educator Dorothy M. Broderick aptly said, "I think it is at best confusing to lump people with diseases such as epilepsy or diabetes with people who are paraplegics, blind, or otherwise physically disabled. In fact, it is not terribly sensible to lump all physically disabled people together" (204). Just as we have literary scholarship specifically devoted to other diverse experiences, I believe we should also have scholarship devoted to individual diseases or disabilities. Each chronic condition, physical disability, or mental illness is best viewed separately in order to fully appreciate the nuanced ways in which these unique experiences interact with the literary theories presented by children's literature and disability studies.

## Type 1 Diabetes in Children's Literature

At the beginning of my research, I compiled a list of fictional children's literature books that feature Type 1 diabetic protagonists.[8] My search was limited to books published in English

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[7] I know this from personal experience. My daughter has this pass.

[8] For a complete list of titles, see Appendix A.

and printed in North America. This list includes picture books, middle-grade fiction books, young (YA) adult novels, and more than one hundred Baby-Sitters Club titles. The publication dates of these titles range from 1973 to 2021. I would like to point out that only one title on my list (Branfield *Why Me?*) was published prior to 1980. In my search for book titles, library databases proved cumbersome to search because they are not designed to locate books based on criteria such as a character's illness or disability. Even though a library may carry several juvenile fiction books with diabetic characters, searches typically rendered these titles only if "diabetes" was in the book's title or if it was labeled as a "key word." My search also included Amazon, websites for used bookstores, recommended reading lists promoted within the Type 1 diabetes community, and Project Gutenberg. The website for Project Gutenberg produced only one result, which was a nonfiction book from 1915 entitled *The Starvation Treatment of Diabetes*.

When considered together as a subgenre within disability literature for adolescents, the fictional stories of protagonists with Type 1 diabetes reflect an added tension in the process of identity formation. As a chronic condition which can often be concealed, Type 1 diabetes can allow characters complete agency over disclosing their Type 1 status. Adolescents with Type 1 can often "pass" for "normal," or they can choose to publicly identify with their condition, which is also unique in its ability to exist in the overlapping spaces between illness, disease, and disability. It is described using various terms which all invoke slightly different meanings. It can be called a *chronic illness*, or a *disease*, or a *disability*. Or—it can be all three of these things simultaneously. None of these categories are mutually exclusive. The ability of Type 1 diabetes to transit between seen and unseen as well as illness, disease, and disability further complicates its representation within fiction.

One clear pattern I noted, particularly for picture books and middle-grade fiction, was story books written and published by diabetes advocacy groups such as Lilly Diabetes, The American Diabetes Association, and JDRF (formerly known as the Juvenile Diabetes Research Foundation). While I have seen copies of these books at the doctor's office where my daughter has her diabetes appointments, they are not easily found in public libraries, or even for purchase online. One of these books, *Rufus Comes Home* (first published in 1998) is distributed through JDRF's Bag of Hope program, which gives newly diagnosed children a plush version of Rufus along with a paperback copy of his story. In fact, my family owns a copy of *Rufus Comes Home*, which we received when my daughter, Winnie, was diagnosed with Type 1 diabetes on August 12, 2014. We use the Rufus bear and accompanying book when we talk with Winnie's classmates for World Diabetes Day in November. The story is didactic at times, but it's difficult to explain the diagnosis and treatment of a demanding chronic illness without a bit of didacticism. Some of the books published by advocacy groups have clear ulterior goals, though. The Great Katie Kate, for example, is a diabetes superhero who encourages families to join the TrailNet study in *Be the Hero! Help Prevent Diabetes*. Even the Rufus book, which frames its teaching about diabetes within the frame of a cute story, is stamped all over with the JDRF acronym—which appears on the book's cover, on the characters' clothing, and in giant letters across the T-shirt of the stuffed Rufus that accompanies the book.

As noted earlier in this introduction, another pattern I noticed is that it is very rare for adolescent characters with Type 1 diabetes to recur within a series. This is why Stacey McGill is such a standout. There are only three other Type 1 characters I have found that recur in fictional series for adolescents, and these three characters appear in two books each, compared to the more than 130 Baby-Sitters Club titles that include Stacey—this number does not even take into consideration the BSC graphic novel adaptations or mentions of Stacey's character in the BSC Little Sisters spin-off series.[9]

Sami Schalk's close analysis of disability within the American Girl brand, a series of historical chapter books and dolls marketed to young girls, demonstrates how even a series which is dedicated to diversity and inclusivity can have significant gaps in disability representation. Schalk's essay, "Ablenationalism in American Girlhood*,"* provides compelling evidence to suggest that the American Girl Company treats disability as *supplementary* and *temporary*.[10] She claims that American Girl promotes disability acceptance as a good behavior of able-bodied girls, rather than showing disability as a lived experience. She refers to American Girl branded disability paraphernalia (such as toy wheelchairs, crutches, and insulin pumps) as items that treat disability as "an accessory" which can be worn, or not, much like a bracelet or a pair of earrings (44). Schalk writes:

> The argument is not then that disability has no place in American Girl, but that disability does not need or does not deserve a central place. Instead, it is implied that disabled girls should be satisfied with this marginal level of inclusion since it is better than nothing and, from the perspective of ablenationalism, it is better than those unnamed other places where disability is supposedly not included at all. (43)

Schalk also emphasizes that, "[t]his form of including disability [as an accessory] stands in stark contrast to the more frequent representation of central [American Girl] characters from marginalized racial and class backgrounds throughout the brand" (43). For example, while it is

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[9] See Footnote 3 for details on the three other adolescent book series with recurring T1D characters.

[10] It is also surprising to me that a book series dedicated to building narratives around important historical events—such as wars, the Great Depression, or Women's Suffrage—seems to ignore one of the most miraculous scientific discoveries in the past century. I wonder if it is the simple fact that insulin was discovered in Canada which prevents American Girl from engaging with this historic moment. For whatever reason, there are no American Girls with diabetes.

possible to purchase a “diabetes care kit” for an American Girl doll, there is not a single character within the series that has Type 1 diabetes. Therefore, it is logical to assume that the toy diabetes kits American Girl sells exist mostly to appeal to children who are already familiar with Type 1 diabetes. Schalk further analyzes American Girls’ use of disability as an accessory in order to show how more apparent disabilities often take precedence over “invisible” disabilities. For example, American Girl offered its first wheelchair for dolls in 1996, but a kit for dolls with diabetes was not available until two decades later (Schalk 44). This problem of precedence is also an issue within intersectional scholarship on children’s literature and disability studies.

### Children’s Literature and Disability Studies

In my own preliminary research, I have easily found scholarly discussions of characters with more apparent conditions (e.g., vision impairment, hearing loss, or mobile impairment), but I have yet to find a single scholarly article within the field of children’s literature which interrogates a fictional Type 1 diabetes narrative. There does not even exist any criticism for the diabetic characters created by well-known adolescent literature authors such as Ann M. Martin or Lurlene McDaniel. If not even the diabetic characters created by these giants of the paperback industry are drawing the attention of scholars, it is hardly surprising that the titles produced by lesser known authors and smaller presses are not drawing any critical attention.

The scholarship that explores the intersection between disability and children’s literature is currently limited, especially when it comes to chronic illness. The 2004 winter issue of *Disability Studies Quarterly* (DSQ), a multidisciplinary, international journal which is dedicated to developing theory and practical knowledge of disability, opens with a preface from the editors which highlights the unexplored nature of the interdisciplinary links between children’s literature and disability studies. In this issue, themed “Disability Culture in Children’s Literature,” editors

Beth Haller and Corrine Kirchner write, “Overall, this *DSQ* issue provides a multi-faceted look at a largely unexplored disability studies area. In fact, a Google search on ‘children's literature and disability studies’ yields no links. Hopefully this *DSQ* issue will remedy that absence.” As this *DSQ* issue is now almost two decades old, I did my own internet search as an experiment. In the summer of 2022, my top search results in Google Scholar for “children’s literature and disability studies” were mostly articles published by *DSQ*, many of which were originally published in Haller and Kirchner’s 2004 issue.[11]

It is possible that a lack of children’s literature scholarship devoted to disability begins with a lack of children's books that accurately portray life with a disability. According to Joan Blaska, former professor in the Department of Child and Family Studies at St. Cloud University, “Perhaps no group has been as overlooked and inaccurately presented in children's books as individuals with disabilities.” Blaska emphasizes her point by citing a statistic that of 500 award-winning picture books for children, only six titles included characters with disabilities who were integral to the story.

While Blaska’s research led her to delve deeply into the relationship between children’s literature, disability studies, and early childhood education, her findings have limitations in correlation to this thesis because her evidence comes almost exclusively from picture books, and she offers little critical analysis. This is evidenced by her book, *Using Children’s Literature to Learn About Disability and Illness* (2003), which gives advice for parents and early childhood educators who work with children from birth to age nine (1). Blaska’s book is a how-to guide for talking about disability with children. It explains “person-first” language, includes definitions of

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[11] Of the top ten links produced by Google Scholar, six links are for articles published by Disability Studies Quarterly (DSQ). Other journals produced by this search were: *International Research in Children’s Literature*; *International Journal of Inclusive Education*; *Journal of Literary and Cultural Disability Studies;* and *Disability & Society*.

some conditions (e.g., asthma, blindness, diabetes), and provides an annotated bibliography of children's books that feature disabilities. Books in the bibliography are reviewed, but there is no deep analysis of the stories.

A more recent book which offers more critical analysis of disability in children's literature is Patricia Dunn's *Disabling Characters* (2015). Like Blaska, Dunn is a university professor. One obvious difference between Blaska and Dunn's scholarship is that Dunn's work addresses *contemporary* books written for an *adolescent* audience. A second difference is that Dunn's book employs methods of literary analysis in order to explore common myths and tropes about disability.[12] This is a fundamental difference from Blaska's interest in using texts as a kind of bibliotherapy. Dunn refers to the books she analyzes as "cultural artifacts" (Dunn 4) and employs a rhetorical approach to unearth the underlying cultural ideologies reflected in the books' narratives, as well as the stories' potential social impacts.

Both Blaska and Dunn do the important work of drawing the reader's attention to disability narratives within children's literature, but the educational lens that informs their works also imposes pragmatic boundaries on their critiques. *Using Children's Literature* (2003) and *Disabling Characters* (2015) do not reach the level of deep literary criticism that applies postmodern disability theories now popular within the field of critical disability studies. Ultimately, these books are written for the purpose of giving practical teaching advice for how adults can (and should) facilitate conversations about disability in literature with young people.

Throughout the course of writing this thesis, a book which has proved useful in understanding the historical relationship between children's literature and disability (especially with regard to the disability rights movement in the '80s and '90s) is *Disabled Literature: A*

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[12] In *Disabling Characters*, Dunn analyzes twelve novels and one short story, including titles such as Sherman Alexies's *The Absolutely True Diary of a Part-Time Indian* (2007) and Harriet McBryde Johson's *Accidents of Nature* (2006).

*Critical Examination of the Portrayal of Individuals with Disabilities in Selected Works of Modern and Contemporary American Literature* (2015) by Miles Beaucahmp et al. Beauchamp and his colleagues investigate why people with disabilities are often portrayed throughout American literature as characters who are "feared, reviled, misunderstood, or pitied," specifically noting popular texts such as *Of Mice and Men* (ix). The chapters of *Disabled Literature* are organized into themes which delve into different perceptions of disability, such as shame, pity, fear, comedy etc. While the book's focus is predominantly on adult literature, the chapter titled "Swimming in the Mainstream: Children's Literature" provides insight relevant to my thesis inquiry. In this chapter, the authors address another challenge of disability in children's literature: reader access. They write:

> While there are books for every age group whose main characters are children with disabilities… it takes a special effort to find these books. They are often published by small presses, and those are seldom reviewed in standard journals such as *The Horn Book Magazine*. (132)

Also worth noting is the fact that most disabilities referred to in *Disabled Literature* are *apparent* disabilities, but the concepts and themes presented by Beauchamp and his colleagues can also be applied to unapparent chronic illnesses, such as diabetes.

## Research Methods

When searching for links between post-nineteenth century children's literature and disability studies, my strategy is to begin with publications that devote themselves to disability studies and then work backward toward children's literature.[13] Using this search method, I have

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[13] As Type 1 diabetes was not considered a "chronic condition" until after 1921, there do not appear to be any fictional stories of adolescent diabetic characters published before the twentieth century. For scholars interested in disability representations in children's literature from the nineteenth century, I highly recommend Lois Keith's *Take Up Thy Bed and Walk: Death, Disability, and Cure in Classic Fiction for Girls*.

had more success discovering scholarly intersections between the two fields. While there are some issues of children's literature journals which focus on disability as a special topic, their scope of this area is often limited. It is the journals that focus on disability which (I would argue) provide the most resources. In the fall of 2013, for example, *Children's Literature Association Quarterly* published a special issue titled "Disability and Children's Literature," but this issue contains only five scholarly articles on the topic of disability (265). In contrast, the 2004 children's literature issue from *Disability Studies Quarterly* contains more than a dozen articles, exploring narrow topics such as "deafness in picture books," "disability in African American children's literature," and "chronic illness in realistic fiction for children."

Within the field of disability studies, discussions of unapparent conditions such as chronic illnesses do not appear as often as discussions of more apparent conditions. Even scholars who readily acknowledge disability as a social construct, such as Rosemarie Garland-Thompson or Lennard Davis, focus much of their scholarship on perceptions of the physical body. Their arguments often stem from the general idea that society's perceptions of the body, and what is *normal*, are what ultimately lead to disabling social conditions. Often, disability theories focus so heavily upon physique that applying their ideas to unapparent conditions, such as diabetes, poses a challenge. Perhaps this is why it is difficult to find much literary criticism on portrayals of chronic illness in children's literature. The more narrow focus of this thesis—Type 1 diabetes in adolescent literature—appears to have no published scholarship at all.

The closest I have found to criticism of diabetes portrayals in fiction are short reviews of individual books in resource anthologies created for librarians, such as *Health, Illness, and Disability: A Guide to Books for Children and Young Adults* (1983) by Pat Azarnoff, and

*Portraying Persons with Disabilities: An Annotated Bibliography of Fiction for Children and Teenagers* (1992) by Debra Robertson.[14] Their brief reviews are helpful for identifying books with representations of diabetes (and many other disabilities), and possibly even for broadly categorizing those books as *good* or *bad* representations, but they are less helpful in terms of in-depth literary analysis. In their annotations, both Azarnoff and Robertson draw the reader's attention to instances of tokenism and ableism, but their annotations of a few paragraphs per book do not allow for in-depth analysis.

In the case of Type 1 diabetes, the dearth of academic insight from children's literature scholars may stem from the challenges pointed out by Blaska and Beauchamp. To put it bluntly, there are few fictional books written about teenage diabetic protagonists to begin with. Even within annotated bibliographies devoted to disability, Type 1 diabetes is a rarely mentioned condition. Therefore, the secondary sources that often inform this thesis address related disability through related topics such as: chronic illness or conditions that are described as "hidden," "invisible," or "unapparent." Even finding these sources, however, often proves challenging when looking specifically for intersections with children's literature scholarship. As stated previously, it is much easier to find articles which focus on the portrayals of apparent disabilities in children's literature. Because the only criticism of Type 1 diabetes in fiction that I could find comes from short blurbs in bibliographies intended for librarians or teacher educators, it has also been helpful to review medical journals in order to gain a narrow perspective on Type 1 diabetes as experienced in adolescence. While more scientific in nature, these journals sometimes provide valuable insight into the social and emotional challenges an adolescent experiences while managing her blood sugar 24/7.

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[14] Both of these bibliographies were published during a surge of the Disability Rights Movement. At that time, disability was a hot topic.

## Critical Disability Studies: Viewpoints and Theories

One of the primary interests of my thesis inquiry is to consider the added challenges of drawing attention to an unapparent disability when, as disability scholars David Mitchell and Sharon Snyder write, the broader category of disability solicits little social commentary, in spite of its ubiquitous nature (x). Drawing upon research from Mitchell and Snyder in their book, *Narrative Prosthesis: Disability and the Dependencies of Discourse* (2000), I will expand upon ideas such as the *narrative prosthesis*, which calls attention to the social invisibility that the authors claim is dictated by disability (52). In their descriptions of narrative prosthesis, Mitchell and Snyder often refer to the *imag*e of disability. I question how this image applies to chronic conditions, which add another layer of invisibility within a category which Mitchell and Snyder have shown to be overlooked, or easily forgettable (51). What happens when the literal image of the disabled body in question resembles the "normal" body? Apart from wearing a medical device (which is not a requirement for Type 1 diabetes), the diabetic body has no distinct biological markings which aid in its categorization.

Concerning the categorization of chronic illness as a disability, this thesis relies upon current theories and observations in the field of critical disability studies (CDS), which heavily weigh the social, historical, and cultural ramifications in defining the term *disability*. While *impairment* is defined by critical disability scholars as a result of physiological factors which limit function (such as the ability to walk or see), *disability* is viewed as a product of social conditions (Meekosha 50). Therefore, instead of defining *disability* according to a clear binary which separates able bodies and disabled bodies into two distinct categories (according to a medical model), CDS takes a more fluid approach that is intersectional, engaging feminism, queer theory, and other postmodern critical social theories (Meekosha 62). The result is an interpretation of disability that is ambiguous, yet rich, and which is more readily inclusive of chronic conditions, (such as diabetes) which are not always readily apparent.

In this thesis, I often refer to diabetes as a condition that is *unapparent*, which is a term used by Amy Burke Valeras in her study "'We Don't Have a Box': Understanding *Hidden Disability* Identity Utilizing Narrative Research Methodology." In her research, Valeras uses the terms "unapparent," "invisible," and "hidden" somewhat interchangeably in order to describe conditions that she describes as "unapparent to the unknowing observer." Similarly, I use these terms interchangeably in my thesis. In my analysis, I conform with the preferred terminology of the scholarship that I reference. However, when I am not referencing the work of other scholars, I prefer the term "unapparent" because I find it to be the least problematic. The term invisible is problematic because it can be perceived as ableist. To a person without the ability to see, *everything* is invisible; therefore, the term "invisible disability" favors people who have the ability to see. I find the term "hidden disability" also to be problematic because it implies that the person with the disability is willingly or knowingly concealing a disability identity. The term unapparent more accurately captures the sentiment that certain disabilities may not be readily recognized due to their lack of what Tobin Siebers refers to as "visible stigma."

Another important idea which informs this thesis comes from author Julie P. Elman, who posits that the age of adolescence may, of its own accord, be considered a brand of disability. In her monograph, *Chronic Youth* (2014), Elman interrogates U.S. popular culture and the birth of the American teenager in the 1970s to show how "disability became attached to other forms of embodied experiences that have been deemed undesirable, such as adolescence, queerness, or immaturity" (9).[15] Elman's work leads me to ask broader questions: Why, when connections are made between disability studies and children's literature, the "literature" in question is often

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[15] The third chapter focuses on the influence of teen sick-lit and is particularly relevant to this paper.

limited to picture books, or books written to children under age nine, as in Blaska's study? Does our society view adolescence as a period of temporary disability, as Elman suggests? Is the teen brain a troublesome problem which requires a solution, much like the curative theories that, according to Lois Keith, permeate disability literature of the nineteenth century?[16] Is the relationship between adolescence and disability mostly overlooked in children's literature because the period of adolescence is broadly viewed as a disability?

For Type 1 diabetes, the age of adolescence is particularly significant because it is a common age for diagnosis. According to the U.S. Center for Disease Control, "The peak age for being diagnosed with Type 1 diabetes is around 13 or 14 years old" ("Just Diagnosed"). In this thesis, there are two "diagnosis stories" in which a teenage protagonist discovers her diabetes and then learns to cope with it. The diagnosis story of the middle-school-aged Baby-Sitter's Club Treasurer Stacey McGill, for example, occurs as a flashback in *The Truth About Stacey*. This connection between adolescence and Type 1 leads me to a disability theory which relates specifically to diabetes, and which I refer to as *the myth of control.*

## The Myth of Control

The history of Type 1 diabetes management is rife with rhetoric that invites the mythic. It begins with the miraculous discovery of the hormone insulin, which is often referred to by scholars and historians as the "wonder drug." As mentioned in the opening paragraph to this introduction, insulin transformed Type 1 diabetes—a once-deadly disease—into a manageable chronic illness. The miraculous nature of insulin's discovery by Canadian researchers Frederick Banting and Charles Best led lay people and doctors alike to promote a rhetoric that suggested diabetes had been conquered, according to Chris Feudtner in *Bittersweet: Diabetes, Insulin, and the Transformation of an Illness* (2003, 7-8). It's not difficult to imagine their enthusiasm. It is

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[16] See Footnote 5.

impossible to overstate the radical transformation of a centuries old deadly disease into a manageable, chronic condition. It was, truly, miraculous.

Before the discovery of insulin in 1921, Type 1 patients could attempt to delay death. In *Bittersweet*, Feudtner chronicles the grim history of diabetes treatment with strict starvation diets in the early 1900s. Similar kinds of high fat, low calorie diets are noted being used even earlier in the 1800s, according to Hans Schadewaldt in *Diabetes: It's Medical and Cultural History* (1989). But, Feudtner points out that diets could only buy patients a few years of extra time (6); death due to diabetes was inevitable. But what quality of life can a person achieve if they are regularly deprived of basic nutrition as a method of survival?

Feudtner includes photos of children with Type 1 diabetes who endured starvation diets depict gruesome, emaciated bodies that call the reader's attention to the devastating effects that await a body unable to produce insulin. In one photo, a young boy appears to be crying, and he is held by a woman. His elbow juts out awkwardly and appears unnaturally large in comparison to his thin arm, which is nothing more than a sharp right angle of bones shrouded in skin. This photo appears in *Bittersweet* alongside a second image in which the same boy is shown after beginning insulin therapy. His plump face now stares soberly at the camera. He is unrecognizable from the emaciated child in the first photograph. According to the text, the young boy's weight doubled (Feudtner 7).

The dramatic transformation evidenced by the juxtaposition of patient photographs before and after insulin therapy is an example of what Feudtner refers to as the "mythic account of diabetes history" in which insulin is hailed as a "wonder drug to rescue patients, vanquish disease, and banish suffering" (9). Even the language that Feudtner himself chooses to use is reminiscent of a superhero story with words such as "rescue" and "vanquish." The superheroic nature of insulin's discovery is yet again alluded to in a story titled "Canada's Hero of Science" that appeared in a 1941 issue of the comic book *World Famous Heroes Magazine*. In this issue, Frederick Banting's story of discovering insulin and later dying in World War II is told in comic narrative, no different than if he were Clark Kent or Steve Rogers.[17] Like a traditional comic hero, Banting has a strong jawline and broad shoulders. Instead of a cape, however, he dons a white lab coat. And, instead of super strength or the ability to fly, his superpower is conducting research. When the comic reaches the point in the story when insulin is discovered by Banting and Best, their colleagues are shown in subsequent panels, spreading rumors of a mysterious substance which they refer to as "Secret 'X.'" This superheroic treatment of Banting's discovery contributes to the mythic quality of insulin's history as the "wonder drug" and the misconception that diabetes could be controlled.

Control is often the central theme within diabetes adolescent fiction. The three categories of control as represented within the texts are: (1) A lack of glycemic control that reflects the Type 1 protagonist's emotional or physical weakness, (2) Imperfect control that emphasizes the protagonist's heightened state of dependence (such as with sick-lit), or (3) Total control that demonstrates the protagonist's illness acceptance and her sense of responsibility. These three categories are admittedly problematic. The first issue with these themes of control is that they can present so strongly within a story that the disability itself has a tendency to fade into the background and become merely a metaphor. The metaphorical use of disability is referred to as the *materiality of the metaphor* by David Mitchell and Sharon Snyder in their book, *Narrative Prosthesis: Disability and the Dependencies of Discourse* (2000). Mitchell and Snyder define the materiality of the metaphor as a narrative technique in which "disability [sic] serves as a metaphorical signifier of social and individual collapse. Physical and cognitive anomalies

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[17] These are the real names of Superman and Captain America.

promise to lend a ‘tangible’ body to textual abstractions” (47-48). A shortcoming of the *material metaphor*, according to the argument presented by Mitchell and Snyder, is that it does not address “disability as an experience of social or political dimensions” (48). For Type 1 diabetes, a representation that is only a metaphor can problematically elevate illness acceptance to the level of a cure. This can often occur in diagnosis stories where illness acceptance is presented as the primary conflict—the resolution of which can be suggestive of a partial cure.

The second issue with the three themes of control within diabetes fiction is that they can easily result in an extremely polarized portrayal of Type 1 diabetes, where the protagonist is either in complete control or totally out of control. (The exception to this is the second category, which allows for imperfect control, but at the expense of the protagonist being cast as weak and dependent. That dependency is often placed upon a male love interest, as is the case in much teen sick-lit.) When control is the primary objective, “good” control often renders the disability irrelevant, whereas “bad” control reflects physical or mental weakness on the part of the diabetic character. A clear example of the binary of control can be seen in the 1989 film *Steel Magnolias*, which is infamous for its diabetic heroine, Shelby. Film critic Kevin Ferguson describes how a scene in which Shelby experiences low blood sugar splits her character into two people: a “frightening figure” who is “out of control” and a “gentle bride-to-be” who is “grateful” for the intervention of her friends (184). As the scene in *Steel Magnolias* demonstrates, these opposing states of control are communicated through the visibility of diabetes. Ferguson’s example from *Steel Magnolias* demonstrates how visibility represents the absence of control. A lack of visible diabetes management within adolescent fiction, therefore, might erroneously suggest that insulin is a cure for diabetes, or that diabetes only poses a threat when it causes a visible problem.

Contrary to the theme of control that is prevalent in adolescent diabetes fiction, daily life with Type 1 diabetes revolves around the idea of *management.*[18] Blood sugar must be monitored, measured, and responded to 24/7. Numbers count carbohydrates. Numbers measure insulin and blood glucose. Blood glucose numbers can be high or low, and there may even be one special number (such as 100), which is whimsically referred to as a "unicorn" (Wheeler).[19] But the numeric unicorn is elusive, almost as mythical as the "real" unicorns. The numeric unicorn represents a fantasy of perfect control. A numeric unicorn may appear occasionally, but its appearances are somewhat random and always fleeting. Ideally, blood glucose measurements will fall within *a set* of numbers referred to as the "target range." For the Type 1 diabetic, the common medical rhetoric imposed by terms such as *set* and *range* imply the expectation that management (i.e., glycemic control) is imperfect and limited in its precision. If control was precise, the numeric unicorn, a single ideal number, would be predictable and regularly attainable. Interestingly, despite the mythic history of the "wonder drug" insulin, most novelized diabetic protagonists are found in books of *realistic* fiction. It is rare to find such a protagonist within the genres of sci-fi or fantasy, for example.

## The Structure of the Thesis

In Chapter One, I explore the theme of food control and how diabetes is made visible by Stacey McGill in the Baby-Sitters Club series by Ann M. Martin. As I noted earlier, Stacey is the

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[18] In *Managing Diabetes: The Cultural Politics of Disease*, Jeffrey Bennett expresses some criticism of the term "diabetes management," which he argues confusingly consolidates the complexities of daily life and "diabetes's puzzling incoherencies" (7). Despite Bennett's apparent criticism, however, I believe his further observation that "management operates as a shorthand for multiple rhetorics" (7) also proves management's comprehensiveness. The expectation of imperfection seems simultaneously supported and challenged by the term *management,* which implies a level of control, but also acknowledges outside forces.

[19] The word "unicorn" also has a second meaning for people with Type 1 diabetes. It can also refer to the rare instance when the blood glucose reading obtained via a finger prick matches exactly with the number on a Type 1 person's continuous glucose monitor (CGM). The CGM is a device that approximates blood sugar levels by measuring interstitial glucose (found between cells) with a thin sensor that is inserted under the skin.

undeniable, unofficial spokesperson for Type 1 diabetes in adolescent fiction. Therefore, it is impossible to write a thesis on this topic without including her. While Stacey's diabetes is at least referenced in nearly every BSC book, even when she is not narrating, it is a particular focus in these three books: BSC #1, *Kristy's Great Idea* (in which Stacey reveals her diabetes to her friends); BSC #3, *The Truth About Stacey* (which tells her diagnosis story) and BSC #43, *Stacey's Emergency* (in which Stacey is hospitalized for complications due to diabetes).

In Chapter Two, I investigate the impact of sick-lit upon the teen diabetes narrative by analyzing two books that were published about forty years apart: *Will I Ever Dance Again?* by Lurlene McDaniel (1982) and *Let Me List the Ways* by Sarah White (2018). I chose to include McDaniel's novel because it is one of the first teen diabetic stories I have found to be published in the United States, and because McDaniel has undeniable notoriety as a writer of sick-lit for teens. I chose White's novel because I wanted a more recent example of sick-lit with which to compare McDaniel's work. There are some fundamental differences between these books which admittedly makes them a less than perfect comparison. In *Will I Ever Dance Again?* Rachel is diagnosed with T1D as a teenager, whereas in *Let Me List the Ways*, Zie has been living with T1D since the fourth grade. Also, Rachel's story is told in the third person by a narrator, and Zie tells her story in the first person. Thematically, though, these two books have a lot in common. The genre of sick-lit provides a fertile ground for talking about them together.

The book I discuss in Chapter Three, *Sweetblood* by Pete Hautman (2003), was chosen for this project because it won the Minnesota Book Award for Best Youth Literature. This puts *Sweetblood* on a short list of award-winning books with fictional Type 1 diabetic characters. My primary focus in this chapter is exploring how illness acceptance is impacted by a perception of being feared, or othered. In Hautman's novel, the main character, Lucy, struggles to reconcile her identities as a “normal” teenager and as a “diabetic.” In order to regain agency over her identity, she dresses in all black and claims that she is a proto vampire. As the story progresses, Lucy experiences a phase of “burnout,” which results in her near-death and hospitalization.

In the fourth chapter of this thesis, I discuss *The Girls Are Never Gone* by Sarah Glenn Marsh (2021). Although the protagonist of this book, seventeen-year-old Dare Chase, fits the typical pattern of a White, adolescent, female, it breaks new ground by presenting a T1D character who is bisexual. Although my chapter will not delve into the potential ramifications of Dare’s sexuality, I wanted to make mention of it here due to its uniqueness within the subgenre of Type 1 diabetes fiction. The other unique feature of Marsh’s book, which I discuss in my chapter, is the book’s gothic setting and supernatural elements that set it a literal and figurative world apart from the realistic fictional settings that are more commonly associated with Type 1 diabetes fiction. In this chapter, I interrogate how Dare’s Type 1 narrative is transformed by its intersection with gothic elements and a supernatural serial killer.

In the conclusion of this thesis I summarize the findings of my chapters and call attention to several common themes and tropes that unite them within the subgenre of diabetes fiction. I describe the trope of the diagnosis story, examples of which can be found in the first and second chapters of this thesis, as well as the burnout story, an example of which appears in the first and third chapters. An underlying theme throughout many of the texts I examine is the theme of control, which I break down into three different subcategories. Next, I refer to my personal experience, as the caregiver of a child with Type 1, in order to reflect on what appears to be a growing trend of disability inclusiveness in the United States, as well as the increased visibility of Type 1 diabetes through the 2022 Disney-Pixar film *Turning Red*. Finally, I look toward the future of Type 1 diabetes in literature. I call for the increased attention to diabetes, as well as other chronic illnesses, within scholarly research—specifically with regard to children's literature and other media created for children.

### A Caveat: Why All My Protagonists Are White, Female Adolescents

One of the primary purposes of this thesis is to explore representations of Type 1 diabetes in juvenile fiction in order to expose the underlying ideology that informs them. According to my ongoing research, the majority of fictional adolescent characters with Type 1 are White females. With very few exceptions, all of the adolescent protagonists on a book list that I have compiled in the final appendix of this thesis are White, and more than two thirds are female. My findings align well with results from a study conducted by Chris Saad (2004), who notes a disturbing disparity in gender representation among chronically ill characters in adolescent fiction published between 1970 to 1994. Saad's article "The Portrayal of Male and Female Characters With Chronic Illnesses in Children's Realistic Fiction" found that a chronically ill teenage character is four times more likely to be female than male. Saad also notes that "with few exceptions, chronically ill characters are female, heterosexual, and white… in the world of children's books with chronically ill main characters, people of color and gays and lesbians rarely even exist." This conclusion by Saad, points to the fact that disability portrayals within adolescent fiction represent a specific viewpoint: one that is White, female, and heterosexual.

Each of these labels, White, female, and heterosexual, imposes its own interpretation of disability within the text. The whiteness of the characters I discuss in this thesis seems to always coincide with living a comfortable, middle-class, suburban lifestyle. The problems these girls experience are mostly social and emotional—rather than economic or political. For example, they do not worry about having good health insurance or whether or not they can afford their insulin and other medical supplies. They mostly worry about how their peers will perceive them, specifically with regard to diabetes and the cultural baggage it carries as an illness, a disease, or a disability—it goes by all three. When these girls experience physical distress due to diabetes, it is not uncommon for them to be saved by a male romantic interest. Several examples of girls with diabetes being rescued by teen boys appear in Chapters Two and Three of this thesis.

Saad's observation regarding the disparity of gender representation in chronic illness narratives begs a related question. What is it about diabetes that lends itself more easily as a "female" condition? I propose that a common thread which unites disability, chronic illness, adolescence, and femininity is the pervasive cultural misconception that each of these conditions are a kind of weakness. By limiting my research to the narratives of female characters, I hope to expose common patterns within fictional diabetes narratives, while also challenging preconceived notions about what it means to be an adolescent girl with a chronic illness.

# Chapter One: Visible Food Control as a Rejection of the "Gross" Diabetes Identity in The Baby-Sitters Club, a Series by Ann M. Martin

When Anastasia "Stacey" McGill is first introduced to the other three founding members of the Baby-Sitters Club (BSC), they immediately notice something odd when she tells them she is on a diet. Kristy Thomas, the club president, yells at her, "You? You're skinny already!" (*Kristy's Great Idea*, Martin 32). Stacey, who is in seventh grade, is described as thin, stylish, and model-like. At the start of the BSC series, Stacey's family has just moved from New York City to Stoneybrook, Connecticut, and she is excited to join her classmates Kristy, Claudia, and Mary Anne in their new club. Once a week, they meet in Claudia's room where they take phone calls for babysitting jobs, which they divvy up amongst their group. Throughout the first book in the BSC series, Stacey appears to stick to her diet as she abstains from all kinds of sweet snacks that are shared by her friends: M&Ms, Gummi Bears, Jawbreakers, Twinkies, and Coke–she politely refuses them all. Later, Kristy confides that she suspected Stacey might be anorexic (150). But Stacey does not have an eating disorder; she is a Type 1 diabetic.

The inclusion of a diabetic character in the BSC series is noteworthy due to the series' immense popularity with readers, who have purchased more than 180 million copies of Martin's books since the series' inception in 1986 (Soloski). Not only did the BSC treasurer, Stacey, provide a steady voice for Type 1 teens, her stories also informed literally millions of readers. Reading about Stacey's symptoms has even prompted multiple young readers to seek out their own diagnoses and avoid the disastrous consequences of undiagnosed Type 1—such as a diabetic coma (Becker 155). From her debut, Stacey's story resonated with newly diagnosed pre-teens like Buzzfeed staffer April Decosta, who was diagnosed at age 11 in 1991. In an online article titled "What the Babysitters Club Taught Me About My Disease," Decosta writes, "As a girl, I knew no diabetics, or really any other kids afflicted with disease. The fictional character of Stacey McGill alleviated the loneliness of being sick." Decosta's story illustrates the feelings of isolation that a diagnosis can create, as well as the therapeutic effect of experiencing a disability through fiction. Multiple adaptations of the Baby-Sitter's Club over the course of three decades—and a *lack* of Type 1 diabetes representation in other adolescent fiction—have solidified Stacey as a fictional Type 1 spokesperson for adolescents. The recent BSC Netflix series reboot, which lasted for two seasons between July 2020 and October 2021, makes the discussion of Stacey's role in Type 1 diabetes fiction especially timely.

From Stacey, readers of Ann M. Martin's books learn that blood sugar levels are controlled through a strict diet. When treats are passed around during BSC meetings, Stacey abstains. When the group orders pizza, Stacey eats salad instead. When the group eats ice cream treats, Stacey internally laments her inability to join them. She remembers a time before diabetes, when she could have enjoyed ice cream, too, just like the other girls. In *The Truth About Stacey*, she summarizes her condition this way:

> The thing is, I *am* allowed a certain amount of sweet stuff each day. In fact, I *have* to eat a certain amount of sweets in order to maintain that delicate balance between food and insulin. My diet is so exact, though, that I can't just snack whenever I feel like it. I can't, for instance, suddenly decide to eat a Twinkie or something over at Claudia's and then make up for it by giving myself extra insulin. It just doesn't work. In fact, it's a good way to make myself sick. (Martin 26)

Although Stacey tells readers that she *can* and *must* have a certain amount of sugar each day, her encounters with sweet foods *always* leads to her abstention. In the BSC series, the consistent adherence to a strict diet in order to prevent sickness seems to override Stacey's initial assertion that some sugar is necessary for her health. Stacey's persistent rejection of sugary foods reveals a large gap between what she tells readers about her condition, and what readers "see" her do to manage her diabetes. Stacey's rejection of sugar in the BSC series adds a visible component to an otherwise unapparent chronic illness. It creates a tangible, ever-present reminder that Stacey is different. However, by focusing so narrowly on interactions with food, the BSC series stigmatizes perhaps the most vital element for survival with Type 1 diabetes: insulin injections. As Stacey's story demonstrates, the theme of food control recurs throughout the BSC series, promoting a confusing representation of the diabetic lifestyle that, at face value, can be confused with anorexia. Stacey's choice to publicly diet while concealing the more inherently diabetic parts of her lifestyle (insulin injections and finger pricks) reveals two things to readers: a deeply-rooted desire for normalcy and an insecurity that links her Type 1 with shame.

This chapter seeks to explore the character of Stacey McGill as a Type 1 diabetes icon, primarily as she exists within the novelized universe of the Baby-Sitters Club. In order to guide readers, I will first introduce Stacey's character, how she connects with readers, and why she matters to people with Type 1 diabetes. Then, to understand the role of Stacey's chronic illness within the BSC series, I will closely analyze three books which each reveal a different aspect of Stacey's diabetes: disclosure, diagnosis, and management. *Kristy's Great Idea* (BSC #1) is the first book in which Stacey's diabetes is revealed. This is also the first time that Stacey's diabetes is compared with eating disorders. *The Truth About Stacey* (BSC #3) tells the story of Stacey's diagnosis in flashbacks, and reveals a history of keeping her diagnosis a secret, even from close friends. In *Stacey's Emergency* (BSC #43), Stacey's diet fails to control her diabetes, and she ends up in the hospital due to high blood sugar.

While I am confident that the titles I analyze in this chapter reveal much about Stacey's identity formation in relation to her diabetes, I also recognize that this chapter only scratches the surface. I have insufficient space to fully probe the entire Baby-Sitters Club book series, which is an ever-expanding universe with more than one hundred titles, spin-off series, numerous reprints and adaptations still in production as of 2022. Even though this review of the BSC literature is cursory, I would be remiss to completely ignore the power of the graphic novel and film adaptations to destabilize Stacey's long-established literary narrative. Therefore, the final section of this chapter considers the impacts of two relatively recent adaptations: the graphic novel series (2006-2022) and the Netflix reboot television series (which released two complete seasons: July 2020 and October 2021). These modern adaptations are important because, I argue, it is thanks to them that the Baby-Sitters Club continues to have a new audience.

### Why Stacey?

Stacey's continued presence as a fictional Type 1 role model does not just span decades, it bonds generations of readers. Her staying power in adolescent media made her a relatable touchstone for 11-year-old Decosta in 1991—and for Robin Benway, a female author in her 40s who wrote a personal essay on the Baby-Sitters Club in 2020. Her enduring presence as a Type 1 literary spokesperson is why Stacey's story is so important to the field of Type 1 literature, and why she deserves critical examination as an example of chronic illness in adolescent fiction. While Stacey continues to survive the passing of each decade with new clothing and updated hairstyles, common themes persist in her stories which hurt her disability narrative: food control and diabetes secrecy.

Throughout the BSC series, Stacey's relationship to her diabetes is communicated largely through food control, whereas the details of her diabetes management (blood tests and insulin injections) are kept extremely private. Stacey's sugar avoidance, which is always on full display, is so extreme and so persistent that her diabetes is sometimes misconstrued by other BSC characters as anorexia. In a 2010 prequel to the BSC series, *The Summer Before*, Stacey shares this fear when she spies a female classmate eyeing Stacey's meager tray of food in the lunchroom. Stacey observes, "I could see her thinking 'Anorexia?'" (Martin 201). Avid BSC fans have taken note of the connection to anorexia as well. In a 2011 "Where are They Now?" blog post, writer Emily Weiss facetiously writes about how grown-up Charlotte (whom Stacey often babysits) "developed an eating disorder" because she always wanted to be like Stacey. Weiss' dark humor points out a potentially critical flaw in Stacey's representation of diabetes: its tendency to manifest itself as something else entirely.

To fully appreciate the findings in this chapter, it is crucial to understand how Stacey's character marks a significant shift away from the tendency of other adolescent disability narratives, which Miles Beauchamp et al. argue within *Disabled Literature* (2015) often contain little subtlety and "are about disability set in the matrix of a story, not a story that happens to include a disability" (146). Most other adolescent Type 1 protagonists exist only in stand-alone novels whose plots revolve around either a diagnosis story or a period of mental exhaustion where the character becomes complacent in the management of his or her disease, resulting in dramatized consequences.[20] In the diabetes community, this mental exhaustion is referred to as "burnout." Both of these narratives (the "diagnosis story" and the "diabetes burnout story") exist within the BSC universe, but the constant expansion and adaptation of the series over time has

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[20] Examples of the diagnosis and burnout themes are found in Pete Hautman's 2003 novel, *Sweetblood*, and Jolene Perry's 2014 novel, *The Summer I Found You*. In *Sweetblood*, the sixteen-year-old protagonist Lucy (who was diagnosed with Type 1 at the age of six) becomes complacent in her care, landing her in the hospital. In *The Summer I Found You*, teenage Kate is struggling with how to balance her social life with her recent Type 1 diagnosis.

created opportunities for more "every day" glimpses into Stacey's life.[21] Titles such as *Boy Crazy Stacey* (1987), *Stacey and the Fashion Victim* (1997), and *Stacey the Math Whiz* (1997) emphasize her interests rather than her diabetes. By making Stacey's other traits the focal points in most of the stories she narrates, Ann M. Martin arguably presents a more well-rounded version of a character with a disability. Readers—both diabetic and non-diabetic—can connect with Stacey's love for fashion, her innate math skills, or the drama of a middle school crush. These narratives, where diabetes is not the central focus, give dimension to her character. When paired with her style, which is always updated to match the decade, these layers of dimension create the illusion that through Stacey readers experience a current, comprehensive view of life with diabetes.

However, as the three BSC books I analyze in this chapter demonstrate, the identity that Stacey presents to the reader through her actions is not necessarily suggestive of a diabetic teenager. Stacey's diabetes management (her extreme dieting) could easily be confused with an eating disorder.[22] The issue of food control is a recurring, dominating theme with regard to Stacey's disability identity. Synonymizing dieting with diabetes management allows Stacey to present a "normal" public identity. Although her friends worry that she may be anorexic, dieting does not necessarily suggest an eating disorder in the same way that insulin injections are indicative of Type 1 diabetes. Ultimately, Stacey suppresses her disability identity by embracing

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[21] These themes appear in two books from the BSC series: *The Truth About Stacey* (1986), which reveals Stacey's diagnosis story, and *Stacey's Emergency* (1991), where Stacey ignores warning signs of high blood sugar and ends up hospitalized for most of the novel.

[22] In fact, the BSC president, Kristy Thomas, falsely concludes that Stacey is anorexic in BSC #1. In a prequel to the series published in 2010, *The BSC: The Summer Before*, anorexia is mentioned again when Stacey worries that students from her new school will label her "anorexic" due to her diet.

food control, a visible symptom of her condition which could simply suggest healthy eating habits.[23]

## All Eyes on Stacey: Beauty, Staring, and a Sense of "Otherness"

It is significant that the reader's first introduction to Stacey's diabetes is controlled by a narrator other than Stacey herself. The focalization upon Stacey via a normative preteen narrator undermines Stacey's ability to define her illness on her own terms. The tendency to visualize Stacey's diabetes through food is established early in the series as a way of "detecting" Stacey's illness in the series's inaugural book, *Kristy's Great Idea* (BSC #1), which is narrated by the club's president, Kristy Thomas. In BSC #1, observations of Stacey's disability are filtered through Kristy, the girl-next-door narrator. Through control of the narration, Kristy is able to focalize upon Stacey's character in a manner that evokes staring and eventually, as the novel progresses, develops into the medical gaze—culminating in Kristy's misdiagnosis of anorexia (Martin, *Kristy's* 150). In a term coined by Rosemarie Thomson-Garland, Stacey's character is the *staree*. She becomes a character who is looked at, studied, and analyzed by Kristy. Even before Stacey's disability is revealed, Kristy's implied staring marks Stacey McGill, the new girl from New York City, as different.

Stacey's "otherness" is galvanized through Kristy's direct comparison of Stacey with Claudia, an Asian character who represents both anxiety and fascination, and who becomes Stacey's first friend.[24] Like Stacey, Claudia is noted for her physical superiority. Kristy describes her as "much more grown-up" (Martin, *Kristy's* 8), "growing up faster than *us*" (24) and, like Stacey, resembling "a model" (32). Kristy's insistence on repeatedly noting these physical

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[23] Another phrase commonly used is "disabled identity." However, I prefer the term disability identity because I find that the former term might imply that the identity itself might be impaired or limited in some way.

[24] Notably, at this point in the series Claudia is the only ethnic minority member of the Baby-Sitters Club. Jessi Ramsey, a Black club member known for her love of ballet, makes her first appearance in BSC #14, *Hello, Mallory*.

differences underscores their significance and points to growing anxieties of the female body. Kristy's anxiety over Claudia's changing body becomes overtly evident when she says, "Recently, I haven't felt quite as comfortable visiting Claudia as I used to. This year she had to go and start growing up faster than *us*" (24). Kristy's use of the word *us* in both of these scenes creates a physiognomic dichotomy between the girls whose bodies have begun to mature and those who have not. As the narrator, Kristy speaks for the majority (i.e., the less developed girls, the *us*), who are represented by her and Mary Anne. Claudia and Stacey, on the other end of the spectrum, are othered for their more developed bodies and the anxiety they induce.

It is Kristy's fascination with Stacey's physical beauty—a different type of "otherness"—which invites the reader to analyze her by gazing upon her body. Stacey's more grown-up body and sophisticated clothing, all noted by Kristy, separate her from the rest of the group and elevate her to a pseudo teen beauty queen status among her elementary-looking peers. Kristy mentally notes in the narration that she and the club secretary, Mary Anne, "look like second graders," which is a stark contrast to Stacey, whom Kristy thinks looks like "a model" (Martin, *Kristy's* 32). According to Garland-Thomson, idealized beauty is fetishized within culture in the same way as the anomalous freak. Garland-Thomson writes that, "both the beauty pageant and the freak show produce figures—the beauty and the freak—whose contrasting visual presence gives shape and definition to the figure of the normative citizen" (459). Kristy's fixation on Stacey's beauty, therefore, is an invitation for the reader to scrutinize Stacey's body, as well as the food that she puts into her body.

### Stacey's Complicated Relationship with Sugar

Through Kristy's point of view, readers are directed to closely analyze Stacey's eating habits, which are referenced throughout BSC #1 and become a hallmark of her character as the series progresses.[25] Stacey's eating habits appear like bread crumbs for the reader to follow along with Kristy, creating the sense that Stacey is an unsolved mystery and Kristy (along with the reader) is the detective. Over and over again, the reader is exposed to scenes of Stacey rejecting sugar. She runs out of the room when Gummi Bears are passed in her direction (Martin, *Kristy's* 43), she declines to eat even half a Twinkie (85), and she falls silent when the rest of the club makes plans for a slumber party with "all of the junk food [they] can eat" (103).[26] Then, when Stacey misses a BSC meeting, her "weirdness" is directly called out by Kristy, who says, "Stacey's so weird about food and dieting… What is it with her anyway?" (116). This question directly calls upon the reader to evaluate Stacey's behavior.

Stacey's repeated avoidance of sugar could signal a character who is health conscious and cares about nutrition. Instead, however, Stacey's repeated refusal of junk food appears odd because it is juxtaposed against Kristy's behavior—which includes pairing Twinkies with fried chicken during a family dinner. Furthermore, Kristy's food choice in this dinner scene is normalized through her family's reaction. When her mother admonishes Kristy to "Eat your Twinkies and fried chicken" (Martin, *Kristy's* 109), everyone at the table laughs. Although their laughter signals the absurdity of being ordered to eat a Twinkie, the order stands. No one asks Kristy to save her Twinkies for later, or to add a helping of fruits and vegetables to her plate. The

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[25] A strong link between Stacey's disability and sugar is suggested by the cover art for BSC #3, *The Truth About Stacey*, and BSC #43, *Stacey's Emergency*, two stories in which diabetes is integral to the plot (see Appendix B, figs. 1-5).

[26] My reading in this essay treats the "Gummi Bear scene" as a material metaphor for Stacey's aversion to sugar, but a more literal reading is that the author intends this to be a false clue that steers readers toward a Red Herring diagnosis of an eating disorder. The reason Stacey runs home is never clarified later on, but it can be presumed that she leaves to inject herself with insulin. This is partly proven by the fact that she clarifies to her friends that she forgot to *do* something. Being confronted with food could feasibly remind Stacey that she forgot insulin earlier in the day (as insulin is regularly administered at meal times). Also, once Stacey's diabetes is revealed to her friends, the series establishes that she always injects insulin in private. Because Kristy later concludes that Stacey is anorexic, it can also be assumed that in the "Gummi Bear scene" Kristy thinks Stacey runs from the room to induce vomiting.

lack of parental direction in this scene affirms that Kristy's food choices may be comical, but they are not a cause for concern because they reflect normal teen eating habits.

Frequent mentions of candy shared during club meetings makes the consumption of junk food an integral part of the girls' interactions with one another. But, as I demonstrated in the previous paragraph, Stacey always deviates from the other girls' "normal," unrestrained interactions with junk food—even to the point of literally running out of the room. Strikingly, it is Claudia (whose body induces anxiety and with whom Stacey is often paired) who becomes a purveyor of unhealthy, sugary snacks. An excellent example of this occurs during a planning session as the girls form their new babysitting club:

> Claudia gave her the thumbs-up sign. Then she pulled a package of peanut M&M's from under her pillow. "We should celebrate," she said, handing the candy around.
>
> Mary Anne and I were starved and each gobbled down a handful, but Stacey just glanced in the package and then passed it back to Claudia. "These are—you've only got five left," she said.
>
> "Oh, go ahead," replied Claudia. "I've got lots of stuff stashed away. Mom and Dad don't know about it." She said she had bubble gum in her underwear drawer, a chocolate bar behind her encyclopedias, a package of Twinkies in her desk drawer, and some Wint-o-green Lifesavers in her piggy bank. (Martin 35-6)

Claudia's role in this scene, works to relieve some of the earlier anxiety caused by her body. Her full participation in the ritual of teenage snacking allows her character to be partly recuperated. The social experience of eating together endears Claudia to the group; her stash of hidden treats also demonstrates that she will go to great lengths to be of service to her friends. But for

Stacey—who continues to avoid sugar—there is no such recuperation. Frequent interactions with food are a source of further alienation and social isolation for her character.

The suggestion of social isolation caused by her Type 1 diabetes (i.e., the absence of normalcy) is reinforced by a pre-diagnosis memory Stacey shares, in which she and her former best friend enjoy eating chocolate together. By the end of the first book in the series, *Kristy's Great Idea*, Stacey's close friends are aware that she is diabetic. They are used to Stacey passing on sweet snacks shared during club meetings in accordance with her no-sugar diet. Their familiarity with Stacey's extreme sugar aversion is what causes their shock when Stacey excitedly shares a happy pre-diagnosis memory of spending time with her friend Laine in New York: "I loved to go to [Laine's] apartment because her mother would buy Milky Way bars and keep them in the freezer. Biting into one of those was like biting into a frozen chocolate milk sha—Oh well, that was *before* I got sick" (Martin, *Truth* [1986] 32). The stares of the other girls, who did not know Stacey before her diagnosis, remind her of her present reality, in which she is insulin dependent and sugar is taboo. The memory of eating candy bars with Laine in New York shows a direct connection between Stacey's past happiness (before her diagnosis) and unrestrained access to sweet foods. The abrupt way that Stacey concludes this memory mirrors the suddenness of her diagnosis. It symbolizes a profound shift in her relationship to her food, and thereby the way that she relates to her peers.

Stacey's fixation on sweets is significant because it adds a layer of complexity to an argument shared by Anne Hazell, whose research suggests that it is unique for middle-class adolescent characters to care deeply about food. In her study of 1990s adolescent fiction, Hazell notes that in real and fictional middle-class worlds, such as the one that Stacey lives in, "food is of little importance, as long as it appears at regular intervals, with minimum effort on the part of the teenager" (151).[27] Hazell observes a heightened importance of food in stories that fit one of three categories: "where the setting is financially depressed rural areas; in single parent and/or dysfunctional families; and in stories about street kids" (153). However, as I demonstrate repeatedly throughout this chapter, food *is* important for Stacey, a middle-class girl living a comfortable life in the suburbs.[28] Hazell connects her findings on the basis of economics (156); however, I think the three categories that she describes are connected by more than economics. Thus, using Hazell's findings I propose that Stacey's fixation upon food acts as a material metaphor that represents profound loss.

For Stacey, sugary foods hold two symbolic meanings that are at odds with one another, but which are connected by feelings of loss. First, sugary foods represent carefree interactions with friends in Stacey's pre-diagnosis life in New York. This is a bittersweet connection because it brings up feelings of nostalgia (such as the memory with Laine and the frozen candy bars), but the memory is tainted by the reality that Stacey cannot relive those moments. Second, in the post-diagnosis present, sugary foods represent an unbreachable barrier between Stacey and the rest of the BSC. The frequent pairing of sugary foods with moments of social bonding in the BSC series leads to a pattern of missed opportunities for social and emotional connections. Every time sweet foods are passed around at BSC meetings, Stacey experiences a new loss. In BSC #3, Stacey stands outside of a candy shop with Charlotte (a little girl she babysits) and thinks to herself:

> The inside smelled of chocolate, and much more—ginger and cinnamon and licorice and marzipan and cream and raspberry filling and roasted nuts and raisins

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[27] Although Hazell's study, "Meals in Minutes: Food in Contemporary Australian Adolescent Fiction," focuses only on books published in Australia, the theme of her work—and the fact that she is looking at adolescent books from the 1990s, the height of the BSC series, make her conclusions relevant to this chapter.

[28] In BSC #3, when Stacey shares the memory of the frozen Milky Way bars, her parents are still married. However, Stacey's parents eventually get divorced in BSC #28, *Welcome Back, Stacey!*

> and cherries and spun sugar. The air was heady and warm. It was almost more than I could stand. I tried to figure out how much it would hurt to have just one piece of white chocolate. (Martin, *Truth* [1986] 41)

Stacey's earlier claim, "I can't just snack whenever I feel like it… in fact, it's a good way to make myself sick" (25), makes it evident that the question of *how much it would hurt* relates to physical detriment. Stacey is weighing desire against self harm. But she is also weighing the possibility of a shared experience with Charlotte against the isolation perpetuated by a strict diet. For a moment, Stacey even places money on the counter of the candy shop, demonstrating the power of her desire. Ultimately, though, Stacey puts the money away and adheres to her no-sugar rule. As Stacey and Charlotte walk away from the candy shop, empty handed, Charlotte looks "longingly over her shoulder," as if to draw the reader's attention to the loss of happy memories that could have been.

The themes of loss and isolation in connection with sugar are made painfully clear by the cover image of BSC #43, *Stacey's Emergency*, where Stacey is at the epicenter of a chaotic kitchen scene.[29] She leans over a counter that is covered in baking paraphernalia and smeared with chocolate. Her mouth hangs open in an expression of terror as she reaches for a bowl sloshing with liquid as it tips over the counter's edge. Written over this image is the biting tagline: "Stacey just can't win." The chaos surrounding Stacey is amplified by the juxtaposition with two other girls, one on either side of her, who appear to have the control that she lacks. These younger girls appear smiling, composed, and balancing plates of neatly stacked baked goods. The obvious reference of "Stacey just can't win" is to the scene in the kitchen, where Stacey appears momentarily out of control. The subtext, though, is that Stacey is unable to control her desire for sugar and therefore cannot control her diabetes. This reading of the subtext

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[29] See Appendix B, fig. 5.

is supported by the plot of BSC #43, in which Stacey breaks her strict no-sugar diet and sneaks chocolate for the first time since her diagnosis. When confronted with sugar on the book's cover, the two "healthy" girls and their "normal" bodies epitomize control and composure, but Stacey's diabetic body becomes a transmitter of chaos.

## Stacey Just Can't Win

Stacey's loss (vis-à-vis her diagnosis) is what necessitates food control in her life, but food control ultimately perpetuates her feelings of loss by isolating her in social situations. The linking of loss (i.e., sugar and what it symbolizes) and control, or lack of control, is an essential aspect of Stacey's diabetes narrative. Multiple moments in the BSC series demonstrate Stacey's loss of social connection (her isolation) due to an emphasis on strict food control, but BSC #43 further complicates the relationship between loss and control by suggesting that Stacey's profound feelings of loss prompt her to give up control over her diet and thereby lose control of her blood sugar. In a moment of exasperation, she reveals the extreme exhaustion and isolation she feels as a result of her diet. She tells the reader: "I was sick and tired of being sick and tired. Nobody else I knew had to stick to a diet like me" (Martin, *Stacey's* 37). The first part of this confession has a meaning that is twofold. Stacey is sick and tired of her diabetes, but she is also literally sick and tired from symptoms of diabetic ketoacidosis (DKA) that she is experiencing at the start of BSC #43 (3).[30] Stacey's next choice reveals how the emotional distress of her diet outweighs the physical toll of the DKA symptoms.[31] Shortly after confessing that she is "sick and tired" of her diet, Stacey cheats and eats chocolate for the first time since her diagnosis.

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[30] DKA is a constant threat for people living with Type 1 diabetes. It is a life-threatening condition caused by too little insulin in the body. If left untreated, DKA can result in coma or death. People with undiagnosed Type 1, or people with Type 1 who are ill are at an increased risk for developing DKA.

[31] Increased hunger can also be a symptom of DKA, but Stacey's craving for chocolate is very specific. Therefore, her choice to eat chocolate, a food which she knows is forbidden, suggests a lack of self control more than it suggests hunger caused by DKA.

Paradoxically, Stacey's abandonment of her diet (the very source of her social-emotional isolation) isolates her even further. The control she gives up to be "normal" and enjoy chocolate like her friends results in her hospitalization. In fact, Stacey narrates more than half of BSC #43 from a hospital bed. While at the hospital, Stacey's lack of control is emphasized when a doctor visits her room with a group of medical residents. Stacey tells the reader:

> The doctor greeted me, then turned back to his class. 'This patient,' he said, 'is a thirteen-year-old girl' (he didn't even use my name!) 'with juvenile onset of diabetes. She was hospitalized last Saturday, at which time she was found to have an abnormally high blood sugar level, despite the fact that she's been taking insulin and has been on a strict diet since she was first diagnosed. . . (Martin, *Stacey's Emergency* 80)

The doctor's failure to name Stacey, and his use of the word "abnormal" further alienate her by dehumanizing her. Furthermore, the assertion that her high blood sugar is "abnormal," despite her management routine, might suggest that "normal blood sugars" (i.e., perfect control) is possible for a person with T1D. In fact, there is nothing abnormal about a person with diabetes experiencing high blood sugar. Even a person with excellent control of their T1D cannot prevent every high and every low. The impossibility of perfect control is why diabetes educator Gary Scheiner includes the Serenity Prayer in his field guide for living with T1D: *Think Like a Pancreas* (2011). Scheiner writes, "The Serenity Prayer reminds us that not everything is within our control" (100). The scene with Stacey's doctor, however, seems to suggest that her high blood sugar is somewhat of a mystery. He presents it as an odd reaction to the prescribed treatment, of diet and insulin, and not a normal part of life with T1D. As the book cover of BSC #43 suggests, Stacey "can't win." Either she is in control of her diet and diabetes, which leads to emotional isolation, or her diabetes and diet are out of control and she is physically isolated and deemed “abnormal.”

Perhaps the most perplexing detail in the plot of BSC #43, however, is the introduction of the phrase “brittle diabetes.”[32] The introduction of “brittle” diabetes in BSC #43 suggests that Stacey’s diabetes is difficult to control, a point which starkly contrasts the evidence from the rest of the BSC series. Up until BSC #43, the reader is led to believe that if Stacey follows her diabetes management routine, her diabetes will not pose any problems for her. This is evidenced by a supreme lack of high or low blood sugar episodes throughout the series. Instead of hypo- and hyperglycemia being normalized, these events are specifically tied to plots revolving around extreme emergencies, such as Stacey’s diagnosis in BSC #3, or her hospitalization for what readers may presume to be DKA in BSC #43.[33] This dual portrayal of the out-of-control brittle diabetic and the well-controlled, sugar averse diabetic creates conflict in how the reader might be assumed to interpret the problems that Stacey encounters in *Stacey’s Emergency*.

The plot of BSC #43 confusingly permits Stacey to have poorly controlled diabetes, while also simultaneously insinuating that Stacey may be to blame for her high blood sugar because she cheats on her diet. Stacey’s “brittle” diabetes and the fact that DKA symptoms appear *before* she cheats on her diet are details that both imply perfect adherence to a diet is not enough to control diabetes. This is why the copious amounts of chocolate that she secretly consumes in Chapters 4-6 creates confusion for the reader. At this point in the series, readers are fully aware that Stacey cannot eat sugar because it is “dangerous” for her. The “uncovered”

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[32] It is my personal opinion that Ann M. Martin’s use of the term “brittle” diabetes within the BSC series is highly problematic. As Professor Stephanie Amiel explains in the article “Brittle” Diabetes: Usually Settles Down” (1991), diabetic brittleness (sudden swings from high to low blood sugar) can exist at certain intervals of time (e.g., adolescence), but the term is mostly overused in attempts to rationalize glycemic control. According to Amiel, there are very few people who truly have “brittle” diabetes and when the diabetes is “brittle” this brittleness may be attributed to factors secondary to Type 1 diabetes.

[33] The text never directly states that Stacey has diabetic ketoacidosis, but all of her symptoms suggest this diagnosis.

chocolate that Stacey sneaks has a compounding effect on her already elevated blood sugar levels and it damages her credibility as a narrator.[34] The primary plot of BSC #43 is that Stacey's body is slowly deteriorating from high blood sugar (presumably DKA), but the secondary plot involving her diet redirects the responsibility for blood sugar control to Stacey and her control of food. Ultimately, even if the onset of Stacey's persistent high blood sugar can be attributed to "brittle" diabetes, it is also equally true that she can be held partly responsible for exacerbating her symptoms. Even when the presumed volatility of Stacey's disease is acknowledged, as in BSC #43, she is still held responsible for being in control.

### Public Dieting, Private Injections: Hiding the "Gross" Diabetes Identity

Even though Stacey narrates with confidence regarding the medical aspects of her diagnosis, she often appears insecure with the idea of engaging in public behavior that might signal she is diabetic. The first time that Stacey declines candy during a BSC meeting, Kristy's immediate skepticism proves to the reader that more analysis is needed: a puzzle needs to be solved. Kristy's reaction is a response to the novel's established viewpoint that normal teenage girls do *not* pass on free candy. In this moment, which takes place in BSC #1, Stacey could have disclosed that she has Type 1 diabetes. However, instead she chooses to respond vaguely. She tells Kristy and the other club members that she is on *a diet,* but she does not go into any details about what kind of diet—or why (Martin, *Kristy's* 36). Although Kristy expresses further concern in this scene, because she believes that Stacey is "too skinny" to be dieting, Stacey's choice to employ the word *diet* represents a desire to appear normal. Even though dieting for teens can sometimes signal an eating disorder (as Kristy points out later on) Stacey uses the word "diet" to appear *healthy* and *normal*. Unlike insulin injections—which almost exclusively signal

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[34] "Uncovered" refers to the fact that Stacey has not "covered" for her food by taking the appropriate amount of insulin. Food eaten without insulin is often referred to as "uncovered" or "free."

diabetes treatment—dieting has a range of interpretations. For Stacey, disclosing that she is on a diet does not necessarily indicate that she has a diagnosis of any kind. The word *diet* can also allude to more nutritious eating choices out of a desire to be health conscious.

Dieting and food control as the only visible sign of diabetes is a theme that begins with *Kristy's Great Idea* (BSC #1) and is repeated in *The Truth About Stacey* (BSC #3) and *Stacey's Emergency* (BSC #43). Although these books clearly demonstrate the classic symptoms of Type 1 diabetes, along with the serious risks of the disease, readers are rarely (if ever, depending on the publication year of the book) exposed to Stacey's daily management routine.[35] In Stacey's narration, she prioritizes the diagnosis story, which all three books summarize. For example, in *The Truth About Stacey* she lists off the symptoms she experienced, along with some of the false conclusions her parents initially arrived at (such as an eating disorder) (Martin, *The Truth* [1986] 16).[36] All of the symptoms that Stacey lists off in her diagnosis memories are classic markers of untreated Type 1: bed wetting, increased thirst or hunger, and unexplained weight loss (JDRF). Stacey also provides a detailed medical definition of diabetes and explains that when a pancreas stops producing insulin, sugar builds up in the blood and makes a person sick—resulting in death if treatment does not begin (17).

These lists serve the dual purpose of informing the public and connecting with readers who have experienced a diabetes diagnosis. In fact, an 11-year-old reader once wrote to the author, Ann M. Martin, and told her that reading about Stacey helped her to recognize her own symptoms and get a diagnosis before she became dangerously ill (Becker 154). In contrast to these detailed descriptions of diagnosis, however, Stacey shows the reader very little of her

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[35] In Chapter Thirteen of *The Truth About Stacey*, a dinner scene at the house of Stacey's friend Laine contains some information about an insulin injection, but this scene is altered in a later edition (1995), resulting in readers receiving even less information regarding Stacey's meal-time insulin routine.

[36] With Type 1, it is common for symptoms to be confused with the flu or another disease.

day-to-day diabetes regimen. Although Stacey *tells* the reader that she tests her blood sugar and injects insulin, these three texts provide little (if any) tangible evidence of her actually performing those actions. The reader never witnesses an injection, nor does Stacey describe what her insulin looks like, where she stores it, what it feels like under her skin, etc. Stacey also does not share that it is necessary for a diabetic to "rotate" injection sites—an important detail for a person who relies on insulin injections to live.

In fact, *The Truth About Stacey* paints a confusing, self-stigmatizing disability narrative when comparing the original text from 1986 and an updated version published in 1995. In the 1986 text, Stacey explains her condition this way:

> I had to learn to give myself injections. I didn't like it then and I don't like it now, but it's better than being tied to my parents—or dying. The one thing I will never do, though, is let my new friends in Stoneybrook see me give myself an injection. It's just too gross. And the truth is, every time I give myself one, I feel like a very sick person—just for a few moments. And I never want my friends to think the same thing, whether it's the truth or not. (Martin, *The Truth* [1986] 18-19)

In the above passage, Stacey exhibits a troubling personal disdain for her condition that problematically pits her against her disease, which is presented as shameful for its association with sickness. Stacey's negative views of her own treatment are passed onto the reader who is given implicit permission to agree with Stacey that injecting insulin is "gross" and a symbol of sickness, as opposed to a normalized part of the treatment that keeps her healthy. Additionally, Stacey's refusal to *ever* inject insulin in front of her friends promotes the idea that diabetes treatment should be conducted behind closed doors. That refusal reinforces her opinion that injections are gross (thus the need to keep them private). As the person experiencing the injection, Stacey is the text's ultimate authority on all things diabetes. It is through Stacey that readers understand how diabetes management should be viewed, and she is in the best position to normalize her condition. However, even though she has been living with diabetes for six months at this point in the story, and has performed countless routine injections, Stacey's view of injections as "gross" parallels views typical of uninformed outsiders, such as Kristy.[37]

Stacey fixates on the *appearance* of insulin injections and not what they do for her. First, Stacey stigmatizes her own treatment by referring to injections as "gross." For a Type 1 diabetic, injections are a normal, necessary part of treatment. These injections literally keep Stacey alive because her body no longer makes insulin on its own. Then, Stacey goes on to tell readers that every time she injects herself she "feel[s] like a very sick person." Again, the emphasis is upon appearances. Insulin prevents Stacey from becoming critically ill. The injection doesn't make her feel physically ill. It's the perception of illness that troubles her. From the point of view of a diabetic, insulin could be a symbol of health and vitality. It is her body's inability to produce insulin, after all, that leads to Stacey's unexplained weight loss and diagnosis. While Stacey understands that "If you don't treat diabetes properly you could *die*" (Martin, *The Truth* [1986] 17), her fears of being perceived as sick prevent her from taking steps to normalize her diabetes routine.

This fear of being looked at as diabetic is most evident when Stacey declares that she will *never* inject insulin in front of her peers. She tells readers, "The one thing I will never do, though, is let my new friends in Stoneybrook see me give myself an injection" (Martin, *The Truth* [1986] 18). This statement is problematic for two main reasons: (1) Stacey is the text's authority on diabetes—the one providing readers with symptoms and medical treatments—and

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[37] Although Kristy has a cousin with Type 1 diabetes, and is able to regurgitate a basic medical definition of diabetes (Martin, *Kristy's* [1986] 150) her initial assumption that Stacey has an eating disorder suggests a limited awareness.

here she condones the stigmatization of injections; (2) it creates an impractical barrier between Stacey and her friends. Injections are a non-negotiable part of Stacey's disability identity; by insisting that injections remain private, Stacey is severely limiting her ability to interact with her peers. Ultimately, Stacey's insistence on passing as non-diabetic, even in front of her closest friends, reveals her failure to accept her illness. If Stacey cannot reconcile the acceptability of her insulin injections, how can she expect her friends to do so?

The overriding message to the reader is that this element of diabetes care is (at a minimum) something private or (to the extreme) a source of shame. It is impossible to say how Stacey's friends would react to witnessing an insulin injection because neither they, nor the reader, ever witnesses an injection. In the original text for *The Truth About Stacey*, Stacey tells the reader during a dinner scene at her friend Laine's house: "When I needed to give myself an injection of insulin, I did it quickly in the bathroom," (Martin, *The Truth* [1986] 142). Confusingly, she does not contextualize this information for the reader. Why is she going to the bathroom to give herself insulin? Does she always go to the bathroom to administer an injection? Or—is she living up to her vow to *never* inject insulin in front of friends? (18) More importantly, though, Stacey does not allow the reader to follow her. What happens behind the closed bathroom door remains as much of a mystery to the reader as it does to the other characters in the book, whom Stacey walks away from at the dinner table so that she can inject in private. From her secretive behavior, the reader might infer that Stacey is embarrassed, or feeling shame.

The shame implied by keeping insulin therapy a private affair continues in the 1995 updated edition of *The Truth About Stacey.* This continued secrecy reinforces Stacey's desire to appear normal through the suppression of her diabetes identity—which she associates with sickness and being gross. In the scene with Laine's family, 1995 Stacey wears an insulin pump, which she "keeps out of sight" (Martin, *The Truth* [1995] 141). The addition of the pump brings Stacey's diabetes treatment up to date with treatments available the year the reprint was released (Kesavadev et al. 1257).[38] Again, though, Stacey's desire for privacy is made apparent by the fact that the pump is hidden, and by the details she omits. Readers are left in the dark regarding specific information such as what the pump looks like or how insulin is administered.

In this revised version of the text, the interaction with the pump is arguably less clear than the injection Stacey gave herself before dinner in the 1986 edition. For example, it is not even mentioned if Stacey *uses* the pump. She tells the reader only that the pump is kept concealed. But what does she do with it? And when? The introduction of the insulin pump may modernize the scene, but it raises more questions than it answers. Readers never learn where the pump is located on Stacey's body. Also, she does not provide details that would allow the reader to fully grasp the meaning of concealment, such as the size of the pump. Again, the overriding idea is that administering insulin is a private affair—so private that Stacey does not even dare narrate about it in an internal monologue. Even though the reader and everyone in the dinner scene already knows Stacey is diabetic, she appears ill at ease with her diagnosis. Is this because she is embarrassed? Has she internalized the idea that injections are "gross?" What Stacey *is* willing to show the reader, over and over again, is how she interacts with food. In this way, she presents dieting—which is arguably more normal than public injections—as a more acceptable identity that is detached from potential feelings of shame.

Another update to the 1995 edition of *The Truth About Stacey,* is that Stacey's description of her diabetes treatment is rewritten using softer language that places Stacey on the path toward

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[38] The very first insulin pump was introduced in the 1970s, but at this time they were too large and cumbersome for outpatient treatment. The first pump was the size of a backpack. The first compact pumps were released in the 1990s. By 1995, the year *The Truth About Stacey* was updated to include an insulin pump, subcutaneous insulin therapy (insulin delivery with a pump) had undergone multiple technological improvements (Kesavadev et al. 1257).

illness acceptance. The reason for these updates to the text may reflect changing public perceptions regarding disabilities after the 1990 passing of the Americans with Disabilities Act, a federal ruling which prohibits discrimination on the basis of disability. In the revised scene, Stacey no longer refers to her injections as *gross*, and she no longer works hard to keep her injections a secret from her friends:

> [Diabetes management] was a lot of responsibility. I would have to watch what I ate and make sure I was getting the right amount of insulin. As much as they wanted to, Mom or Dad couldn't always do that for me. Still, I feel weird having to check (or sometimes inject) insulin in front of my friends. I don't like the thought of them thinking I'm sick. (Martin, *The Truth* [1995] 18)

Stacey's tone in 1995 is much softer, and less critical, than in 1986. In referring to her injections she replaces the word "gross" with the word "weird," a word which indicates *strange* or *different*, but doesn't have the same direct association with outright disgust. Also, Stacey is less adamant in her insistence to keep injections private. Instead of *never* injecting in front of her friends, Stacey concedes that *sometimes* doing so is necessary. This concession shows that Stacey is taking steps to normalize her treatment by integrating it into her everyday life. These two revisions to the original text are a step in the right direction, but they do little to correct the undertone of disability shame created by Stacey's constant desire to hide her diabetes management.

In *Stacey's Emergency*, another book in which diabetes is central to the plot, the presumption of shame is evident once again when the word *gross* reappears in conjunction with injections. However, a slight change in syntax reframes the disability narrative from one from self-disgust to one of self-doubt, or a fear of social rejection. In the opening chapter of BSC #43, the word *gross* appears when Stacey explains to readers why it is necessary for her to inject insulin: “Some people just stick to a low-sugar diet. Other people have to have injections every day. (I’m one of those people. I know giving yourself shots sounds gross, but the shots save my life)” (Martin, *Stacey’s Emergency* 2). This quote represents a slight shift from Stacey’s diagnosis story in BSC #3 where she stigmatized her own behavior as “gross.” In *Stacey’s Emergency*, she attributes the word “gross” to the sentiments of other people, freeing her character to hold an alternative view. Gross is no longer used to explicitly describe how Stacey feels about injections; instead it reflects Stacey’s perception of other people's views. Furthermore, she defends the act of injections by describing them as “life-saving.” This minor addition to Stacey’s explanation of her routine defends the act of the injection (even if the reader deems it gross) by highlighting its necessity and its positive effect on her health.

**Conclusion**

Ann M. Martin’s three books, *Kristy’s Great Idea*, *The Truth About Stacey, and Stacey’s Emergency*, reveal a desire for normalcy at the cost of othering and stigmatizing the management elements that are an essential part of life with Type 1 diabetes. Although readers are taught to recognize the warning signs of Type 1 diabetes, they never see Stacey pricking her finger to check blood sugar, treating hypoglycemia with a sugary snack, or injecting herself with insulin. While Stacey may talk about the necessity of doing these things, the reader rarely (if ever) witnesses her *doing* them—even when she is alone.[39] Instead, Stacey’s secrecy regarding her day-to-day diabetes regimen can be read as her agreement with the assertion in BSC #3 and BSC #43 that the more innately diabetic aspects of her treatment, such as injections, are “gross.”

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[39] While I have yet to find a single example of Stacey performing a blood test or an insulin injection “in front of” the reader, my survey of the BSC series is ongoing. I have read beyond the three books outlined in this chapter, but I have not read every book in the series, of which there are more than 150.

Stacey explains that she prefers not to inject insulin in front of her friends, because *they* might think it is gross or *they* might perceive her as ill—but even when she is narrating alone, or when she is in the safety of her own home, the primary evidence of diabetes management appears in the form of a strict exchange diet. What these three texts show is a girl with Type 1 diabetes whose diagnosis is the root of an extreme aversion to sugar that creates a social wedge between her and her friends. This repeated emphasis on diet control is reminiscent of an outdated diabetes management strategy that was common in the 1980s; but when presented alongside Stacey's diabetes secrecy, the focus on food also points to Stacey's insecurity. Stacey's decision to keep her injections and blood tests private, even from close friends and family, sends a message to the reader that some aspects of diabetes are shameful or embarrassing.

Although I have found no published analysis of Type 1 diabetes in adolescent literature, a 2022 article published in the *Canadian Journal of Diabetes* also makes note of T1D's common association in film and television with shame. As Alexandra Katz et al. point out in their study of T1D representations in North American media—(which includes the Netflix revival of the Baby-Sitters Club),

> The majority of the media [for youth] depicts characters with T1D as being ashamed of their disease…although these storylines do not expose the audience to any danger and end with the character finally being accepted by their peers and family, the productions still demonstrate the embarrassment of the character living with T1D, including the need for external validation and acceptance. (1-2)

Stacey's hesitation to share her disability status, and her frequent insistence on diabetes secrecy even after her diagnosis is known reflects an unhealthy desire to appear "normal."

I want to emphasize that I do not think fictional characters with T1D need to showcase their diabetes all of the time. This tactic can prove counterproductive by making a story all about the disability instead of a story about a character *with* a disability. The occasional reference to normal diabetes routines, however, can help normalize these behaviors as a typical part of life with T1D. Additionally, children's literature can help to normalize the futility of complete glucose control, rather than emphasizing good control as a sign of normalcy. For a person living with diabetes, "normal" should be inclusive of shots, finger pricks, and the treatment of high and low blood sugar. In the words of playwright Robert Harling, whose sister was diabetic, low blood sugar should be responded to with "no alarm, just efficient action" (26).[40] The lack of alarm underscores the normality of situations requiring urgency. Sequestering Stacey's diabetes stories to books revolving around urgency (her diagnosis in BSC #3 and a phase of burnout in BSC #43) creates a false perception that Stacey is *usually* in full control of her diabetes. It is so much in the background of her story that, aside from her highly visible diet, she functions merely as a girl obsessed with her diet.

## Coda

In 2006, the first graphic novel adaptations of the Baby-Sitters Club books by Graphix Publishing were released, reimagining the BSC series for a new generation of readers. The graphic novels' preservation of Stacey's strict exchange diet reveals a close adherence to the original texts, which rarely mention blood tests or injections outside of a hospital setting.[41] Variations in the ways that different artists illustrate Stacey's insulin delivery device (insulin

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[40] These are the stage directions for M'Lynn, the mother of Shelby, a young bride in *Steel Magnolias* with Type 1 diabetes.When Shelby experiences hypoglycemia on stage, M'Lynn comes to her aid.

[41] The BSC graphic novels have been illustrated by various artists: Raina Telgemeier (books 1-4), Gale Galligan (books 5-8) Gabriela Epstein (books 9 and 11), Chan Chau (books 10 and 12), Cynthia Yuan Cheng (book 13), and Ellen Crenshaw (book 14).

injections vs. a pump) underscore the ambiguous nature of Stacey's insulin regimen in the original books.[42] Different artists interpret Stacey's treatment differently.

Rania Telgemeier's hip illustrations repackaged the first four books from the BSC series into a comic format that is gaining traction, even as print book sales dwindle: "In 2015, the North American comic-book industry raked in an estimated $ 1.03 billion from print and digital comic-book and graphic novel sales, a new twenty-year high… In a time when many lament the decline of the print book, comics maintains crucial attention to the book as object" (Chute 3). But while the BSC characters are updated to reflect modern hair and clothing styles, Stacey's relationship with food is still the same as it was in 1986. Hillary Chute, an expert on comics and graphic novels, writes about the power of images in disability stories: "Stories about illness and disability use the show-and-tell aspect of comics so basic to its hybrid form to reveal hard-to-convey truths about sickness or ability. . ." (239). According to Chute, then, the graphic novel should enhance our understanding of Type 1 by showing us the silent moments hidden between the lines of the text.

A strong example of "show and tell" can be found in *The Truth About Stacey*, which includes a full-page layout of Stacey's dinner plate (Martin [2015] 18).[43] Here, the image reveals what the original text does not. Readers are introduced to the word "exchange" in reference to Stacey's diet. Each item on the plate is labeled with a carbohydrate count, a calorie count, and an exchange label. This labeled dinner plate gives the reader a detailed glimpse into Stacey's life that is missing from the original book. This is what Chute refers to as a didactic diagram, which she says is a unique feature of comics that enhances the story and doesn't "feel disruptive in the flow of a page" (241). From Stacey's labeled plate, readers can see firsthand the detailed

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[42] See Appendix C, figs. 6 and 7.

[43] See Appendix C, fig. 8.

mathematical equations that accompany every meal she eats. They can better understand the weight of the word *can't* that Stacey uses when describing the limitations imposed upon her by her diet.

Stacey's strict diet is further reinforced by other scenes drawn from the original book, but what we see is a shift in tone where Telgemeier draws our attention to food as a social experience, one which Stacey often feels left out of. Food, particularly sweet food, makes frequent appearances on Telgemeier's illustrated pages of *The Truth About Stacey*, and each appearance is an opportunity for Stacey's diet to be showcased and for her to be excluded. At the first meeting of the BSC, Stacey responds to a friend's offer of candy by saying, "Um, my diabetes? I can't have one." While Stacey does not offer any internal dialogue at this moment, we can see the sad expression on her face as the candy is passed onto the next person and Stacey replies, "It's OK." The illustrations show us, however, that it is *not* OK. Stacey is shown holding her knees to her chest in a fetal position while the other girls in the room appear to be smiling and oblivious to Stacey's internal anguish (Martin [2015] 12).

These real-time interactions with food are often juxtaposed against flashback scenes, which include three elements: friendship, food, and happiness. More than once, Stacey simultaneously laments the loss of a friendship and her ability to freely enjoy sweets. In one flashback, Stacey and her friend Laine snack on frozen candy bars, and in another flashback they eat ice cream (24, 61). Although Stacey doesn't always offer the reader her thoughts in these moments, we can see the sad expression on her face in the present, which is juxtaposed against the smiling, carefree Stacey of the flashback scenes. Telgemeier's illustrations highlight a theme presented in the text: the intertwining of food and social experiences. Understanding this link between food and social acceptance makes it clear that Stacey's strict exchange diet imposes a barrier between her and the rest of the BSC. This fact is further reinforced by the 2015 cover image, which shows three members of the BSC gleefully enjoying a snack, while Stacey appears alone in the background with a wide-eyed expression on her face. Telgemeier's cover art forces readers to view Stacey's diet as more than just a diet; it is portrayed as a socially isolating experience.

The Netflix reboot of *The Baby-Sitters Club* television series (released between July 2020 and October 2021) maintains a strong emphasis on the connection between food and blood sugar levels, but it takes a more holistic approach than Telgemeier by exploring Stacey's experiences of both high *and* low blood sugar. Low blood sugar is a detail that is often neglected in the Baby-Sitters Club series, including the two books whose plots focus on diabetes issues: *The Truth About Stacey* (BSC #3) and *Stacey's Emergency* (BSC #43). The constant attention to food restrictions and dieting in these books overshadows the necessity of sugar in Stacey's life to stave off dangerous insulin reactions.[44] The necessity of sugar is briefly mentioned in *The Truth About Stacey*, but it is framed as a part of her normal meal routine: "I'm allowed a certain amount of sweet stuff each day… in order to maintain that delicate balance between food and insulin" (Martin [1986] 30). The use of the word *maintain* presents the "sweet stuff" in Stacey's diet as preventative, whereas treating hypoglycemia in real life is often reactionary. Increased activity levels, sickness, stress and a myriad of other factors can influence the way that a body absorbs insulin, making the threat of hypoglycemia constant. In a sense, it is an always-planned-for event, but it is not always predictable. This is why it is so significant that on Netflix Stacey treats her low blood sugar in the middle of a babysitting job. The timing of this

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[44] While the use of insulin to treat diabetes is considered nothing short of a medical miracle, the use of insulin created new problems for patients, such as the risk of severe hypoglycemia (Feudtner 8-9). Too much insulin, the cause of hypoglycemia, can result in seizures, coma, or even death (JDRF).

event clues viewers into the unpredictable nature of low blood sugar. As Stacey explains, “I keep apple juice with me to elevate my blood sugar when I need it” (“The Truth About Stacey” 4:44).

Robin Benway, a children’s author who has lived with T1D for many years, was pleasantly surprised to see this scene of Stacey treating a low blood sugar event without fanfare. “And I, a woman in my early forties, sat on my couch and sobbed because this was the first time I’d seen someone do what I do: save my own life and keep on living,” she said. Benway’s emotional response reveals a deeply rooted desire to see the everyday aspects of her disease, such as calmly treating a low blood sugar, portrayed in the media. Through Stacey’s character, Netflix normalizes the diabetic’s lifestyle by making it common practice for anyone who is Type 1 to carry sugary snacks.

In addition to normalizing the relationship between sugar and diabetes management, Netflix also draws upon the contemporary trend of cyber bullying to make Stacey’s secrecy regarding her illness relatable to a modern audience. For teens managing chronic illnesses today, social media can provide a system of support, but it can also be an arena of trepidation where teasing and harassment occur. In episode three, “The Truth About Stacey,” Stacey reveals that a video of her experiencing a seizure at school (the result of insulin shock at the start of her diagnosis) was shared online and went viral (15:43-16:43). Stacey explains that this viral video was the impetus for her family’s move from New York to Connecticut, and also the reason she kept her diabetes a secret from her new friends.

Reframing Stacey’s identity conflict as a response to cyberbullying makes her struggle relatable for contemporary adolescents with disabilities. A 2020 qualitative study of social media use by thirty-five teens with Type 1 found that participants who openly shared about their diabetes online were extremely conscious of how and when health information was shared. One

16-year-old diabetic said, “Like if I meet a new person, [diabetes] won’t be the first thing I talk about” (Chalmers et al. 4). The study also touched on the use of humor as a strategy for building connections and discouraging online harassment. A fifteen-year-old male participant said, “[I post] lots of jokes about it so I can kinda make it seem like it’s less of a big deal and kinda normalize it. . . I just have to eliminate that chance [of bullying] by like making fun of me before they do” (3). These insights from teens in 2020 align with Stacey’s initial decision to keep her diagnosis a secret from her BSC friends.

Stacey’s inner conflict in the Netflix series, whether to disclose her disability or pass as “normal,” reflects the original text’s desire for normalcy; however, the reason for desiring normalcy is reframed in a way that shifts the source of diabetes’ stigmatization away from Stacey’s view of herself. This marks a significant change in the disability narrative. Instead of Stacey labeling her own treatment as “gross,” as she does several times in Martin’s original books, in the Netflix series Stacey strives to appear normal in order to avoid cyberbullying. As discussed in the previous two paragraphs, this is a *real* fear for Stacey, because she experienced an extreme, viral version of bullying in New York. The addition of the viral cyberbullying video to the show’s storyline brings the BSC’s portrayal of diabetes sharply into the twenty-first century. It opens discourse around how technology exacerbates bullying for teens with disabilities, and, perhaps more importantly, it redirects Stacey’s fear of disclosure away from negative feelings of her own body and toward a specific social issue.

## Chapter Two: The Tragic Future of the Type 1 Diabetic Girl in Teen Sick-Lit

In the introduction to this thesis, I refer to the work of Chris Saad, who notes that an overwhelming majority of fictional teenagers with chronic illnesses are female.[45] According to Saad, "This preponderance of ill female characters reflects the traditional societal view that female bodies are inherently pathological." In this chapter, I explore how teen sick-lit (a genre often guilty of exploiting feminine weakness) interacts with the Type 1 diagnosis narrative. I define teen sick-lit according to Julie Elman, author of *Chronic Youth* (2014):

> Often called "ten-hankie novels" or "tearjerkers," teen sick-lit utilizes a characteristic formula that combines an illness plotline with a romance plotline. The illness plot begins with a white teen girl's manifesting unexplained bruises or fatigue, which end up being symptoms of a chronic illness, such as cancer. During her treatment, the obligatory romance plotline begins, in which the ill girl's pursuit of a boy parallels and positively affects her process of "getting well." (94)[46]

In tandem with Elman's definition, a fictional Type 1 diagnosis story often begins with a young, White female's body deteriorating and her symptoms (such as unexplained weight loss and increased thirst) progressing until she is diagnosed with Type 1. Elman's analysis focuses almost exclusively on cancer narratives, specifically the *Dawn Rochelle* series by Lurlene McDaniel. While Elman mentions HIV/AIDs as another type of sick-lit narrative in a footnote (190), she does not clarify how she defines "chronic," nor does she refer to any other specific chronic illnesses and their treatment within teen sick-lit. According to the US Centers for Disease

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[45] Saad's work focuses on fictional books for adolescents published between 1970 and 1994.

[46] The emphasis on "getting well" is in the original text. Elman does not clarify why this phrase is in quotations, but it can be presumed that because it is paired with conditions labeled "chronic," the implication is that *well* implies "better" or "improved," but not necessarily "cured." This may also be a reference to the fact that "well" may be an improved spiritual state, and not a physical healing.

Control and Prevention, “chronic” is a broad term that is used to define illnesses lasting for one year or more (“About Chronic Diseases”). A similar definition is adopted by Chris Saad, who defines “chronic” as “a protracted (lasting for at least one year) physical disorder that is progressive or changeable.” In this chapter, I intersect Saad’s definition of “chronic” with Elman’s analysis of teen sick-lit to examine books with Type 1 diabetic protagonists. While Elman’s work has broad implications for my discussion of Type 1 within teen sick-lit, it is important to note that “chronic” only refers to the lasting nature of an illness, but says nothing about the symptoms or the day-to-day management.

Since teen sick-lit is such a small genre, I feel confident in stating that when a Type 1 diagnosis story intersects with teen sick-lit, the protagonist learns to accept and care for her diabetes with the help of a male love interest.[47] This *male* love interest is often presented as both physically and mentally superior to the *female* protagonist who is doubly weak: first by her gender, and then by her chronic illness. Type 1 teen sick-lit stories lean heavily into their amorous plots, often imposing romantic tension upon moments of diabetes caregiving.

Although John Green’s *The Fault in Our Stars* (2012) is often cited as the pinnacle of sick-lit (MacDonald 2014; Nykvist 2016), in this chapter I refer to Elman’s research, which suggests that sick-lit has roots further back—in the 1980s. Furthermore, I agree with Elman’s

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[47] Two other YA novels that emulate these patterns, all or in part, can be recognized in Jolene B. Perry’s *The Summer I Found You* (2014) and Pete Hautman’s *Sweetblood* (2003). Perry’s book closely follows the pattern of introducing the recuperated male character (what op de Beeck refers to as the “special protector”) at the time of the female’s diagnosis. *The Summer I Found You* follows the story of Kate, a high school senior who struggles with a recent diagnosis of Type 1 diabetes, until she meets a young, male army veteran who sustained permanent physical injury during the war. Through Kate’s romantic relationship with this young man, she is able to come to terms with her diabetes diagnosis. *Sweetblood* is the focus of the next chapter of this thesis, but I want to mention it here as well to point out that it also includes an arrival of a “special protector” at the moment of diagnosis. Hautman’s novel follows the story of Lucy Szabo, a teenager who has lived with Type 1 for several years and becomes complacent in her care—resulting in heart failure and hospitalization. Although Lucy’s story is not sick-lit per se, because it lacks an overtone of teen romance, Lucy’s best friend Mark fits the role of the special protector. A flashback scene describes how Mark discovered Lucy lying unconscious in the woods, before her diabetes was diagnosed. Just as Zie claims that Nolan “saved” her life, Lucy literally owes her life to Mark—making her future dependent upon his past decisions.

stance in her monograph *Chronic Youth* (2014) where she states that sick-lit is often "ableist" and "antifeminist," terms she uses to describe the work of Lurlene McDaniel, whom Elman refers to as the most "prolific" sick-lit author in American publishing history (125).[48] In this chapter, I argue that these patterns of sexism and ableism continue to emerge when realistic fiction mixes teen romance with a female protagonist's Type 1 diagnosis. To demonstrate my argument, I interrogate two T1D teen sick-lit novels published almost forty years apart. Lurlene McDaniel's *Will I Ever Dance Again?* (1982) establishes a precedent of employing a recuperated male body in order to save a weaker female body, which is perpetuated by later T1D narratives, such as Sarah White's *Let Me List the Ways* (2018). In both of these books, the agency of the female T1D protagonist is threatened and undermined through the prescription of a male love interest as the key to the Type 1 teen girl's future happiness.

Arguably, the first T1D sick-lit novel was written in 1982 by Lurlene McDaniel, whom many critics of adolescent literature refer to as "the queen of sick-lit."[49] As noted in the introduction, I follow Elman in defining teen sick-lit as a diagnosis story that intersects with a romantic plotline. The story begins with a teen girl, usually White, experiencing symptoms of illness that eventually lead to a diagnosis of chronic illness. The diagnosis story is paralleled by a romance in which a teen boy helps the ill girl to achieve some form of physical or spiritual wellness. McDaniel's first adolescent novel, *Will I Ever Dance Again?,* follows thirteen-year-old Rachel as she struggles to overcome the shock of a T1D diagnosis and return to ballet. When Rachel initially resents her diagnosis, her doctor introduces her to Shawn, a handsome, talented

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[48] *Washington Post* reporter Julie Weil agrees with Elman's assessment of McDaniel as a prolific author of YA sick-lit. In a 2018 news article covering McDaniel's transition to adult novels, Weil writes about the author's "thirty-five-year quest to make teens think about their vulnerability to death" and how she "has probably written more hospital-room scenes than any other writer for young people."

[49] One such reference to McDaniel as "the queen of sick-lit" can be found in issue 61 of the women's magazine *Bust*. Writer Marni Grossman assigns this title to McDaniel in pull-quote at the top of her article, "Die, Die My Darling" (57).

athlete who has “conquered” his T1D. With Shawn’s help, Rachel returns to dance. Almost four decades later, Sarah White’s *Let Me List the Ways* tells the story of Mackenzie “Zie” Clark, a high school senior who is secretly in love with her best friend, Nolan—a baseball player with a shoulder injury. Similarly to Rachel and Shawn, Zie’s romantic interest in Nolan coincides with her T1D diagnosis. She tells the reader that, “I was a sick child—and Nolan Walker had saved my life” (White 2). Although Zie’s story begins several years after her diagnosis, her story also reflects a theme of dependence. The young men on whom these T1D protagonists depend, Shawn and Nolan, both experience sickness or weakness, but they are shown to be *more* resilient and *more* self-reliant than their female counterparts. In *Will I Ever Dance Again?* and *Let Me List the Ways*, it is only through reliance on a young man’s masculine strength that the female T1D protagonist is able to thrive.

In this chapter, I analyze *Will I Ever Dance Again?* and *Let Me List the Ways* to demonstrate multiple ways in which the romantically attached teenage female with Type 1 diabetes is shown to be tragic, weak, and helpless. In both McDaniel’s and White’s novels, the T1D female protagonist is weakened by her adolescence, her disease, and by her juxtaposition against (and reliance upon) a male romantic interest. Applying David Mitchell and Susan Snyder’s criteria of “marked” (2000 ix) to the research of Julie Elman (2014) demonstrates how the T1D teenage female is also “marked” due to her adolescence—a condition which Elman refers to as “chronic.” Together, these “marked” elements work to undermine the adolescent T1D protagonist’s agency over her illness acceptance and her ability to imagine an independent future—all of which is exacerbated by the female T1D protagonist’s continued dependence on the validation and care of a male love interest.

My approach in analyzing *Will I Ever Dance Again?* and *Let Me List the Ways"* is to use a *feminist disability* lens, informed by Rosmarie Garland-Thomson's essay titled "Feminist Disability Studies" (2005). My work in this chapter uses Alison Kafer's argument (2013) of the tragic future disability implies to build upon the writings of Lois Keith (2001), whose book, *Take Up Thy Bed and Walk*, identifies disability in nineteenth century fiction for girls as "a metaphor for dependency and weakness" (14).[50] The final chapter of Keith's book looks toward the latter half of the twentieth century, and this is where my chapter begins—with the birth of sick-lit.

Multiple scholars, including Elman, have previously written about cancer narratives within adolescent sick-lit. I believe this chapter of my thesis is the first scholarship ever to analyze portrayals of Type 1 diabetes within sick-lit for teens. My analysis is informed by two critical modes: to understand the broad impact of sick-lit upon the teenage narrative, I rely upon the work of Elman (2014) and Nathalie op de Beeck (2004), whose writings critically analyze sick-lit and the genre's implications for a teenage audience. My analysis of the relationship dynamics specific to Type 1 are informed by the work of Justine Debelius (2021), who writes about T1D representations in fan fiction. The two categories that Debelius identifies, *comfort as care* and *comfort as control*, provide a helpful framework for analyzing the relationship dynamics within *Will I Ever Dance Again?* and *Let Me List the Ways*. However, in this chapter, I will show that Debelius' categories are somewhat complicated when applied to YA protagonists.

## The Tragic Future of the Disabled Girl

In *Will I Ever Dance Again?*, thirteen-year-old Rachel Deering's symptoms of fatigue and unquenchable thirst progressively worsen until she is diagnosed with Type 1 diabetes and is

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[50] Keith's book references the social model of disability (7), but I find Alison Kafer's *political/relational* model (Kafer 7) to be more inclusive of chronic illnesses—which often have a fraught relationship with disability due to what Susan Wendell refers to as a conflict between the *healthy* disabled and the *unhealthy* disabled (ie. the chronically ill) (26).

faced with what she views as a new, tragic future. The helplessness that Rachel initially feels is evidenced by her decision to give up her dream of dancing professionally. In an emotional hospital-bed scene she cries to her mother, “How can I even think about ever dancing again?” (McDaniel 45). According to Marilyn McEntyre’s essay, “Friends in Need: Illness and Friendship in Adolescent Fiction,” the tragedy that Rachel perceives within her circumstances is made more acute by her adolescence. McEntyre writes, “The irony of sudden illness or disability in [teenagers’] lives can seem especially cruel, poised as they are in the midst of preparation for independence and adulthood” (133). At thirteen, Rachel is on the precipice of increased independence, but the sudden diagnosis of T1D pulls her backward, tragically, into a heightened state of dependence that calls the future she envisioned for herself into question.

Perceiving her diagnosis as tragedy inhibits Rachel’s ability to imagine a future where she is a ballerina with diabetes. Rachel’s initial skepticism of a happy, disabled future is an example of an argument posed by Alison Kafer in *Feminist, Queer, Crip* (2013). Kafer argues that when culture views disability as pitiable then “a future with disability is a future no one wants” (2). At first—(before she meets Shawn), Rachel chooses a path of self pity. She wallows in the tragedy of her diagnosis. This is evidenced by the fact that she labels herself a “freak” (45) and refuses to dance—even though she is a serious ballerina with aspirations of joining a professional dance corps. Due to Rachel’s feelings about her diagnosis, she now lacks her previous sense of agency. The overwhelming negativity that Rachel feels may be partly attributed to a heightened sense of loneliness and misconceptions of disability. According to Lois Keith in *Take Up Thy Bed and Walk: Death, Disability and Cure in Classic Fiction for Girls*

(2001), adolescent fiction from the twentieth century often lacks *adult* characters with disabilities, to the detriment of the adolescent.[51] Keith writes:

> There are few 'enlightened adults' to provide experience and guidance for young [disabled] people growing up… Perhaps it is difficult for writers to imagine an adult disabled person having qualities necessary to act as teacher and guide, so the character has to learn to do these new things all by herself, with only negative ideas about the lives of disabled people. (227)

Although Rachel is eventually introduced to other teenagers with Type 1, the only adult with diabetes whom she encounters is her *male* physician (44).[52] In my opinion, the medical credentials of Dr. Malar make him a less relatable T1D role model. Because Dr. Malar has a responsibility to uphold a professional relationship with Rachel as her doctor, he is prevented from being open and honest about his personal lived experience. Furthermore, his adult livelihood is confined to a hospital, a fact which suggests the future of a person with diabetes never escapes a medical setting.

The teenage girls with Type 1 that Rachel meets, who might arguably represent her immediate future, foreshadow Rachel's sadness by drawing attention to their physical deterioration and emotional stress. In a support meeting for teens with Type 1, one girl says, "I hate these gross lumps under my skin from giving shots all of these years" (McDaniel 84). According to op de Beeck, this type of comment is a hallmark of McDaniel's brand of sick-lit, which "impl[ies] the adolescent female body's vulnerability to disease and injury" (63). Even

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[51] Where do YA characters with disabilities go when they grow up? Keith's observation regarding a lack of adult characters with disabilities is tangible proof of Kafer's argument that viewing disability as tragic in the present makes futures with disability undesirable (2). This future is so undesirable that YA fiction often refuses to include adult Type 1 role models, unless they are doctors.

[52] Dr. Malar and Shawn are the two Type 1 characters in this novel who seem to exude confidence in their abilities to care for themselves. Although Dr. Malar is not a love interest, it is possible to argue that his gender contributes to the pattern of sexism within McDaniel's novel.

though the "lumps" are beneath the skin, and potentially undetectable to the naked eye, the Type 1 girl's comments draw the reader's attention to them. She negatively labels them as "gross" and links them to prolonged diabetes management by referencing her "years" of injections. The Type 1 girl's linking of "gross" and "years" creates a direct connection between diabetes and what she tells the group that she "hates" about her body. Her degrading comments about her body are absorbed by a group of Type 1 peers, whose silence appears to affirm that feelings of body shame are a normal part of a female's life with T1D.

In *Let Me List the Ways*, Zie's story echoes the feelings of diabetes body shame that Rachel encounters in the support group meeting. As a girl who has lived with T1D for nearly a decade, Zie's body offers a glimpse into the female T1D's future. What she shows the reader are feelings of shame and embarrassment caused by the marks diabetes leaves on her body.[53] Zie's extreme self-consciousness is evident in a scene at the beach with her classmates. While changing into her swimsuit, she describes the careful steps she takes to conceal an old insulin pump site:

> I took a minute to tug on my bottoms to make sure they covered the last [insulin pump] site I had used, as it was still a bit bruised. You couldn't always see where my pump was last, but if you pressed just hard enough, you'd feel the bumps and dips from where it had been.[54] Over the years, scar tissue had built up just beneath the surface. (White 54)

Zie's detailed description of her scarring and bruises alerts the reader to the brokenness of her chronically ill body. The fact that she takes effort to hide the marks left by her pump implies a

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[53] While a diagnosis of diabetes does not imply corporeal evidence of disease, the management of diabetes (e.g., injections, finger pricks, and using an insulin pump) can leave behind visible marks. In another scene, Zie also worries what boys might think about her callused fingers (White 63).

[54] People with diabetes who wear insulin pumps must "rotate" their infusion sites (where the pump connects to their body) every 2-3 days. I have personal experience with this process because my daughter has worn an insulin pump since the fall of 2014.

sense of shame that is emphasized by “a little jolt of envy” that she feels when she sees the unmarked bodies of the non-diabetic girls (ie. the normates) who “quickly [strip] down to their bathing suits” (54). Disability scholar Rosemarie Garland-Thomson defines the “normate” as “a constructed identity” that is absent of any qualities marked by the social order that may otherwise make an identity deviant. She includes this definition in the preface to her book, *Extraordinary Bodies: Figuring Disability in American Culture and Literature* (2017). In the beach scene of *Let Me List the Ways*, it is Zie’s observations of the nondiabetic girls’ unmarked bodies that cast them into the role of “normate.” The speed with which the other girls undress sharply contrasts the care exercised by body-conscious Zie. The quickness of the “normal” girls implies a carefree attitude due to a higher level of comfort with their bodies. For chronically ill adolescent characters, comfort with their bodies might imply illness acceptance and confidence regarding their disability identities. Zie’s diabetes is incurable, which makes this acceptance and comfortability a crucial component to her future success.

## The Type 1 Diagnosis and the Arrival of the Special Protector

*Will I Ever Dance Again?* establishes a pattern of providing a strong, male counterpart for the ill, female protagonist that fits into the “special protector” archetype identified by Nathalie op de Beeck in her essay “‘Sixteen and Dying’: Lurlene McDaniel’s Fantasies of Mortal Endangerment.” In *Will I Ever Dance Again?*, Rachel’s sudden diagnosis of Type 1 diabetes is almost immediately followed by the introduction of Shawn, a male love interest (i.e., her “special protector”). According to op de Beeck, the “special protector” can be a person, supernatural event, or asset (such as finances or medical treatments) that rescues a sick, young heroine from spiritual or physical pain (79). The appearance of the male “special protector” at the time of diagnosis draws acute attention to the weakness of the female protagonist’s body and mind.

While Rachel is still in the hospital, her endocrinologist introduces her to Shawn McLaughlin—a fourteen-year-old soccer star with bright blue eyes. Shawn, who has lived with Type 1 diabetes since the age of three years old, explains, "Dr. Malar sent me… He told me you were pretty. He's right" (McDaniel 48). This moment invokes a historical tradition of sexism within YA teen romance.[55] Referencing teen novels from the late 1960s to the early 2000s, Julia Eccleshare notes that it was not until the "girl power" movement of the 1990s that fictional teen girls began to pursue relationships on their own terms. Eccleshare writes that "the traditional roles of girls as weak and boys as strong [sic] lasted an unnaturally long time" (547). If Dr. Malar only wanted to provide his young, female patient with a mentor he could have paired her with a dancer, a female peer, or an adult. Dr. Malar's actions insinuate that Rachel is a weak female who can only be saved by a strong male. Furthermore, the fact that Shawn is invited to the hospital under the pretense that Rachel is "pretty" alerts the reader to the doctor's potential ulterior motive of match-making.

In *Let Me List the Ways*, the introduction of a handsome, male "special protector" is even more closely aligned with the timing of the T1D diagnosis. Zie, a high school senior who was diagnosed with diabetes in fourth grade, begins *Let Me List the Ways* with a prologue that flashes back to the day of her diagnosis. During recess in elementary school, Zie experiences symptoms of undiagnosed Type 1 and literally falls into the arms of Nolan Walker (the young man she secretly pines for during the rest of the novel). Although the opening scene tells Zie's diagnosis story, the focus is on Nolan—who is mentioned in the prologue's opening and closing lines. Zie begins with the words, "I fell in love with Nolan Walker" (1), and ends with "I was a sick child—and Nolan Walker had saved my life" (2). This bookending of Zie's diagnosis story with

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[55] Elman's analysis of teen sick-lit observes similar trends.

references to Nolan establishes her literal and figurative dependence upon him. He is a part of her life with T1D from the very beginning; and according to Zie, Nolan literally "saves" her life.

## Friends with Benefits: Caregiving Males and Vulnerable T1D Females

Unlike Rachel and Shawn, who have known each other for less than a year, Zie and Nolan's friendship has grown over the course of almost a decade, and therefore Nolan is more intimately involved in Zie's diabetes care. Nolan's dual role in Zie's life, as a friend and caregiver, complicates the power dynamics of their friendship and blossoming romance. For this reason, I will focus only on *Let Me List the Ways* in this section—as I feel the caregiver concept explored in this section is less applicable to *Will I Ever Dance Again?*

To help me explore the complexities imposed by the caregiver-patient relationship in terms of Type 1 diabetes, I want to reference two tropes within diabetes-centric stories, which are named by Justine Debelius in her article, "Hurt, Comfort and Intimacy: Representations of Diabetes in Fan Fiction." In her article, Debelius explores how "the dichotomy of control and crisis builds vulnerability" (262), and she names two common, recurring narratives within hurt/comfort fan fiction with Type 1 characters: *comfort as control* and *comfort as care.*[56] Neither category that Debelius identifies is a perfect fit for Zie and Nolan's relationship. However, Debelius' observations provide Type 1-specific insight into McEntyre's argument that illness can reconfigure a relationship. According to Debelius, *comfort as care* narratives typically involve a high level of daily diabetes care from a non-diabetic narrator, whom Debelius refers to as a care*taker*.[57] The patient of the story, a character with diabetes, is infantilized and

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[56] According to Debelius, hurt/comfort (H/C) is a subgenre of fan fiction that "centers around disability, the perception of disability, and recovery" (259).

[57] I believe that Debelius' label of "caretaker" evokes a slightly stronger sense of control than the term "caregiver," which I apply to Nolan. The term "caretaker" often implies an absence—such as a caretaker for a property while the homeowner is away. This is also supported by Debelius' statement that caretaking is done "with little help or input from the diabetic character" (263). A "caregiver," however, might refer to anyone who provides any level of care. I believe the latter term is more representative of Zie's and Nolan's relationship, in which Nolan often confers with Zie when providing care.

controlled—emphasizing their vulnerability (262-4). In the second diabetes fan fiction trope, *comfort as control*, the character with T1D is a first-person narrator who manages their diabetes independently, with little outside intervention from other characters (268-9). The story of Nolan and Zie exists somewhere in a tension between these two narratives. In Debellius' examples, first-person T1D narrators tend to be fully independent in terms of their diabetes management. If the T1D character is vulnerable, he or she is managed by a non-diabetic narrator. Unlike the tropes in Debellius' examples, Zie is both vulnerable *and* the narrator.

Although Zie is in charge of her own story (as a first-person narrator), she is also frequently reliant on Nolan's support, accentuating her vulnerability—which ultimately leads to her fear of losing Nolan. This fear seems to stem from her physical dependence upon him, and the realization that her dependence may be taxing for Nolan. Nolan reassures her when she is body conscious (White 54), tests her blood sugar (45), counts her carbohydrates for her (25, 200), and rescues her from low blood sugar episodes (168). Crucially, Nolan is the only friend who provides these types of care for Zie—establishing him as an integral part of her diabetes management. He appears to be more involved in her care than her parents. Sometimes this care comes from moments of crisis, such as when Zie faints at a diner and requires assistance (214), but sometimes Nolan's intervention takes on a parental quality that infringes on Zie's agency. In one scene, for example, he tests her blood sugar when she is fully conscious and able to test herself (45). For Zie, it is not a fear of losing control over her diabetes management that creates doubt in her mind; Nolan is already highly involved in her care. Instead, her fears come from thoughts of losing Nolan as a result of the care he provides being a burden.

It would be melodramatic to say that Zie's worry causes her to view her future as "tragic," but there is a definite sense of doubt regarding the impact diabetes has on her relationships. In an inner monologue, Zie reveals that she sees herself as a burden: "I hated the idea that I was someone anyone had to worry about, let alone Nolan" (White 193). Zie's use of the word *had* implies that worry is an obligatory condition of Nolan's friendship with her. From Zie's perspective, Nolan does not choose to worry about her, he *has* to worry. She views worrying as a conditional burden of being her friend. Viewing herself as a burden causes Zie to ponder the possibility that Nolan will someday replace her with a less complicated friend. In a conversation about post-graduation plans, Zie asks Nolan, "Aren't you looking forward to when we go to college and you can have friendships that won't involve math?" (White 193). Here, Zie refers to the "math" needed to calculate carbohydrates at meal times (something Nolan often helps with), but the need for math is predicated on a diagnosis of Type 1. The implication is that friendships without math (ie. diabetes) are easier, preferable—a problematic realization that Zie only clarifies at the end of the novel.

## The Recuperated Male Body Is a Well Body

For both Zie and Rachel, whose bodies are shown to be damaged and weakened by chronic illness, their diabetes burdens appear to be too emotionally and physically heavy without the assistance of a recuperated male body. According to Julie Elman, it is common in teen sick-lit narratives for the chronically ill female to depend upon a non-disabled (i.e., "well") male. However, Elman points out that the romantic male leads can also be "ill boys who demonstrate their virility and athleticism 'in spite of' their illness" (95). In both *Will I Ever Dance Again?* and *Let Me List the Ways*, the male romantic leads are star athletes who show determination and resilience despite personal illness or injury. Shawn performs a hyper-masculine form of "overcoming" a disability; promoting sexism as well as ableism. Nolan does not have a disability, but he performs a similar kind of "overcoming" when he continues to act as a caregiver for Zie even after he reaggravates an old sports injury. Focusing first on Shawn, I will show how both Shawn and Nolan are examples of "ill boys who demonstrate virility," according to Elman's definition of teen sick-lit.

*Will I Ever Dance Again?* begins with a driven, talented dancer and throws her into the "depths of despair" where she is guided back to the future she desires by a strong, capable male.[58] At various points throughout *Will I Ever Dance Again?*, Rachel looks to Shawn for emotional support and athletic inspiration. She is impressed with his ability on the soccer field, despite his diabetes. Rachel is so inspired by Shawn that she thinks to herself that they can both "beat" diabetes (McDaniel 110). Shawn is more than inspiration, though. Rachel directly attributes her illness acceptance and future success as a ballerina to him. She says that her determination to succeed is "all because of Shawn" and that "he'd made her realize life was beautiful" (105). Although it is true that Shawn played an important role in Rachel's return to ballet, I think her praise undermines the value of her hard work. She attributes "all" of her success to Shawn. Shawn supported Rachel on her journey, but *she* did the physical work. Her dependence upon Shawn is emphasized so strongly, however, that Rachel appears to be without individual agency. If "all" of her success is really due to Shawn, it is questionable that Rachel could have achieved any success without him.

Even though Shawn also has diabetes (like Rachel), his character is emblematic of conquering his illness, and his character (ironically) promotes ableism, as well as anti-feminism. Through Rachel's point of view, Shawn appears strong, impressive, and unphased by his chronic illness. This fact is illustrated during a soccer game: "The game of soccer was strenuous. Almost a full hour of nonstop running. No time-outs, except for injuries. And Shawn played every minute of the game. He ran as much as any of them. And he never once had an insulin reaction"

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[58] As quoted by Anne Shirley in LM Montgomery's *Anne of Green Gables* (37).

(McDaniel 80). At the end of the game Rachel asks him, “Don’t you ever have insulin reactions?” To which he replies *flatly*, “Nope” (81). Shawn elaborates on his answer to explain that he plans for games by eating extra carbohydrates and keeping Gatorade nearby at the game—but the reader never experiences this firsthand. Through Rachel’s eyes, readers are confronted with an athlete who is seemingly unaffected by his chronic illness—even when he is pushing his body to the brink with “a full hour of nonstop running.” While this depiction appears to promote the strength of the disabled body, it does so at the expense of misrepresenting chronic illness as something totally within the control of the athlete. His character represents an ableist trope that disability scholars, such as Lois Keith, refer to as “overcoming” a disability (222). Shawn tells Rachel that the Gatorade is there, but she doesn’t see him drink it. Furthermore, Shawn makes it clear that the Gatorade is a preventative measure. He says he *never* experiences hypoglycemia (low blood sugar). What would happen if Rachel saw him take a drink of Gatorade in order to fend off plummeting blood sugar levels as a result of strenuous running? The presumption is that publicly acquiescing to the demands of his chronic illness would challenge his image as a strong athlete.

In *Let Me List the Ways*, Nolan is also a talented athlete, but instead of a chronic illness, he suffers from an old sports injury. Although Nolan’s injury is aggravated during the course of the story, and his character expresses some weakness, he ultimately represents the idea that the male body is less vulnerable than the female body. For example, even while injured Nolan is able to carry Zie and a can of soda (one in each arm) in order to help her treat a severe low blood sugar at school (White 168). Also, there are fundamental differences in the cause and course of Nolan and Zie’s physical weaknesses. Zie’s Type 1 happened *to* her. She was acted upon by an unstoppable aggressor (diabetes), which makes her seem passive and weak. In contrast, Nolan’s injury was caused due to *his* aggression during a game of baseball. He overexerted himself in a display of masculine behavior. He was the instigator. He was in control. The second difference between their weaknesses is the course of their injuries/illnesses. Zie's Type 1 is incurable, progressive, and sometimes requires urgent action. Type 1 diabetes is life-threatening, and as time goes on, it causes external and internal damage. Nolan's injury, on the other hand, is a temporary problem which will eventually heal. Even within the context of the story, his shoulder improves. Nolan's short-term weakness may allow Zie to offer him some level of mutual care, but ultimately, she relies on him more often and with more urgency than he relies upon her. Thus, the sexist themes of YA romance-based teen sick-lit are perpetuated.

Just as Rachel links her future success with her relationship to Shawn, Zie demonstrates her inability to imagine an independent future without Nolan. In *Let Me List the Ways*, Zie's dependency upon Nolan is made acute when she tries to imagine her first year in college without him, but she is unable to do so (White 285). Although Zie can't (or won't) imagine a future without Nolan, she does not take proactive steps to secure the future she wants. Instead, she acts passively, responding to Nolan's moves. Therefore, her inability to imagine a future without Nolan suggests a lack of agency. At various points in the story, it is Nolan who makes the first move in their romantic relationship. For example, he decides that they will kiss for the first time (125), and he decides that they will make their relationship official (290). The text demonstrates that it is Nolan who controls the relationship's direction. This makes Zie's desire to have Nolan in her future appear more wishful than hopeful. For Zie, the tragedy in her life is not living with Type 1 diabetes, it is her lack of agency over her future.

As demonstrated by the characters of Shawn and Nolan, the chronically ill male maintains control over his future—and he is simultaneously able to direct the future of another character. *Will I Ever Dance Again?* and *Let Me List the Ways* both wield the recuperated male body as a necessary device for rescuing the weak, diabetic female from certain tragedy. The romances in these novels capitalize on moments of tragedy by inserting a “special protector” at the time of diagnosis. This “serendipitous” timing of the special protector’s arrival establishes the teen girl’s care dependence early and creates confusion (for the reader and the female protagonist) between moments of caregiving and moments of intimacy. This intermingling of romance with medical care also creates doubt regarding if the female Type 1 protagonist can survive on her own. In her present state of being she is frequently dependent, which works to erode the agency she requires to determine an independent future.

## Conclusion

My findings in this chapter suggest that within Type 1 diabetes teen sick-lit, there is a gendered aspect to Alison Kafer’s observation that culture often views the disabled future as “an obstacle to a good life” (2). In this chapter, I have carefully analyzed two T1D teen sick-lit books, *Will I Ever Dance Again?* and *Let Me List the Ways*, to show how it is only the future of the chronically ill *female* protagonist that is called into question. The “obstacles” to their short-term futures are revealed by the girls’ broken bodies. Unlike the male bodies of Shawn and Nolan, which these novels show to be athletic and recuperated, the chronically ill female bodies are marked by the scars and lumps of diabetes. These marks represent both physical and mental weakness. They remind the reader of the chronic nature of diabetes, and they are a source of embarrassment or shame for the female protagonists and other female T1D characters. These novels reveal that young girls with T1D require male validation in order to cope with the demands of their chronic illness and physical deterioration. This same level of frequent validation and support is not shown to be true for the male characters.

Although both Rachel and Zie have futures that are dependent on their romantic partners, I believe that my comparison of these two novels also reveals a slight shift in the representation of hegemonic masculinity within T1D teen sick-lit. Through Shawn, readers experience a chronically ill character who exudes strength and confidence, and who reveals no weaknesses. The character of Nolan, from *Let Me List the Ways*, is also a talented athlete and self-reliant, like Shawn; but unlike Shawn, Nolan's character displays *some* weakness. Nolan's weakness allows mutual care between him and Zie, providing *some* balance to their relationship. This sense of balance is a marked difference from the more one-sided relationship of Rachel and Shawn in which she says her return to ballet was "all because of him" (McDaniel 105).

Although Zie still often relies on help in the management of her diabetes, her character represents a slight shift in the role of female chronically ill characters in teen sick-lit. Zie's own vulnerability is lessened through the care and concern she expresses for Nolan's injury, because in those moments she is functioning as a caregiver. In those moments in particular, Zie's character challenges the stereotypes of sexism and ableism that Elman notes as hallmarks within teen sick-lit, and which are evident within *Will I Ever Dance Again?* In comparison, *Let Me List the Ways* is not, on its own, indicative of a pattern with T1D teen sick-lit; however, the comparison of Rachel and Zie's relationships does reveal one way in which the rampant sexism within this genre can be challenged: through mutual care and concern expressed by the protagonist and her love interest.

# Chapter Three: She Makes Herself a Monster: The Disability Masquerade as False Agency in *Sweetblood* by Pete Hautman

"Sickness breaks down the body, and it breaks down identity,
but it cultivates beautiful monsters."—Catherine Pugh

Although they have different goals, the diabetic and the vampire are both experts in extraction. The diabetic pricking her finger to squeeze out a red droplet for a glucose test even bears a striking similarity to the puncture marks a vampire leaves on the necks of its victims. In fact, vampires are merely people with undiagnosed Type 1 diabetes—at least, that is the theory according to Lucy Szabo, a sixteen-year-old diabetic and the narrator of Pete Hautman's young adult novel, *Sweetblood* (2003).[59] Lucy was diagnosed with Type 1 at six years old, shortly after being bitten by a bat and having received a series of rabies shots (Hautman 2). She refers to herself as "undead," wears black clothing, and writes a grisly English essay in which she theorizes that symptoms of diabetic ketoacidosis, a condition common at the time of diagnosis for Type 1 diabetes (Scheiner 192), led to the creation of vampires from folklore.[60] Lucy argues that vampires are nothing more than undiagnosed diabetics. In *Sweetblood*, she masquerades as a vampire in the making, saved from her true fate by the miracle of insulin. In her essay entitled "The Sad Truth About Bloodsucking Demons," Lucy writes:

> Diabetics were the original, the *real* vampires. They weren't evil or superpowerful or immortal. They were just sick. Like me. I am actually a proto-vampire. When I take an insulin shot now, I think of it as vampire vaccine. If I quit taking insulin

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[59] Hautman's choice to name his protagonist "Lucy" is likely a reference to Bram Stoker's 1897 novel, *Dracula*—in which the 19-year-old Lucy Westenra is transformed into a vampire.

[60] Diabetic ketoacidosis (DKA) is a life-threatening condition that is brought on by a lack of insulin in the body and is typically accompanied by elevated blood glucose levels. Symptoms of DKA can include excessive thirst, weight loss, impaired cognitive ability, fruity smelling breath, rapid breathing, etc. (Scheiner 239).

> altogether I would become that starving vampire girl from the Middle Ages. (Hautman 42-43)

While Lucy claims to have adopted her vampire persona because of historical and scientific evidence that she has uncovered, it is clear that the monster facade she has chosen is also a safety mechanism designed to protect her from a fear that her diabetes *others* her. Like a vampire, Lucy straddles two worlds. She can "pass" for a non-disabled teenager in the same way that a vampire can "pass" for a human.

In a 2004 essay in *Literature & Medicine*, Tobin Siebers expands on the concept of passing and discusses a practice that he refers to as "akin to passing": the disability masquerade. Siebers defines *the masquerade* as "disguis[ing] one kind of disability with another or display[ing] [sic] disability by exaggerating it" (4). Siebers' argument demonstrates how the masquerade complicates the straightforward binary of passing as able-bodied (concealment) or identifying as disabled (disclosure). His essay is part of an ongoing discussion among disability scholars regarding disclosure and identity, referred to as the "coming-out discourse" by Ellen Samuels or as Eve Sedgwick calls it, "the epistemology of the closet." Although Siebers' essay acknowledges the relevance of these discourses for invisible disabilities, his discussion often favors physical disabilities—the primary exception being deafness. The majority of the examples Siebers provides involve performance of "visible stigma," such as wheelchairs, crutches, white canes, or hearing aids. Therefore, his essay leaves much to be explored in terms of chronic conditions, such as Lucy's diabetes, and their relationship to *the masquerade*.

In this chapter, I perform a close textual analysis of Hautman's *Sweetblood* in order to explore how *the masquerade* applies to diabetes—an invisible disability that is "marked by a crisis of signification" (7), according to Jeffrey Bennett (2019). Although there are some visible stigma that may be attached to Type 1 diabetes (insulin pumps, glucometers, CGMs, drops of blood), Bennett's assertion of a "crisis of signification" implies that these stigma may not be culturally recognized.[61] Within the "schema of diabetes," for example, Bennett notes the overall perception that Type 1 diabetics are "victims" (13), but a victim is a state of being, which is very different from the physical props that Siebers' examples often rely upon for their exaggerated performances of disability. The word "victim" might be said to apply to any number of physical conditions—it is very unlike a white cane (one of Siebers' examples) which strongly signifies blindness.

A lack of cultural understanding can be common for invisible disabilities, according to health scientist Stephanie Mantilla, who interrogates the "economies of invisible disabilities." Mantilla uses the term *culturally invisible* to explain how signifiers for invisible disabilities "may go unnoticed due to a lack of awareness or may not be legible due to a lack of awareness of the symptoms of the disability" (423). Siebers' essay argues that disability legibility is "clouded" further by the masquerade. He connects the masquerade with desires. Siebers writes that the masquerade "fulfills a desire to tell a story about disability;" and it is the person with the disability whom Siebers identifies as the storyteller (19). In this chapter, I question the type of disability story that sixteen-year-old Lucy communicates through her masquerade as a proto-vampire. I argue that Lucy's adoption of a vampire identity is in response to the social stigma of fear that she perceives to be associated with Type 1. As a vampire, she embodies this fear through her masquerade as a powerful monster. However, unlike Siebers' assertion that the masquerade "claims disability," Lucy's vampire identity is a rejection of the realities of her diabetes identity. which prevents her from achieving illness acceptance. Therefore, Lucy's

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[61] CGM stands for "continuous glucose monitor."

decision to shed this facade at the end of *Sweetblood* marks a turning point in her acceptance of her diabetes.

I begin this chapter with a close analysis that defines the three identities that Lucy uses in Hautman's novel. It is crucial to be familiar with these three identities (Lucinda, Lucy, Sweetblood) and the different social contexts they represent in order to understand Lucy's participation in *the disability masquerade*, as defined by Tobin Siebers. As previously mentioned in the introduction, Lucy's use of *the masquerade* does not perfectly align with Siebers' theory, which asserts the exaggeration of disability through the use of socially recognized stigma. The social and physical *invisibility* of Type 1 diabetes, as noted by Bennett (2019), complicates the masquerade. In Lucy's version of the masquerade, I argue that she "becomes" a proto-vampire in response to the perception that society views the diabetes identity as fragile and fearful for its closeness to death. Within Lucy's family, it is the normalization of the fear of severe hypoglycemia (low blood sugar, which can be fatal) that creates (for Lucy) the perception that *she*—a diabetic who cannot be cured—is a feared *other*. To illuminate the historical and contemporary connections between Type 1 and fear, I refer to accounts of Type 1 in adolescents that establish a clear connection between Type 1 and death (Feudtner 2003; Koltin and Daneman 2008; Tanja Pate et al. 2019).

Lucy's self-identification as a proto-vampire is a form of self-othering that performs the fear and death (i.e., stigma) she perceives associated with Type 1 and redefines them as powerful, rather than as a symptom of diabetes. It is through the contortion of her disability identity, from diabetic to vampire, that Lucy twists Siebers' version of *the masquerade*. Rather than "claim" diabetes and the fear of death it represents, Lucy reinvents herself as a powerful member of the undead. I refer to disability scholar Catherine Pugh's writing on gothic monsters and Angnieszka

Stasiewicz-Bienkowska's book, *Girls in Contemporary Vampire Fiction* (2021), to explore the vampire as the embodiment of fear and othering, as well as a symbol of power, control, and what Pugh refers to as being "hyper-alive." I further show how her masquerade as a vampire (a nearly invincible creature) problematically prevents her from acknowledging the realities of life with Type 1—a disease which demands a high level of vigilance.[62] Finally, I establish that Lucy's decision to shed her monstrous vampire persona at the end of the novel marks a turning point in her acceptance of her diabetes.

### Summary of *Sweetblood*

Lucy Szabo is a sixteen-year-old girl who was diagnosed with Type 1 diabetes at age six. In *Sweetblood*, Lucy is a formerly straight A student who experiences a phase of diabetes "burnout." She becomes complacent in her diabetes care, and imagines that she might be what she terms a "proto-vampire." Lucy theorizes that there exists a historical connection between undiagnosed diabetes and the original tales of vampires in legends and folklore. When she meets a new boy in school, Dylan, Lucy even introduces herself as a vampire, but she later clarifies that she is "of the mortal variety" (Hautman 84). This acknowledgement of her mortality indicates that Lucy does not actually believe she is an immortal vampire but that she is merely masquerading as one. Her masquerade as a proto-vampire represents a crisis of identity, rather than a belief in the supernatural. But her vampire persona often seems to conflict with her identity as a diabetic. When Lucy is performing her vampire identity, she often hides her diabetes identity, even when it is to her detriment. Her complacency in her diabetes care could be described as a phase of "burnout"—the mental and physical exhaustion that can come from the constant demands of a chronic illness. In *Sweetblood*, Lucy's masquerade often leads her to treat

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[62] "Diabetes [sic] is unique among chronic illnesses in that it requires a larger degree of self-management by the patient, and the threat that poor self-management can be both acute and serious in their health impact" (Carroll and Marrero, "How Do Parents" 1223).

her diabetes care cavalierly, an approach which eventually leads to her near death and hospitalization. In this final moment of crisis, she appears to let go of her vampire identity.

## The Multiplicity of the Type 1 Identity: Lucinda, Lucy, Sweetblood

In *Sweetblood*, Lucy performs three identities which reflect a "multiplicity and malleability" to her identity that disability scholar Aimee Burke Valeras notes as a common trait of persons with hidden disabilities.[63] Furthermore, Valeras refers to this multiplicity as a "revolt against the pressure our society upholds to dichotomize, segregate, and place people into clear-cut categories"—a notion which echoes Siebers' claim that the masquerade is "a way to manage social stigma and difference" (8). Lucy's revolt appears to be against her diabetes diagnosis. Understanding Lucy's relationship to each of her three identities in *Sweetblood*, and how they interact with her diabetes, is a crucial first step to understanding her response to the stigma she perceives and thus her participation in Siebers' *disability masquerade*. She is Lucinda. She is Sweetblood. She is Lucy.

The meaning of "Lucinda," Lucy's given name at birth, is "light" (Hautman 17), a meaning which contrasts her dark identity as a vampire and evokes a sense of truth. One "truth" that the name Lucinda represents is the reality of her diagnosis. In *Sweetblood*, the name "Lucinda" is not used by many people, but it is *always* used by Lucy's endocrinologist, Dr. Fisher. In an endocrinology appointment with Dr. Fisher, whom Lucy calls "Fish," the name "Lucinda" becomes connected to reminders of the complications of diabetes. During a diabetes check-up, Fish checks Lucy for signs of neuropathy, retinopathy, and he evaluates her blood glucose control by measuring the HbA1C[64] (86). When she is "Lucinda" in the exam room, these

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[63] In the essay "We Don't Have a Box: Understanding *Hidden Disability* Identity Utilizing Narrative Research Methodology," Valeras defines a "hidden disability" as "one that is unapparent to the unknowing observer."

[64] HbA1C refers to hemoglobin A1C and is a test that endocrinologists use to determine a patient's average blood glucose for the three months prior to the appointment.

tests are reminders of the long-term and short-term complications of diabetes. They remind Lucy that diabetes poses a constant risk to her health.

In a party scene where Lucy is exceptionally cavalier with her health, testing the limits of her body, the name “Lucinda” appears again. Lucy attends a party with her classmate Dylan, who is unaware that she is diabetic, and she consumes alcohol—which poses risks for a person taking insulin (not to mention the fact that Lucy is underage). At the party, the name “Lucinda” is spoken by an older man named Wayne. Even though Lucy does not disclose her diabetes to Wayne, he refers to her by the name “Lucinda,” which is a signal to her diabetes because this is the name her endocrinologist uses. When Wayne performs a tarot reading for “Lucinda,” he reveals the five of cups (Hautman 124). According to *The Girls’ Guide to Tarot* (2002), the five of cups signifies emotional loss, wallowing in self-pity, and bitterness (Olmstead 60). When Wayne produces the five of cups card, therefore, the message of the card could be interpreted as a reminder of the physical and emotional loss created by Lucy’s diabetes.

As an escape from the reality of life with diabetes, Lucy creates an online persona for herself that she names “Sweetblood.”[65] Even online, where no one can see her, Lucy attempts to distance herself from her feared diabetes so that she can appear “normal.” Sweetblood is a young proto-vampire who exists only in internet chat rooms and who embraces the image of living death. As Sweetblood, she frequents internet chat rooms for vampire enthusiasts and self-proclaimed vampires. In the chat rooms, Lucy explores her diabetic vampire theory, but she never identifies herself as diabetic. Although her continued interest in diabetes represents the inseparable nature of this part of her identity, her reluctance to disclose herself as “diabetic” demonstrates a revolt against the stigma that she perceives connected to diabetes. Even as a vampire, Lucy distances herself from diabetes so that she can appear “normal.” Lucy’s creation

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[65] In the novel, Lucy’s screen name is often shortened to Sblood.

of a proto-vampire identity is revolt against her diabetes identity, and it is also a way to manage the stigma (i.e., fear) she perceives. As a vampire, Lucy exposes the fear and othering she perceives by claiming it and redefining it as a symptom of a powerful monster identity, rather than a symptom of chronic illness.

For teens with chronic illnesses, social media platforms can create opportunities to develop identities separate from their diseases, and therefore unhindered by any stigma (Chalmers et al. 4). A conversation with a friend after an insulin reaction reveals Lucy's fear of the stigma that "everybody at school thinks [she's] a time bomb" (Hautman 232). Not only are bombs dangerous, but they have the potential for mass destruction. Even though she is already afforded a high level of anonymity as Sweetblood, the image of diabetes detonating and creating chaos is strong enough for Lucy to distance herself from her diagnosis. Furthermore, a 2021 study of diabetic teens and social media use concluded that decisions about what diabetes information to share online was directly impacted by positive or negative experiences offline (Chalmers et al. 5). As Sweetblood, a vampire among vampires in the Transylvania chat room, Lucy does not need to worry about being feared. The online atmosphere provides a safe place where she is free from the stigma of her disease and can safely explore her theories. Sweetblood only exists online, though. In the real world, Lucy is a teenager whose identity as a teen goth is formed in the tension that erupts from embracing Sweetblood the proto-vampire while attempting to suppress Lucinda the diabetic human.

In school, Lucy dresses in all black and hides her diabetes in order to avoid being labeled as "Diabetes Girl" or as a "cripple" (Hautman 130), terms she uses and which imply the weakness she perceives to be associated with diabetes. However, there is no evidence that any of her classmates ever refer to her as a "cripple" or call her by any other derogatory names. For

Lucy in particular, who adamantly resists wearing an insulin pump, there are no easily visible corporeal markers or prosthetics that label her as “diabetic.”

Lucy’s yearning to be in charge of her identity is why when she meets Dylan, a new boy in school, she introduces herself to him as a vampire (Hautman 34). Even after they have hung out several times, Lucy neglects to share her diagnosis with Dylan. When she needs to treat an episode of hypoglycemia in front of him, she creates a cover story. As low blood sugar can often be corrected by eating something sweet, Lucy stuffs some Gummi Bears in her mouth and claims that she was just “hungry.” She feels conflicted about this decision, but ultimately decides to keep her secret in favor of protecting her “normal” identity. As the scene progresses, she explains to the reader, “For a moment I regret not telling him about my diabetes. But it’s really none of his business. I get so bored with being Diabetes Girl. It’s nice to have friends who don’t think of me as a diseased cripple” (130). Lucy’s thoughts in this scene further reveal the internal conflict created by her desire to be “normal.” According to a study of visible and invisible chronic illnesses, the conflict surrounding disclosure is not uncommon: “Coping with stigma involves a variety of strategies including the decision about whether to disclose the condition and suffer further stigma, or attempt to conceal the condition or aspects of the condition and pass for normal” (Joachim and Acorn 243). Additionally, she risks being exposed as a “fraud” if and when an event out of her control reveals her secret (which is what eventually happens) (Hautman 138). However, Lucy’s momentary regret cannot outweigh the overwhelming need to control her identity.

Lucy’s rejection of the label “Diabetes Girl” makes it clear that she wants to be seen as more than her disease, but omitting important details about her care puts her in a potentially precarious situation with both long and short term consequences. If she reveals her condition too late, will she be viewed as deceptive? What if she has an insulin reaction and Dylan doesn't know how to help her? In one study, teens with diabetes noted that their peer relationships acted as a safety net, but only with friends who were aware of their condition and knew how to help (Carroll and Marrero, "The Role of Significant Others" 248). For Lucy, it seems, the desire to appear "normal" supersedes her desire for safety. It also again demonstrates the fact that Lucy views diabetes as an abnormal part of her identity that dominates the way others view her once it is revealed. To protect herself, she is willing to deceive her friend through her masquerade as a "vampire" and put her health at risk.

The way that Lucy introduces her friendship with Mark, her closest confidant, confirms that what she values most in a relationship is the absence of fear or worry (i.e., what she considers to be "normalcy"). When Lucy introduces Mark to the reader, she says, "Right now I don't have a real best friend, but if I had to pick one it would be Mark Murphy, who lives down the block and across the street and is one of the few people at school who doesn't treat me like a freak" (Hautman 6).[66] Lucy's choice appears cool and indifferent because she claims to name Mark out of an obligation to pick *someone*. Also, the fact that Mark is defined by his lack of animosity appears to set a low bar for any kind of friendship, let alone a purported best friend. But, Lucy's use of the word "freak" is significant. Although she does not mention her diabetes directly, I think she is talking (at least in part) about the way Mark responds to her illness. The word "freak" is directly connected to diabetes in a different conversation, with Dylan. After a very public insulin reaction at school, Lucy confronts Dylan and says, "My diabetes doesn't

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[66] Perhaps Mark is not a "real" best friend because he is male. Deborah Kent, who writes about the genre of disabled literature, notes that, "Friendships with women peers are strikingly absent from the lives of many of the disabled women in literature" (49). According to Kent, this lack of female camaraderie is another way in which disabled characters are ostracized from "normal" life. Although Lucy has casual conversations with other girls in the novel, she has no close friends who are female. She is never invited to another girl's home, never invites another girl to her home, and she never makes plans with other girls. The only social interactions she has with her female peers are coincidental, such as when she happens to run into them at the mall one day, or when she happens to see them at a party (Hautman 57, 111).

make me a freak" (173). It is Lucy who introduces "freak" in the conversation, revealing what is already on her mind: She fears diabetes will stigmatize her. In comparison, Mark's behavior doesn't make her feel freakish and thus makes him a good friend. A close examination of Lucy's relationship with her parents directly connects her fears of being othered by her peers to the normalization of "diabetes fear" that she experiences at home.

### Fear Normalized: Lucy's Perception of the Diabetes Identity

At the core of Lucy's masquerade as a vampire is her deeply held belief that diabetes makes her "scary." When describing herself, she often uses the words "freak," "scary," "bad," "evil," or "wicked," words commonly associated with monsters, but which Lucy uses to label herself (often in tandem with descriptions of her illness). As I established in an earlier section, the name Lucinda is particularly associated with diabetes. In one scene, Lucy claims that her mother is afraid of "the wicked-proto vampire Lucinda" (Hautman 100). For Lucy, the sense of fear that she feels directed toward her begins at home. I argue that as her primary caregivers, and the people most acquainted with her disease, Lucy's parents form a relationship with her that serves as a reference point for how she measures the world's response to her disease. This proves to be problematic due to the fact that Lucy continually interprets her parents' concerns for her safety as their fear *of her*—an idea which leads Lucy to fear being "othered" in relationships outside of her family.

It is in a flashback scene where Lucy first reveals an awareness of her mother's fear and directly connects it to her diagnosis. In the flashback, Lucy describes her first insulin shot, "It didn't hurt a bit, but my mother was freaking, crying and asking the poor doctor how this could happen" (Hautman 5). The *but* in this sentence critically pits Lucy against her mother. Lucy, who is six years old in this scene, presents herself as calm enough to be embarrassed of her mother and rational enough to have pity for the “poor” doctor. In contrast, Lucy portrays her mother as someone who is fearful and overreacting. Even now, at sixteen years old when she is reflecting on this memory and can better grasp the gravity of her own diagnosis, Lucy focuses on what she felt in that moment ten years ago. She was calm and felt no pain. Therefore, her mother’s reaction appears overstated and intense. Why should the mother be hysterical when the daughter is not in any physical pain or emotional distress? This scene establishes that fear has always existed as part of Lucy’s diabetic identity, from the moment of the first insulin injection. But it is not a fear that Lucy feels herself; it is a fear *imposed* on her.

Lucy’s awareness of her parents’ fear aligns with the findings from a 2006 study of diabetic teens and the role of significant others[67] in their lives. In this study, Carroll and Marrero noted that the teens’ own perceptions of their illness was “less negative than one might expect” (245). When speaking about abnormal blood glucose readings, most of the teens referred to their parents as “concerned” and some described parental reactions as “overprotective” and “stressful” (247). When Lucy calls herself “the evil sugar-bitch daughter” (Hautman 68) or the “scary diabetic daughter” (185), she is directly connecting her identity as a daughter with fear. In both of these examples, Lucy construes her parents’ concern for her safety (her mother’s in particular) as fear *of her*. Furthermore, according to Lucy, her mother stopped having children so as not to “risk bringing any more diabetics into the world” (90). Even though the mother names “diabetes” as the reason for not having more children, diabetes is an inseparable part of Lucy’s identity. In Lucy’s mind, two permanent parts of her identity—daughter and diabetic—are fused together so tightly that it is impossible to distinguish between fear of one or the other.

The specific fear of hypoglycemia (low blood sugar) also prevents Lucy from being a “normal teenager”—as evidenced when Lucy’s parents call her to dinner one evening and she

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[67] The “significant others” in this study were parents, peers, and physicians.

doesn't respond. In the short term, hypoglycemia poses a constant health threat in the life of a Type 1 diabetic and is known to elicit fear in parents of Type 1 children because the complications of hypoglycemia can be sudden and dire, even fatal (Pate et al. 209). When Lucy takes an unplanned nap, both parents rush into her room, their united approach revealing the urgency of their mission. She is abruptly woken when her father lifts her from her bed and shouts, "ARE YOU ALL RIGHT?" and then, when Lucy does not answer his question, he asks again, "Are you sure you're all right?" (Hautman 97). This doubling down demonstrates that his worries are unabating. He wants to make certain that Lucy is OK, and asking once does not suffice. The mother's fear in this moment is so great that she cannot even put it into words. She says, "We were afraid you… we thought maybe you weren't feeling well, Honey" (98). The ellipses represent the mother's censorship of her fear, which she does not dare to speak aloud. Instead, she replaces her specific thought with a generic comment that fails to address the elephant in the room: Lucy is not allowed to be a normal teenager. She cannot take a nap at an odd time without provoking fear and anxiety in her parents. Her parents' unspoken fear in this scene is that Lucy didn't answer their call for dinner because she was unconscious due to a hypoglycemic event. The threat of an insulin reaction weighs heavily upon their minds.[68]

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[68] While insulin is the life-saving hormone used to manage blood sugar levels for Type 1 diabetics, it is not a cure. The conflicted history of insulin as a miracle drug is summarized in the book *Bittersweet: Diabetes, Insulin, and the Transformation of Illness*, "Emphasizing a miraculous event, these accounts ignore the more sober legacy of this 'miracle'—all the problems that remained, all the new problems created by the transmutation of diabetes into a chronic disease" (Feudtner 10). A frequent concern for Type 1 diabetics is the risk of hypoglycemia, which Lucy refers to as an "insulin reaction," and is caused by using too much insulin (Feudtner 104). As Dr. Gary Scheiner explains in his instructional book, *Think Like a Pancreas*, determining the "right" amount of insulin is a balancing act that is impacted by a person's food choices, exercise levels, and a myriad of other factors (39-58). Lucy summarizes the control she has over her blood sugar in this way, "Sometimes there's just not much you can do" (Hautman 22).

## Fear and Type 1 Diabetes: "Dead in Bed" Syndrome and Other T1D Nightmares

In this section, I clarify Lucy's parents' fears through a brief overview of historical and contemporary connections between Type 1 and adolescent death. Parents of diabetic children are notably laden with constant stress regarding the demanding nature of diabetes management (Pals et al. 371). This stress of diabetes management is magnified for parents of adolescents, like Lucy, who are at a stage in life when they are naturally seeking more autonomy. Relationships between parents of adolescents with Type 1 diabetes are fraught with tension as parents balance letting go of disease management responsibilities with the constant vigilance required to keep their children safe (Carroll and Marrero, "How Do Parents" 1223). In *Sweetblood*, this stress is manifested in the parents' behaviors, such as the way the mother habitually wrings her hands. Lucy describes one of these moments as having so much intensity that her mother might "wring the skin right off her hands" (Hautman 54). This intensity shows just how much Lucy's mother fears for her daughter's safety. She is literally gripped by fear, and it is causing her to tear herself apart. This hand wringing is a behavior that Lucy observes at least three times, which demonstrates the perpetual nature of the mother's fear.[69]

Behind the mother's feelings of stress are historical and contemporary links between Type 1 diabetes and the fear of premature death. Even though T1D is now manageable as a chronic condition, it has a centuries-long history as a purveyor of certain death. Just as vampires drain the lives of their victims, Type 1 diabetes (often diagnosed at adolescence) infamously caused patients to waste away. In *Bittersweet* (2003), a monograph detailing the history of diabetes and its treatment, Chris Feudtner refers to Type 1 as a "deadly disease" before the discovery of insulin. He paints a grim picture for even the patients who could afford "the best care" for their diabetes: "[They] spent these terminal years living in a semistarved state that

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[69] Other examples of this behavior can be found on pages 68 and 97 of the novel.

ended in either coma, infection, or starvation" (8). Feudtner asserts that without insulin treatment, children diagnosed with Type 1 could hope to leave no more than three years.[70] In *Sweetblood*, insulin keeps Lucy alive, and allows her to thrive, but it is also a reminder of the closeness of death. Without insulin, her body would deteriorate. Every injection, therefore, is a reversal of death and a reminder that she is "undead," as she calls herself.

Even with the discovery of insulin and other technological advances of the twentieth century, Feudtner points out that the "vulnerability" of people with Type 1 "persists." He writes that people with Type 1 remain "susceptible to complications even if the disease is treated appropriately" (xxii). Feudnter and others who write about the history of insulin are quick to remind their audiences that the very insulin which is necessary to sustain the life of a Type 1 diabetic is also deadly when administered in excess. Insulin needs constantly fluctuate based on a myriad of moving variables (e.g., health, stress, exercise, menstruation, and diet)—which increases the probability of overdosing.[71] (For readers familiar with the volatility of insulin, Lucy's cavalier approach to meal-time insulin at various points in *Sweetblood*, creates a palpable sense of fear).

In addition to the complications posed by the daily use of insulin, Lucy's diagnosis of Type 1 diabetes makes her susceptible to a rare phenomenon known as "dead-in-bed" syndrome. According to doctors Dror Koltin and Denis Daneman, "dead-in-bed" syndrome is a term exclusively used to describe the unexplained deaths of patients with Type 1 diabetes (505).

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[70] I would like to point out that there are still people with Type 1 diabetes who cannot access insulin, both in the U.S. and abroad, and who die as a result. A simple Google search will turn up numerous news stories of people who suffer the fatal consequence of "rationing" their insulin. To me, it is unconscionable that insulin has become one of the most expensive liquids on planet Earth when Frederick Banting famously sold the patent for $1. At the time of the writing of this thesis, there is growing support for legislation that reduces the cost of insulin in the U.S., but Type 1 can (for many people) still function as a deadly disease. To refer to it as a "chronic condition" is to acknowledge the privilege of access to insulin.

[71] My husband and I often refer to Type 1 diabetes as the "worst science experiment ever" because in a typical experiment you would have controlled variables and one independent (changing) variable. With Type 1 diabetes, there are multiple changing variables that need to be accounted for at any point in time.

Although “dead-in-bed” syndrome is a rare occurrence and far less common than instances of hypoglycemia (506), it nonetheless represents another way in which Type 1 can elicit fear in caregivers. With the knowledge of Type 1 as a potentially deadly disease, whose treatment can also be deadly, it is not difficult to understand why Lucy’s parents appear gripped by fear. It is Lucy’s awareness of her parents’ fear, however, that leads her to worry she will be othered for her diabetes.

### The (In)Visible Other and Passing as an Undead Monster

Lucy’s sense of “otherness” is apparent through her repeated references to herself as “undead.” In place of the terms “normal” or “other” used in disability theory, Lucy categorizes people into what she refers to as the “two races that matter: the *Living* and the *Undead*” (Hautman 12). According to Lucy’s definition, the *Undead* are people who owe their lives to modern science. Her theory concentrates mostly upon people who have had life-saving surgery (such as her father who needed an emergency appendectomy) or people whose daily lives rely upon medical intervention (such as her own dependence upon insulin). She counts her mother among the *Living,* even though it is likely that her mother has taken medicine at some point in her life to fight off a virus or infection (12). She also discounts her friend Wayne’s near-death car accident because she says the use of life-saving technology is canceled out when the initial problem was also caused by technology (i.e., Wayne’s car) (205). Lucy’s insistence on imposing complicated rules for what qualifies a person as *Undead* reveals her strong sensation of her own “otherness.” She could likely count her mother (and most people) among the *Undead*, but she does not. Instead, she chooses to separate herself into a category that marks her as something unnatural. Like Dr. Frankenstein’s monster, she *should* be dead. Like the monster, she exists among the living, but her undeath is a barrier that separates her from them.

In order to prevent being othered or feared as a“crippled” diabetic, Lucy masquerades as a proto-vampire and passes as non-diabetic. Lucy’s twisting of the masquerade as a method of passing complicates Siebers’ theory, which presents passing and the masquerade as mutually exclusive. According to Siebers, the desire to pass is a response to society’s call for uniformity, but the masquerade “counteracts passing” by “exaggerating or performing difference” (19). As a proto-vampire, Lucy simultaneously rejects uniformity and expresses the desire to be nondisabled. As a vampire, Lucy labels herself as a member of the Undead, rather than the Living (Hautman 12). Her identification as Undead is a rejection of uniformity, but it also allows her to pass as non-diabetic by drawing attention away from any clues that may reveal her diabetes. This is because Lucy’s masquerade as a vampire relies on the exaggerated performance of fear, rather than the performance of a stigma that might clearly signal “diabetes.”

In Siebers’ masquerade, stigma associated with a disability are “exaggerated” or “performed” in order to draw attention to the prejudices of society and “claim” a disability (19). I would add to this that Siebers’ theory works best if the stigma being performed are culturally recognizable. As a diabetic, Lucy feels stigmatized by the fear she perceives as associated with her diabetes. As a vampire, Lucy performs this fear—but to the unknowing observer the fear related to diabetes does not directly correlate with the fear related to vampires. In other words, Lucy *claims the fear* that she perceives is directed at her (through the masquerade), but she does not claim her diabetes identity.

Through Lucy’s masquerade as a fearsome vampire she fulfills her role as the feared “Other” while simultaneously regaining agency over her identity. Unlike her diabetes, a permanent part of her, her outward appearance can be altered. As a vampire, Lucy is able to take control of the fear that she perceives directed at her, and she literally cloaks herself in it. As a fearsome Undead creature, Lucy takes ownership of the fear and claims it on her own terms. However, as I will discuss in a later section, “The Masquerade as a Barrier to Illness Acceptance,” the agency that Lucy gains through the masquerade is false. Ultimately, the suppression of her diabetes identity as a “vampire,” results in a loss of physical control that is not sustainable.

## The Vampire as a Symbol of Agency

In *Girls in Contemporary Vampire Fiction* (2021), Angieszka Stasiewicz-Bieńkowska makes a compelling case for vampire fiction as an apt genre for addressing the anxieties of growing up. Stasiewicz-Bieńkowska asserts that vampire fiction addresses young adults’ concerns over things such as “searching for power, autonomy, control and belonging, struggling with unfamiliar yearnings and bodily transformations. . .” (2). As an adolescent with diabetes, Lucy experiences all of the concerns Stasiewicz-Bieńkowska lists through the lens of adolescence and through the lens of disability. Lucy needs to find her place within the world as an adult, and she also needs to find her place within disability culture. Her invocation of the vampire in her masquerade, therefore, is a powerful symbol of her feelings of otherness. The vampire is the embodiment of normalized fear and it challenges the fear of death associated with diabetes in its mastery of death.

In previous sections of this chapter, I have discussed how the vampire and diabetes are united through their connections to fear, specifically the fear of death, but in this section, I will explore a key difference between their relationships to death. Historically, a diagnosis of Type 1 resulted in certain death. For centuries, Type 1 diabetes drained the lives of its victims, very much the way a vampire drains the blood of its victims. Even with modern technological advances, diabetes continues to pose a constant threat to the body (Feudtner, 2003) and remains associated with a fear of premature death (Koltin and Daneman, 2009). The vampire's relationship to death is more complex.

The vampire is a harbinger of death who creates new life, because for the newly created vampire, there is eternal "life" after death. According to disability studies scholar Catherine Pugh in "Beautiful Monsters: Sickness, Disability, and the Extraordinary Body," part of the horror that vampires cause is due to their "hyper-alive" state of being. Pugh cites Rob Hall, who defines "hyper-alive" as "the opposite of death…too much life" (56). As an example of the horror inherent in "too much life," Pugh cites the fact that vampires (and other undead monsters) tend to be associated with vigor, passion and energy (57). Fans of the *Twilight* series may recall an image of Edward Cullen running at superhuman speeds through the forest while carrying Bella Swan. In the same film, there is also a scene where the Cullen family plays baseball during a thunderstorm because they need the loud booms of thunder to disguise their deafening hits to the ball. The athleticism of Edward and his family are an example of the vigor that vampires are known for, and which Pugh associates as a symptom of "too much life."

Thus, Lucy's masquerade as a vampire can be read as a reinterpretation of the fear created by the finality of death. Associating herself with a hyper-alive creature such as a vampire distances Lucy from the more permanent death and decay that result from her chronic illness. As a vampire, Lucy disguises herself as a creature that is brimming over with life, and who has claimed mastery over death.[72] Lucy's vampire image as Sweetblood communicates power and control, the image of which combats the weakness and lack of bodily control that are hallmarks of her diabetes. Unlike the vampires in folklore, the death of a person with diabetes was

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[72] Lucy's "mastery" over death as a vampire is somewhat complicated by the fact that she refers to herself as a "mortal" vampire (Hautman 84). In this section, my reference to the vampire's "mastery over death" is in reference to the vampire as a symbol of immortality. Even though Lucy does not believe she is immortal, her association with vampiric culture alludes to immortality.

permanent. The agency that Lucy gains through the masquerade is ultimately false because she can never fully control her diabetes. The masquerade becomes perilous when Lucy suppresses her diabetes identity so much, even in her own mind, that she fails to accept diabetes as a part of her identity and begins to ignore diabetes' demands.

### The Masquerade as a Barrier to Illness Acceptance

Because her masquerade as Sweetblood the vampire is a way to retreat from Lucy's disability, that identity also becomes a barrier in the path toward managing her illness. Ultimately, Lucy's participation in the masquerade causes her to reject the responsibility of managing her disease. When Sweetblood the vampire is dominant, Lucinda the diabetic suffers. As vampires must accept their nature in order to maintain vitality (Bunson 28), Lucy must accept her illness in order to live. In order for acceptance to happen, however, the internal conflict between these dueling identities must reach a resolution. This is not a simple task, as evidenced by Lucy's recurring health problems that worsen as the story progresses.

Although Lucy often demonstrates complex knowledge regarding her illness, this is not to be confused with acceptance. Illness acceptance is a psychological state which can be defined as, "the successful adjustment to a chronic illness and to the unpredictable and adverse consequences associated with the disease" (Zhen et al. 456). Lucy's repeated disregard for the consequences related to her diabetes prove that she has not successfully adjusted to life with a chronic illness. On several occasions, Lucy makes conscious decisions to forgo diabetes care in favor of acting "normal." In an internal monologue during a meal, Lucy muses over what might be happening to her blood glucose levels:

> I eat my beans and wonder which way my blood glucose is going. If I took too much insulin it will be dropping into the danger zone, below seventy milligrams

> per deciliter. I could be heading for another insulin reaction… Or maybe I didn't take enough insulin and the beans are driving my sugars up, up and away—400,... 500… 800…! (Hautman 23)

Even though Lucy presents two different scenarios which might put her into danger, she never moves beyond wondering and into physical action. She never tests her blood sugar, for example, to confirm or refute her suspicions of an impending problem. Ultimately, she decides to eat her beans and "let the numbers take care of themselves" (23). This would be fine if she had a healthy, functioning pancreas, but for Lucy this is an extremely cavalier approach. First, the numbers are incapable of "taking care of themselves." Second, there are immediate health risks associated with being wrong. Too much insulin can result in severe hypoglycemia (low blood sugar), which can lead to seizures, loss of consciousness, or even death (Scheiner 220).

In a later scene, Lucy shows a similar disregard for hyperglycemia (high blood sugar). After drinking a cappuccino, for which she did not administer insulin, Lucy ponders what might have happened to her blood sugar. She thinks, "I should check my blood sugar… Sometimes when I have weird thoughts—like turning into a bug—it means my glucose is out of whack" (Hautman 96). Even though Lucy has a reason to believe her blood glucose is "out of whack," and she knows what she *should* do, she again fails to take action. Instead of testing her blood sugar, she simply writes the number 112 on a slip of paper. This is the number that she says she hopes for, "A nice, normal non-diabetic number" (96). For Lucy, though, diabetic numbers *are* normal. Her failure to recognize this fact underscores the idea that her disease has not been normalized. It is ironic that by avoiding her diabetes, and the fear associated with it, she creates a more precarious situation for herself and pushes herself farther away from the "normal" numbers she wants. Ultimately, it is Lucy's disregard for her the truths inherent in her diabetes identity—the ongoing management that diabetes requires—that leads her to have a heart attack. In one of the final scenes of the novel, she awakes in a hospital bed, surrounded by her parents and her friend, Mark.

## The Unraveling of the Masquerade

When Lucy realizes that the people who are afraid *for* her are the same people who love her, she is finally able to begin accepting her illness. When she returns home from the hospital, she talks about what it was like to wake up after her heart stopped: "When you die and then come back, the people who are there when you wake up are the people who love you. And that is why I am miserable. Because they are the people I hurt the most" (Hautman 225). In this reflection, Lucy finally accepts responsibility for her actions. She acknowledges that her family loves her, and she admits that her choices can hurt people.[73]

After this realization, Lucy begins taking active steps toward better management of her illness. In a cafe, she questions if she is having an insulin reaction and, instead of dismissing her concerns—as she did previously—she takes out her meter and tests her blood glucose in plain sight. She also makes the observation that, "No one is watching; no one cares" (Hautman 234). At this moment, Lucy's self-identification as feared "other," an *undead* monster, begins to unravel. Because no one in the coffee shop reacts to her testing, she is able to experience feelings of normalcy in conjunction with her diabetes. This feeling culminates in Lucy's decision to alter her outward appearance to reflect the "normalcy" she feels inwardly. She strips the artificial black color from her hair and returns to her natural blond (238), shedding part of the vampire facade that helped protect her by drawing attention away from her identity as "Diabetes Girl."

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[73] In an earlier scene, Lucy's parents stage an intervention and suggest that she see a psychologist. In this scene, her mother says "love" twice in reference to Lucy. But, Lucy's internal dialogue in this scene is merely "BLAH BLAH BLAH." She neither reciprocates nor acknowledges her parents' love for her (Hautman 71-72).

## Conclusion

From the moment of Lucy's first injection, the entire course of her daily routine shifted dramatically. As Lucy's mother demonstrates, the day of diagnosis was terrifying and fraught with questions of *why* (Hautman 5). But, Lucy's diagnosis is not recent in this novel. She was diagnosed at the age of six and she is sixteen during the events of the story. Therefore, it is not just the diagnosis that leads *Sweetblood*'s protagonist to the perception of herself as a feared "other." Her conclusions come from years of influence and observations. Her parents' persistent fears prevent Lucy from viewing her illness as normal and lead her to expect fear from everyone around her. Specifically, this text draws attention to the potential danger of taking the masquerade too far, and the need for normalization of an illness. It is cliché to say that people fear change, but beneath every cliché is a cornerstone of truth. People *do* fear change. As Lucy's mother says, "You know, when someone you love seems to change suddenly, it's a little scary" (Hautman 72). Although she is talking about school and grades in this particular scene, the sentiment expressed can easily be applied to Lucy's initial diagnosis. For a person with Type 1 diabetes, the change from healthy and "normal" to chronically ill and "disabled" is swift and irreversible. Normalizing Lucy's diabetes could have given her the agency over her identity that she desperately craves.

Lucy's disease has infiltrated every corner of her life, tying it irrevocably to her identity. Even when she participates in the masquerade in order to hide her diabetes, she cannot escape the reality of the demanding nature of her chronic illness. This is because Type 1 diabetes in particular is a disease which demands a high level of vigilance. It is a persistent illness which urgently demands not only acknowledgement but immediate response. Lucy's survival depends upon personal acceptance of her illness, but the way she perceives her illness through the eyes of others weighs heavily on her. As disabilities scholar Leonard Kreigel writes, “The cripple is a creature who has been deprived of his ability to create a self. If others cry, like God from the burning bush, ‘I am what I am,’ the cripple in literature is expected to submit to the cries of others to say, ‘I am what you tell me I am’” (Kriegel 33). In *Sweetblood*, Lucy’s personal views of her illness matter much less to her than her perception of how others view her.

While studies show it is possible for adolescents with invisible illnesses to “pass” as non-disabled and coexist in multiple social circles (Chalmers et al.; Valeras), Lucy’s example demonstrates the danger of attempting to pass all of the time. As she clings to the vampire identity that she has created for herself, she pushes further away from identifying with her disabled identity. This inhibits her ability to respect the very real dangers associated with Type 1 diabetes, and it prevents her from understanding the concerns her friends and family feel for her safety. On more than one occasion when posing as a “normal” proto-vampire she suffers the consequences of cavalierly responding to warning signs of high or low blood sugar. The pinnacle of these experiences is two minutes of cardiac arrest. It takes a literal near-death experience and an admission of fear from her best friend for acceptance of her illness to begin. Finally, she wakes up and realizes that the people who love her don’t fear *her*, they fear *for her safety*.

# Chapter Four: Reasonable Doubt: The Diabetes Mindset as Pervasive and Untrustworthy in *The Girls Are Never Gone* by Sarah Glenn Marsh

In this final chapter, I focus on *The Girls Are Never Gone* (2021) by Sarah Glenn Marsh, a book with a fantastic, supernatural premise that has more in line with what film critic Kevin Ferguson refers to as “outlandish” and “low-budget” horror films than the more typical, realistic adolescent diabetes novels discussed earlier in this thesis. In the previous chapters of this thesis, the books I analyze fit into three categories that are common within Type 1 fiction. The books each do one of three things: they tell a Type 1 diagnosis story (*Kristi’s Great Idea, The Truth About Stacey*), intertwine a diagnosis story with a heterosexual romance (*Will I Ever Dance Again, Let Me List the Ways*), or highlight a time of mental burnout that results in diabetes distress (*Stacey’s Emergency, Sweetblood*).[74] Although these categories represent different approaches to representations of Type 1 diabetes in fiction, they share something in common: they ultimately employ diabetes as tragic or pitiable. These stories draw upon a perpetuated cultural schema of diabetes in which, “people with Type 1 are largely cast as victims,” according to Jeffery Bennett in *Managing Diabetes: The Cultural Politics of Disease* (2019, 13). Viewing the Type 1 female as a victim suggests her inherent weakness and a passivity in which she responds to diabetes, the invisible aggressor. In *The Girls Are Never Gone*, Virginia “Dare” Chase, a seventeen-year-old ghost hunter, subverts this common conception of the person with Type 1 as a victim by taking the lead role in a ghost hunt.

What Dare’s character contributes to the canon of YA disability literature extends beyond the limited subgenre of Type 1 diabetes fiction, however. Her story acts as a commentary on the relationship between chronic illness and one’s perception of the world. Dare is more than a

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[74] Although *Sweetblood* nods to the gothic genre with a punk protagonist who dresses in black and is entranced with vampire lore, Hautman’s novel does not venture so far as to confirm the existence of immortal beings who subsist on blood.

teenager dealing with the ramifications of a chronic illness. Through the character of Dare, readers experience a young female detective whose chronic illness has influenced the way she interacts with other people, and how she perceives her surroundings. For example, Dare's interest in ghosts (which began when her grandfather died) intensified after her Type 1 diagnosis at the age of fifteen. Dare says, "My [sic] diagnosis only made me need some proof of the afterlife more… My need for proof is why I started hunting ghosts" (Marsh 9). In this chapter, I will explore Dare's portrayal of Type 1 diabetes and how diabetes informs her mindset. I am particularly interested in the ways that diabetes management practices made visible can expose the ongoing, complex negotiations that diabetes requires—rather than just individual moments of crisis (e.g., diagnosis), but as a way of *thinking*. In *The Girls Are Never Gone*, Dare's management practices made visible reveal the pervasiveness of the diabetes mind. Furthermore, through Dare's pursuit and skepticism of the supernatural, she defines the diabetes mind as both morbid and rational.

## Summary of *The Girls Are Never Gone*

Before I delve into Dare's story and my analysis, I summarize Sarah Glenn Marsh's book and point out several other aspects that make it unique in terms of diabetes fiction for adolescents. Virginia "Dare" Chase is a seventeen-year-old ghost hunter with a podcast titled *Attachments*. She was diagnosed with Type 1 diabetes at the age of fifteen and she manages her condition with an insulin pump, continuous glucose monitor (CGM), and the help of an unreliable, but friendly, service dog named Waffles.[75] In *The Girls are Never Gone*, Dare spends part of her summer interning for the historic Arrington Estate, an old home in New Hope, Virginia which is rumored to be haunted. Dare believes the haunting may be related to the mysterious death of a young girl named Atheleen Bell. She plans to spend her summer solving

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[75] See footnote 1.

the mystery of Atheleen's death and uncovering the secrets lurking within Arrington Estate. In a teen detective story that harkens back to the premise of *Nancy Drew* mystery series, Dare investigates strange happenings at Arrington Estate with the help of two female friends: Quinn and Holly. The narrative structure of three teenage girls solving a mystery while the adults around them remain clueless may be the greatest similarity between Dare and Nancy's stories, though. Unlike the classic *Nancy Drew* mysteries, where the culprit is unmasked or the haunting is debunked, the paranormal events in *The Girls Are Never Gone* turn out to be real.

Although Dare is interested in solving the mystery of Atheleen's death, she maintains her skepticism of the supernatural and presents herself as a rational investigator, focused on the facts. At the start of the story, she expresses doubt that she will encounter any lingering spirits. She says:

> I'm a far cry from the hoaxers and conspiracy theorists willing to disregard the scientific because they *need* something more. But since I crave that something more, too I'll keep stalking the dark and searching for answers—for myself, and for my listeners. If I ever get them. (Marsh 9)

Dare's admission that she, too, needs "something more" in spite of her refusal of supernatural explanations is an early hint at an internal conflict. It is often unclear in the novel if Dare is trying to prove whether ghosts exist, or whether they don't. Even still, she continues her search in order to fill an even stronger desire that seems to defy the absence of evidence she has accumulated after years of exploring haunted sites.

## Diabetes and Paranormal Horror

Although *The Girls Are Never Gone* is a book rife with paranormal activity, it is not the ghosts I am interested in, but the fact of Dare's skepticism and attention to management in a world that is full of confusing events and (eventually) horror. Ironically, it is within the unbelievable genre of horror that film critic Kevin Ferguson claims to find diabetic heroes who are more "truthfully expressive of lived diabetic experience" (200). In "The Cinema of Control: On Diabetic Excess and Illness in Film," Ferguson writes about diabetic heroes from two low-budget horror films. He claims that they "place diabetic heroes in such outlandish scenarios that it becomes nigh impossible to make metaphor of the disease" (200). According to David Mitchell and Sharon Snyder in their book, *Narrative Prosthesis: Disability and the Dependencies of Discourse* (2000), a shortcoming of the *material metaphor* is that it does not address "disability as an experience of social or political dimensions" (48). Mitchell and Snyder's "social and political dimensions," I argue, is an aspect of Ferguson's concern for the "truthfully" lived experience. This suggests that Dare's position as a heroine within a similarly "outlandish" horror scenario might better position her character to portray a truthful diabetes experience that is multi-dimensional.

Arrington Estate is haunted by the tormented ghosts of several young girls, all of whom were murdered by the vengeful ghost of Henrietta "Hettie" Arrington. Hettie, who was wicked in life and is evil incarnate in the afterlife, threatens to kill anyone that reminds her sisters, whom she despised (232). Dare describes the climactic scene of confronting Hettie as a "nightmare come to life" (306). But, in spite of living in a nightmare, Dare maintains her composure and continues to attend to her diabetes. After nearly being dragged underwater to her death by Hettie's ghost, Dare immediately thinks, "Thank goodness my CGM and pump are waterproof" (213). Amidst the trauma of nearly drowning, diabetes is one of the first thoughts on her mind. This reveals the truthfulness of "lived experience" that Ferguson notes within horror. Importantly, I believe this moment achieves its truthfulness by subtly addressing the political dimension posed by diabetes technology. An insulin pump and a CGM are expensive pieces of equipment. Without health insurance, they can each cost thousands of dollars. At one point in the story, Dare demonstrates her ability to order a new pump when she experiences a technical malfunction (166), but warranties have limitations. Even with a warranty, there is always the added burden of a phone call to an insurance company or a medical supply distribution company in order to have the warranty honored. Dare's relief that her equipment is "waterproof" responds to these unspoken political dimensions that would impose an unexpected additional burden on her.

### Dare as a Rational Detective

At first, Dare's insistence on finding "real" explanations for the strange happenings at Arrington Estate makes her appear rational when compared to her peers: Quinn and Holly. Dare continually refers to herself a "skeptic," and she persistently looks for real-world explanations to unexplained events. Dare's search for ghosts oscillates between professed emotional support for her friends (Quinn is convinced of a haunting) and a personal mission to prove that ghosts don't exist. Dare and Quinn's different interpretations of strange events such as a displaced shadow in a photograph—which Dare believes to be a coat rack and Quinn believes to be a ghost (Marsh 174)—emphasizes Dare's rejection of the supernatural.

Dare discounts supernatural explanations in favor of "scientific, natural causes" that mirror the types of explanations she often relies upon to explain high or low blood sugar. When her blood sugar is on its way down during a car ride she says that the insulin is "taking effect" (18), and when it rises after dinner one night she says it is "from the cheesecake" (140). In both of these situations, Dare uses cause and effect to explain how her body reacts to food, insulin, and exercise. References to Dare's blood sugar in *The Girls Are Never Gone* often resemble the two examples in this paragraph, where the rising or falling of glucose numbers is directly attributed to natural, quantifiable causes. These repeated references to blood sugar numbers, therefore, demonstrate Dare's frequent reliance upon science. Thus, Dare's scientific method in ghost hunting, is a reiteration of the method she uses to manage her diabetes. Dare's unique approach to ghost hunting (in comparison to that of her non-disabled peers) is an example of what Susannah Mintz refers to as the ability of the "disabled detective" to "enact intriguing alternatives for how to think, enquire, and understand" (13). In the introduction to Mintz's book, *The Disabled Detective: Sleuthing Disability in Contemporary Fiction*, she argues that for disabled detectives, their detecting often occurs in "surprisingly disabled ways" in which disability becomes a mode, part of the process (13-14). For Dare, the incorporation of her diabetes into the process of detecting seems to be more of a hindrance than a help.

Dare's diabetes hinders her detecting when it causes her to question the reliability of her senses. For example, when Dare notices an extra shadow following Quinn, she doubts what she sees and surmises that a possible explanation is "blurry vision" due to a slightly elevated blood sugar level (Marsh 148). Dare provides a similar blood-sugar-related explanation when she hears a mysterious voice interrupt an audio recording and say, "Leave Dare. She won't save you either." It's late at night and Dare first notes that she is tired; but she quickly follows this with the observation that her blood sugar is a bit low (153). The reference to Dare's low blood sugar implies a relationship between her physiological state and her doubt that the voice she hears is real. These two examples, the misplaced shadow and the mysterious recording, demonstrate Dare's uncertainty in her ability to distinguish diabetes-related physiological effects from other sensory experiences. They also show that multiple senses are impacted: sight as well as hearing. The side effects of Dare's diabetes, therefore, result in her failure to trust her instincts. When the existence of ghosts turns out to be true, Dare's previous analysis of the evidence falls apart. Rather than appear rational, Dare appears to be a girl in denial of the evidence in front of her.

### Blood Glucose Management Is Mundane

Dare's failure to accept supernatural explanations for the strange happenings at Arrington can be traced to her preoccupation with the mundane. Management of a chronic illness, such as Type 1 diabetes, is an ongoing and evolving process that involves the consideration of a multitude of factors. Ferguson, who writes about diabetes in horror films, makes the distinction that he finds diabetes management to be anything but "horrific." He claims that the process of managing diabetes is characterized by "boredom," which he calls the "opposite" of horror (184). The connection between diabetes management and boredom can be further understood through Jeffrey Bennett's description of the daily, mundane activities that complicate diabetes management. He writes: "Diabetes management is not merely about counting carbohydrates and administering insulin but is complicated by factors such as a lack of sleep, stress, exercise, caffeine, and a host of idiosyncratic circumstances" (5). Bennett's description suggests a connection to boredom that results in a necessary preoccupation with the mundane. In *The Girls Are Never Gone*, Dare's preoccupation with mundane is evidenced during "boring" moments when she calls attention to her blood sugar. She describes how her blood sugar can be affected by everyday occurrences such as nervousness (Marsh 7), exercise (33), stress (121), desserts (140), and nightmares (161). The variety of situations she describes reveal the complex nature of management in her life, as well as her necessary attention to moments that are "boring." Dare's repeated attention to these boring, mundane diabetes moments challenges what Ferguson refers to as "diabetic excess" in narratives in Type 1 characters.

In an analysis of Type 1 diabetes representation in films, Ferguson explains how the concept of management is undermined by an intense focus upon crisis.[76] In his essay, "The Cinema of Control: On Diabetic Excess and Illness in Film," he explains that the invisibility of diabetes often "necessitates a dramatic presentation in order to be made legible," but that an emphasis on what he calls an "excessive moment" makes diabetes *more* invisible. As an example, he references the infamous scene from the 1989 film *Steel Magnolias* when Shelby experiences severe hypoglycemia and becomes "intensely out of control" (184). Ferguson argues that defining diabetes by what he calls "excessive moments" creates direct opposition to the concept of management. He states that when diabetes is only revealed through "excessive moments," such as Shelby's severe hypoglycemia, then "diabetes only exists for [the diabetic] and the viewer as a breakdown and never as a lived experience" (189).[77] Although Dare does treat low blood sugar on several occasions in *The Girls Are Never Gone* (Marsh 32, 153, 305), she never experiences an emergency that requires medical intervention. In each instance when Dare is low, she is able to correct her blood sugar by eating glucose tablets or another fast-acting sugar. Her friends occasionally offer her help, but she always appears capable of helping herself—creating distance between her moments of low blood sugar and the concept of crisis.

A crisis allows us to easily "see" diabetes, but in seeing diabetes only through the lens of crisis, we fail to fully understand it. Ferguson's observation suggests the elusiveness of chronic illness management within the public consciousness. I believe this elusiveness stems from a conflation between visibility/crisis and invisibility/control. According to Bennett, diabetes's inherent invisibility, both literally and in the minds of the public, breeds the notion that it can be

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[76] Although Ferguson focuses only on cinematic examples, his findings relate to literature—in which the diabetes diagnosis story and the burnout story, moments marked by tragedy and loss of control, are recurring tropes.

[77] Contrary to the sensationalized depictions found in films, Ferguson describes diabetes management as "more than anything, characterized by boredom" (184).

"casually" managed (11). Bennett explains further that "in some outlets, diabetes is positioned as thoughtlessly managed by swallowing a pill or programming a pump" (7). This passive form of "casual" management that Bennett describes, which he links to invisibility, might suggest the public's understanding of a more active management is directly related to the highly visible "excessive moments" described by Ferguson. Dare's portrayal of diabetes within *The Girls Are Never Gone*, which is frequently evidenced through her thoughts and actions, challenges the notion that active management is necessitated by crisis alone. Furthermore, Dare's frequent attention to her diabetes in regards to social and physiological factors, in moments of calm as well as excitement, demonstrates the pervasive nature of her diabetes-related thoughts.

## Crip Time and the Pervasive Diabetes Mindset

Two disability theories that I believe are helpful frameworks for thinking about management and mindset in *The Girls Are Never Gone* in relation to chronic illness are *crip time* and *everyday attentiveness*. "Crip time" refers to the way that people with disabilities experience time differently. It is an emerging concept made popular by disability scholars such as Alison Kafer and Ellen Samuels. In Samuels' narrative essay "Six Ways of Looking at Crip Time" she compares "crip time" to a form of time travel. Samuels writes:

> Disability and illness have the power to extract us from the linear, progressive time with its normative life stages and cast us into a wormhole of backward and forward acceleration, jerky stops and starts, tedious intervals and abrupt endings. . . We who occupy the bodies of crip time know that we are never linear. . .

For a person with Type 1 diabetes, this concept of "crip time," or altered time, relates to the way management insinuates itself into the fabric of daily life. Management hums beneath the surface of every decision, and it can suddenly impose itself in a moment of urgency, forcing everything else around it to stop. Through Dare's service dog, Waffles, readers experience a sense of time that is subject to the sudden demands of management. Even though Waffles is not the most reliable service dog (Marsh 6), when he alerts Dare that she may have high or low blood sugar, she attends to him, and thereby to her diabetes (32). The urgent attention that Waffles demands helps to clarify the interruptions created by "crip time." Waffles' constant physical presence, even when he does not demand urgent attention, creates an apt metaphor for explaining the next theoretical concept: *everyday attentiveness*.

The *everyday attentiveness* of people living with diabetes is a concept explored through the ethnographic research of anthropologist Tine Gammeltoft. In her article, "Everyday Attentiveness: Understanding Diabetes in Vietnam Through Literary Displacement," Gammeltoft explores the daily physical and emotional demands of life with Type 2 diabetes for residents of Vietnam, but which I argue also has implications for Type 1 diabetes.[78, 79] A key finding in Gammeltoft's research is the disparity between the narrow medical guidelines for diabetes management and the lived experiences of people with diabetes in which the "diabetes mindset" acts more like a lens through which all areas of life are viewed (596). Gammeltoft describes *everyday attentiveness* as the struggle to balance diabetes medical responsibilities (needs) with social pressures (desires) (603). The concept of *everyday attentiveness* demonstrates an altered mindset that expands beyond the personal experience of time (or "crip time") and into the social

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[78] Admittedly, there are cultural differences between the U.S. and Vietnam that may limit the application of Gammeltoft's findings, which are heavily concerned with social interactions. Also, there are fundamental differences between both the medical nature and cultural perception of Type 1 and Type 2 diabetes that are worth noting. One basic difference between Type 1 and Type 2 is the former is considered "insulin dependent," whereas the latter is often referred to as "*non*-insulin dependent." Type 1 diabetes requires injections or infusions of insulin due to the body's inability to produce insulin, but Type 2 does not necessarily require insulin therapy (Feudtner xviii). Furthermore, the two types are perceived differently by the general public. Bennett writes that within a cultural context "these two forms of diabetes are distinct because of the blame assigned to people with Type 2 (13).

[79] Although Type 1 and Type 2 diabetes are different conditions, they are connected by common threads of chronic illness management, as well as the stigma of disease. Bennett writes of the strong stigmas attached to perceptions of improper diabetes management, which "is well known among people with diabetes" (19).

ramifications of how culture and individuals perceive chronic illness. With regard to Type 1, I will hereafter refer to this altered way of thinking as the *pervasive diabetes mindset*.[80]

One aspect of the pervasive diabetes mindset that I want to explore is the concept of disability disclosure as it appears within *The Girls Are Never Gone.* For adolescents with Type 1 diabetes, the process of disclosing their Type 1 status can be beneficial to their health and well being. In a 2016 study of Type 1 adolescents, the majority of participants reported "feeling glad they disclosed their diagnosis to their friends" because of the practical support they received as a result, according to Persis Commassaris et al. (678). In *The Girls Are Never Gone*, Dare smiles when she learns that one of her roommates at Arrington Estate has knowledge of Type 1. She explains to the reader that it's nice to know there is someone nearby who can recognize high and low blood sugar—or know how to administer glucagon in an emergency (34). Dare's smile demonstrates her relief and a sense of ease out of knowing that she is not the only person in the house who is capable of responding to a diabetes emergency. The fact that Dare's thoughts quickly transitioned to emergency planning upon learning that her roommate has a relative with Type 1 suggests that the pervasive diabetes mindset is concerned with not only crisis management, but crisis preparedness as well.

### The Politics of Passing

Even though social support is an obvious benefit to disclosure, and can create a safety net, the decision to disclose is further complicated by the fact that chronic illnesses lend themselves more readily to "passing by default"—a phrase introduced by Ellen Samuels in the

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[80] The *pervasive diabetes mindset* is a phrase that builds upon the concept of everyday attentiveness, but which I feel implies a more active and imposing way of thinking, as opposed to an attentive response. In "Everyday Attentiveness" Gammeltoft often uses the word "pervasive" in a more passive context to describe the attentiveness that is the subject of her ethnographic study (595). However, I find it helpful to apply the term "pervasive" directly to "diabetes mindset" in order to imply the active, imposing nature of this altered and attentive way of thinking. *Everyday attentiveness* suggests that the individual is an actor who responds to diabetes, but the *pervasive diabetes mindset* gives agency to the mindset itself.

article, “My Body, My Closet: Invisible Disability and the Limits of the Coming-Out Discourse.” In her article, Samuels attributes “passing by default” to a lack of disability signifiers (240-1), such as with an invisible chronic illness. In *The Girls are Never Gone*, Dare reveals an awareness of her ability to “pass” when she initially meets the two girls who become her investigative sidekicks, Holly and Quinn, who are also summer interns at Arrington Estate. When Dare “sneaks a glance” at her blood sugar number on her phone (Marsh 18), she simultaneously acknowledges her ability to “pass by default” and transitions to what Samuels refers to as “passing deliberately” (240). Dare acts covertly and discreetly, so as not to draw attention to the visible signifier that might alert someone to her diabetes.

Dare’s thoughts in a later scene, in which she evades answering a question about a diabetes joke printed on her T-shirt, reveals what she perceives as a negative consequence of disclosure. When Quinn asks about the meaning behind the phrase VAMPIRE’S FAVORITE DESSERT, which is printed on Dare’s T-shirt. The phrase is a reference to the sweet blood of people with diabetes, and could have allowed Dare to segway into sharing about her diagnosis. But Dare deflects the question and replies with uncertainty: “I uh, love Halloween” (25). Without further explanation, it might appear that Dare doesn’t trust Quinn, or that she lacks confidence with regards to her disability identity. But Dare’s thoughts after this statement reveal a reasoning that is undergirded by the tension between her responsibility as a friend and the weight of diabetes as a personal burden. Dare thinks to herself: “I shouldn’t be lying to Quinn, but now I don’t have to explain, or deal with the popular misconceptions that always crop up” (25). Quinn is a new friend whom Dare likes. So, the reader can infer that Dare wants to tell the truth in order to show that she trusts Quinn. However, she is reluctant to place herself in the role of being a diabetes educator. Dare’s statement that “popular misconceptions always crop up” refers to her years of experience as a person with diabetes. The thoughts she shares with the reader, therefore, appear insightful.

Dare further illuminates on the responsibility of educating non-diabetics when she experiences a low blood sugar in front of her friends, and she is no longer able to "pass." After going on a walk with Holly and Quinn, Dare's blood sugar starts falling. She "shoves" several glucose tablets in her mouth (to raise her blood sugar) and her face "burns" (Marsh 33) with what the reader might initially perceive to be embarrassment. Again, though, this moment is quickly followed by Dare's thoughts surrounding the idea of diabetes education as a burden. She thinks to herself, "I'm not sure I have the energy right now to give the Type 1 Diabetes 101 lecture" (33). This explanation from Dare suggests that her face "burning" might be from anxiety, rather than embarrassment. Her thoughts point to a concern that her secret will be revealed to her new friends, and she will be forced to teach them about her condition, even though she doesn't have the energy to do so.

## Diabetes "Awareness" and the Crisis of Signification

What is unique about this second interaction, though, is that Holly recognizes the visual cue of Dare eating glucose tablets. Holly infers that Dare has diabetes, and this allows Dare to inform the reader of another concern related to disclosure: the conflation between Type 1 and Type 2 diabetes. When Holly asks, "You're diabetic?" Dare's response is to "wince" and "groan" before thinking to herself, "[Holly's] going to tell me about some relative who lost a foot due to Type 2 diabetes, which is a disease of insulin resistance, not the insulin deficiency that is Type 1" (33). The fact that Dare's narration provides basic definitions of Type 1 and Type 2 diabetes suggests that the confusion is common. Jeffery Bennett describes the confusion between the various kinds of diabetes as a "crisis of signification." His explanation goes beyond a simple confusion between Type 1 and Type 2 diabetes. He writes, “Disparate visions of diabetes and its management circulate unceasingly and inharmoniously in public culture, contributing to a confusion, if not opaque mystification about the disease” (7). In Dare’s mind, she is immediately aware of the cultural confusion surrounding the word “diabetes.” Dare assumes that the reader, and Holly, are both unaware of the difference between Type 1 and Type 2. Dare’s visceral reaction (her wincing and groaning) after Holly’s mention of “diabetic” allows the reader to feel the weight of burden Dare feels from living with a misunderstood chronic illness.

Perhaps this awareness of the “opaque mystification” surrounding diabetes is why Dare willingly allows the reader to enter her bedroom when she changes the insulin pump infusion site on her body.[81] In this scene, she educates the reader on an intimate part of her routine, which demonstrates her willingness to be vulnerable as well as her willingness to educate (even though she previously establishes *needing* to teach as a burden). Dare’s choice to walk the reader through the various steps of her insulin pump routine is unique, and it goes to highlight her character’s emphasis on management rather than control. It is far easier to find an example of a narrator who alludes to an injection or an activity with an insulin pump, but who glosses over the moment and never shows the reader what she is doing. Dare not only describes the process in detail, she even shares that her left hip is her “favorite spot where there are fewer nerve endings to sting” (145). This scene allows the reader to witness a normal part of Dare’s routine where she must exercise care, caution, and precision.

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[81] Insulin pumps are connected to the body using a thin cannula or a small needle that is inserted under the skin. Every two or three days, the insulin pump should be moved to a new location on the body. Old infusion sites can become “exhausted,” where they no longer absorb insulin properly and they can also be prone to infection. My daughter has worn an insulin pump since 2014 and when she was about five years old, one of her infusion sites became infected. The infected area resulted in a large abscess that needed to be drained by a surgeon, twice. In spite of the risk of infection, my daughter continues to wear an insulin pump because she prefers changing the pump every few days to the alternative: multiple injections daily.

## Conclusion

Dare's actions and narration reveals an active, attentive way of perceiving the world that is both informed by and influenced by living with a culturally misunderstood chronic illness. Her skeptical approach to ghost hunting reveals a concern for empirical evidence and precision that parallels her careful approach to her diabetes management. In the same way that she carefully measures her blood glucose, and weighs the consequences of her decisions upon her body, Dare's instinct as a ghost hunter is to seek a real-world, rational explanation for supposedly supernatural events. There are more than one dozen references in *The Girls Are Never Gone* to specific, numeric glucose readings. Furthermore, Dare's frequent attention to her diabetes is made apparent through other mundane management practices such as treating low blood sugars with glucose tablets or giving herself a dose of insulin via her pump.

She does not appear encumbered by her disease, however. She is a lead investigator who tenaciously pursues the truth, even when the truth leads her to a "living nightmare." The most telling aspect of Dare's representation is the thought processes she narrates for readers, which reveal the deep political and social dimensions behind decisions related to her diabetes. Rather than simply presenting a diabetes diagnosis as a burden, Dare's hesitation to disclose elaborates on the ways in which Bennett's "crisis of signification" around diabetes has complicated her life. Her hesitation to disclose her diabetes to her friends, Quinn and Holly, is presented as an emotional burden due to a cultural lack of understanding. Unlike Stacey McGill and Lucy Szabo, who hide their diabetes out of shame or the fear of rejection, Dare's character directs our attention to society's misconceptions. It is the cultural invisibility of diabetes and the self-imposed responsibility to teach others (rather than the disease itself), which appears to be the heaviest burden upon Dare's mind.

Dare's diabetes mindset not only encourages her interest in the paranormal, it informs her approach to ghost hunting. A self proclaimed skeptic, Dare instinctively looks for rational explanations to unexplainable events. The pervasiveness of her diabetes mindset reveals the disruptive, unrelenting nature of diabetes's demands in Dare's life, which do not yield. Even in dramatic moments, when Dare is distracted by evil ghosts who threaten the lives of her and her friends, she still attends to her diabetes. Dare's management made visible challenges the cultural perception noted by Bennett that diabetes management is "casual" (11). As Bennett and others referenced in this chapter have argued, the issues related to diabetes extend into areas of social concern because the term "diabetes" is deeply embedded with conflicting cultural significations and understandings. Through Dare, readers experience a *pervasive diabetes mindset* that insists upon being plunged into the morbid world of horror.

# Conclusion

Through my exploration of the treatment of Type 1 diabetes within adolescent fiction, I hope this thesis will begin to chip away at what Bennett (2019) refers to as diabetes' "crisis of signification." The books I analyzed in the previous chapters, *Kristy's Great Idea* (1986), *The Truth About Stacey* (1986), *Stacey's Emergency* (1991), *Will I Ever Dance Again?* (1982), *Let Me List the Ways* (2018), *Sweetblood* (2003), and *The Girls Are Never Gone* (2021), all are linked by their teen girl protagonists. These girls continue a pattern noted by Chris Saad's study of chronic illness in adolescent novels, which claims that the vast majority of chronically ill teen characters are female. Although these books represent different genres, their stories mostly fall under the broader category of realistic fiction—the one exception being Sarah Glenn Marsh's book, *The Girls Are Never Gone*.

My analysis of the Type 1 diabetes representation within fictional texts for adolescent readers reflects a complex relationship between diagnosis and identity formation, but a lack of cultural or political dimensions that inform the disability narrative. Overall, the seven novels explored in this thesis are persistent in establishing the straight, White female as the "every girl" of diabetes fiction.[82] The general homogeneity of these texts' protagonists, as well as the tendency for texts to be *realistic* fiction, critically limits the scope of their diabetes portrayals. As disability narratives, these texts often prioritize emotional struggles, such as illness acceptance, and they tend to minimize issues with cultural or political dimensions. Furthermore, these texts often appear to elevate blood sugar control as a kind of pseudo "cure," because specific glucose readings are more often mentioned when diabetes is out of control, or a subject of concern.

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[82] Dare Chase in *The Girls Are Never Gone* is a partial exception to this pattern. Dare is White and female, but she is not straight. She is bi-sexual.

In the first three chapters of this thesis, the six texts that I analyze reference specific blood glucose numbers most often when there is a perceived diabetes-related problem. These problems usually occur within the context of the two primary diabetes narratives that commonly recur within adolescent fiction: the "diagnosis" story and the "burnout" story. Each of these narrative tropes—the diagnosis story and the burnout story—have an important place within disability fiction. The diagnosis story provides a platform for educating readers on the symptoms of Type 1 diabetes, as well as the prescribed methods of management. For readers familiar with Type 1, these books can also be a source of comfort, or bibliotherapy. Multiple readers of the Baby-Sitters Club series have written fan letters to Ann M. Martin, thanking her for the creation of Stacey McGill. Since the advent of the BSC series in 1986, Stacey has helped young girls with Type 1 feel less alone (DeCosta); and her story has even helped some readers identify their own diabetes symptoms before the condition became fatal (Becker 154). Like the diagnosis story, the burnout story is another common narrative trope within diabetes fiction that represents a moment of crisis.

Burnout is a condition that can result from the ongoing management of a chronic illness. Girls experiencing burnout cheat on their diets, stop counting their carbohydrates, become careless in their approach to using insulin, or in general treat diabetes in a cavalier manner that often results in hospitalization. Examples of the burnout story appear in Chapters One and Three of this thesis, through the characters of Stacey in *Stacey's Emergency* (1991) and Lucy in *Sweetblood* (2003). In the case of the Type 1 narrative specifically, the burnout story highlights the danger in complacency with regard to daily diabetes management. Diagnosis and burnout stories both represent a very real aspect of living with diabetes, but at their cores, they both represent heightened moments of danger that fail to capture what film critic Kevin Ferguson refers to in “The Cinema of Control” as the “mundane” that generally defines life with diabetes.

In the final chapter of this thesis, which focuses on *The Girls Are Never Gone* (2021) by Sarah Glenn Marsh, readers are introduced to a story that breaks free from typical Type 1 diabetes tropes. Marsh’s novel immediately defines itself as something different by gesturing to its paranormal plot with a striking, macabre cover design. The book’s title appears hastily painted in messy, broad strokes across the top of a deep blue and black cover jacket. Under the title, a ghastly feminine hand with blackened fingernails reaches up out of murky waters, alluding to the impending horror within the book’s pages. Marsh’s novel, about a seventeen-year-old ghost hunter named Dare Chase, represents a stark contrast to the vast majority of books with adolescent Type 1 protagonists. A more typical book cover may depict some type of sugary food, or a Type 1 teen female who is pale skinned with long hair. The “typical” Type 1 teen girl might be in a candy store, or leaning on another person for physical or emotional support. The expression on her face might be pensive or sad.[83] Often, the sadness of these girls is more apparent than their diabetes. As Bennett writes, “In the cultural schema of diabetes, people with Type 1 are widely cast as victims” (13).

In recent years, the U.S. appears to have shifted toward a culture of increased inclusivity. For disabilities, this appears in the form of increased visibility in advertising campaigns and increased access to specialized products. In 2017, I was thrilled when Target released an “adaptive” children’s clothing line, and I immediately made a purchase. I bought a purple sweatshirt fitted with an accessible front pocket. The pocket contained a button-hole sewn at the back—perfect for threading insulin pump tubing through the shirt so that it wasn’t exposed to

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[83] A few example book covers, all from the BSC series, can be seen in Appendix B.

getting caught on door knobs, etc.[84] Then, in 2020, the Minneapolis *Star Tribune* announced the line's expansion (Kumar).

Target is not the only retailer to expand its children's clothing lines in recent years with special needs in mind. In 2021, the *Washington Post* published an article titled "No Seams, Buttons or Tags: Retailers are Rethinking Back-to-School Clothing for Students with Disabilities" that observed similar adaptive lines from other major retailers such as Kohl's and JCPenney (Bhattarai). Unfortunately, access to these adaptive clothes is sometimes limited. For example, Target is currently selling Cat & Jack fleece pajamas with an "abdominal access panel + insulin pocket" for eighteen dollars, but it is an "online-only" item.[85] On one hand, the limited availability of these products makes sense. They are intended for a smaller market of consumers, after all. On the other hand, when these products are *only* sold online they replicate themes of inaccessibility and invisibility that commonly accompany the experience of living with a disability. As stated in the introduction, my personal experience comes from being the caregiver of a child with Type 1 diabetes.

This thesis began as a very personal journey for me, which began all of the way back on August 12, 2014 when my daughter, Winnie—(sixteen months old at the time), was diagnosed with Type 1. Our daily routine transformed in an instant. My husband and I spent nearly a full week at the Minneapolis Children's Hospital in Minnesota re-learning how to be parents. In that

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[84] In order to fully appreciate why Target's new adaptive clothing line thrilled me, I need to provide a bit of backstory. Clothes became a challenge when my daughter, Winnie, was given her first insulin pump at the age of eighteen months. Zip-up "feety" pajamas posed a problem because they limited access to the pump at night. Figuring out how she could carry the pump during the day time was difficult, too. Due to the AA batteries inside, it was a relatively heavy device. The pump was connected to her body by about six inches of thin, medical tubing. If the pump dangled, it could rip out the infusion site that delivered insulin under her skin. Adults will often clip their insulin pumps to belts, or conceal them in the pockets of clothing. Women will sometimes clip their pumps to their bras. None of these options were available to Winnie, who was a toddler at the time. Most of the "pockets" on her clothing were ornamental rather than functional. The few real pockets that she did have were too shallow to hold much more than a few spare Cheeri-Os. For years, our solution was to purchase handmade "diabetes pouches" from a woman who ran an online boutique specializing in little fanny packs perfectly measured to carry diabetes devices.

[85] This was according to a search on Target.com as of February 2023.

first week, we attended classes with other parents of newly diagnosed children. Nurses taught us how to count carbohydrates and perform injections. We learned about the dangers of hypoglycemia and hyperglycemia. We learned how to mix glucagon in the case of a severely low blood sugar. We were given workbooks and manuals that would answer all of our diabetes-related questions. We were given a logbook so that we could track our daughter's blood sugar once we arrived home—because her insulin doses would still need to be adjusted. In those first few weeks, we had to test her blood every two hours, around the clock. It was like having a newborn baby again. As overwhelming as it felt at the time, we were much more fortunate than many of the other families of newly diagnosed children whom I have met in the years since that first summer. Not every hospital is equipped with an entire department devoted to pediatric endocrinology.

The hospital also provided us with a JDRF Bag of Hope, complete with a copy of *Rufus Comes Home*, a picture book that tells the story of a young boy who is comforted by a special teddy bear after he is diagnosed with diabetes. My husband and I are both avid readers, so we were anxious to find other books with Type 1 characters who might make our daughter feel less alone. The Minneapolis-St. Paul area is well-known for having a high number of universities per capita, and the Hennepin County Library system is impressive. Shortly after we left the hospital, I contacted the Minneapolis Public Library to ask about picture books with diabetic characters. I still remember the pitiful look on the librarian's face when he handed me a short stack of books that were mostly nonfiction and mostly outdated. The books in that small pile looked like they had been written for elementary-aged children in the 1990s who were doing book reports on diabetes. Some of the information they contained was accurate, but much of it was outdated. My main concern at that time, though, was the lack of narrative. None of the books the librarian found for me told personal stories of people living with diabetes. They read like medical encyclopedias for children.

Almost a decade has passed since my daughter's diagnosis and now it is a little bit easier to find books with Type 1 characters. Partly, this is because I have become more shrewd in my database searching techniques. I am now more familiar with key search terms that produce results, and I know who to ask for advice. People within the diabetes community, I have learned, are often a better resource than librarians. Also, in the past decade, more Type 1 characters have been popping up in mainstream books and films for children. A recent example is Sal Vidón, a young Cuban boy who is a title character in the *Sal and Gabi* sci-fi series published under the banner of "Rick Riordan Presents." The series currently consists of two titles: *Sal and Gabi Break the Universe* (2019) and *Sal and Gabi Fix the Universe* (2020). Perhaps even more exciting than this, was the inclusion of a diabetic character in a Disney-Pixar film.

In the summer of 2021, movie trailers for *Turning Red* created a buzz within the Type 1 diabetes community. Still frames from one of the movie's teaser trailers began circulating social media platforms because some careful viewers had spotted a circular patch on a character's arm. People in the diabetes community speculated that the character had Type 1 diabetes and that the patch on her arm was a continuous glucose monitor, or an infusion site for an insulin pump. The film's technical director, Susan Fong, confirmed in an interview with Alexi Melvin at BeyondType1, a diabetes nonprofit, that the patch on the girl's arm is an infusion site for an insulin pump. Fong, who was diagnosed with Type 1 at the age of four, told Melvin that she was the person who initially approached the film's directors about including a character with diabetes. When the directors said "yes," Fong said the decision to place the infusion site on the character's arm was intentional to make it more visible. She explained, "Very commonly you're filming kind of framing the faces, so if we put an insulin pump on the waist or we have the infusion set hidden, we were afraid you wouldn't see it very often" (Melvin). Although Turning Red promotes inclusivity through visibility of diabetes hardware, it is less clear if the film creates any awareness.

The girl in the teaser trailer is actually one of *two* diabetic characters who appear *Turning Red*, but neither girl plays a central role in the film's plot. One of the girls is named Stacy and has a few lines, but the other is unnamed. Their insulin pumps are visible in several scenes, but their diabetes is never verbally acknowledged. Nevertheless, people in the Type 1 diabetes community flooded online platforms with *Turning Red* screenshots and hashtags such as #diabetesawareness and #representationmatters. In *Managing Diabetes: The Cultural Politics of Disease* (2019), Jeffrey Bennett refers to Type 1 diabetes as "largely invisible—both interpersonally and in the public sphere" (11). I think that the diabetes community's mostly enthusiastic response to *Turning Red* helps to prove Bennett's point. The cultural invisibility of Type 1 is so great that the community erupted in excitement over a few momentary, unexplained flashes of insulin pumps. To the unknowing observer, the presence of diabetes within the film is nonexistent.

The unapparent nature of diabetes and other chronic illnesses seems to have led to a lack of critical scholarship that examines representations of chronic illness in adolescent fiction. Perhaps this is because, as Julie Elman suggests in *Chronic Youth*, U.S. culture views adolescence as a "chronic" condition. Does the supposed chronic nature of adolescence lead to a blind spot in the analysis of juvenile fiction? Or—perhaps, when it comes to disability, it is simply easier to focus on conditions that have more apparent corporeal signifiers. Even scholars who make reference to unapparent conditions often rely upon descriptions of "the body" or "visible stigma" in their theories (e.g., Tobin Siebers and Rosmarie Garland-Thompson). As this thesis has shown, it can prove difficult to capture the nuance of managing an unapparent condition, such as Type 1 diabetes. Type 1 is often made visible through moments of crises (which Kevin Ferguson refers to as "moments of excess"), even though those critical moments tend to be outweighed by mundane management activities. This thesis is the first academic work to critically analyze representations of Type 1 diabetes in fiction, but I hope that it will not be the last. Future scholarship is needed to explore other kinds of diabetes texts such as picture books, books with male protagonists, and books with non-White protagonists. Furthermore, additional scholarship in this area can continue the important work of expanding upon existing disability theories and challenging them to engage more directly with unapparent disabilities. It is through the expansion of the work begun by this thesis that Type 1 diabetes might be more culturally visible.

# Works Cited

Amiel, Stephanie A. "'Brittle' Diabetes: Usually Settles Down." *BMJ*, vol. 303, no. 6797, 1991, pp. 260-261. doi: 10.1136/bmj.303.6797.260.

Azarnoff, Pat. *Health, Illness, and Disability: A Guide to Books for Children and Young Adults*. R.R. Bowker, 1983.

"About Chronic Diseases." *Centers for Disease Control and Prevention*, Centers for Disease Control and Prevention, 21 July 2022, www.cdc.gov/chronicdisease/about/index.htm #:~:text=Chronic%20diseases%20are%20defined%20broadly,disability%20in%20the%20United%20States.

Beauchamp, Miles et al. *Disabled Literature: A Critical Examination of the Portrayal of Individuals with Disabilities in Selected Works of Modern and Contemporary American Literature.* Brown Walker Press, 2015.

Becker, Margot R. *Ann M. Martin: The Story of the Author of the Baby-Sitters Club.* New York, Scholastic, 1993.

Beeck, Nathalie op de. "'Sixteen and Dying:' Lurlene McDaniel's Fantasies of Mortal Endangerment." *Children's Literature Association Quarterly*, vol. 29, no. ½, Spring 2004, pp. 62-87.

Belford, Bibi. *Another D for Deedee*. Sky Pony, 2018.

Bell, Chris. "Introducing White Disability Studies: A Modest Proposal." *The Disability Studies Reader*, edited by Lennard J. Davis, 2nd ed., Routledge, 2006, pp. 275-282.

Bennett, Jeffery. "Critical Conditions." *Managing Diabetes: The Cultural Politics of Disease.* New York University Press, 2019, pp. 1-41.

Benway, Robin. "Stacey McGill, the Girl Who Lived." *Elle.* 7 July 2020. www.elle.com.

Bhattarai, Abha. “No Seams, Buttons or Tags: Retailers are Rethinking Back-to-School Clothing for Students with Disabilities.” *The Washington Post*, 6 Aug. 2021, www.washington post.com/business/2021/08/06/adaptive-clothing-target-kohls-jcpenney/.

Blaska, Joan. “Children’s Literature that Includes Characters with Disabilities or Illness.” *Disability Studies Quarterly*, vol. 13, no. 1, winter 2004.

—. *Using Children’s Literature to Learn About Disability and Illness.* Educator’s International Press, 2nd ed., 2003.

Broderick, Dorothy M. “Fiction: Reality or Ideology?” *VOYA*, vol. 13, 1990, pp. 203-204.

Bunson, Matthew. *The Vampire Encyclopedia*. Crown Publishers, 1993.

Carroll, Aaron E. and David G. Marrero. “How Do Parents Perceive Their Adolescent’s Diabetes: A Qualitative Study.” *Diabetic Medicine,* vol. 23, 2006, pp. 1222-1224, doi: 10.1111/j.1464-5491.2006.01961.x.

Carroll, Aaron E., and David G. Marrero. “The Role of Significant Others in Adolescent Diabetes: A Qualitative Study.” *The Diabetes Educator*, vol. 32, no. 2, 2006, pp. 243-252, doi:10.1177/0145721706286893.

Chalmers, Kristen et al. “It Got Likes, But I Don’t Think People Understood: A Qualitative Study of Adolescent Experiences Discussing Type 1 Diabetes on Social Media.” *Journal of Diabetes Science and Technology*. 27 Oct 2020. pp. 1-8. doi: 10.1177/1932296820965588.

Chute, Hillary. *Why Comics? From Underground to Everywhere*. New York, Harper, 2017.

DeCosta, April. “What the Babysitters Club Taught Me About My Disease.” *Buzzfeed.com*. 24 July 2015. www.buzzfeed.com/aprildecosta/The-truth-about-stacey.

Debelius, Justine. “Hurt, Comfort and Intimacy: Representations of Diabetes in Fan Fiction.”

*(Un) Doing Diabetes: Representation, Disability, Culture*, edited by B.C. Frazer and H.R. Walker, Palgrave Studies in Science and Popular Culture, 2021, pp. 257-273.

Dowker, Ann. "The Treatment of Disability in 19th and Early 20th Century Children's Literature." *Disability Studies Quarterly*, vol. 13, no. 1, winter 2004.

Eccleshare, Julia. "Teenage Fiction: Realism, Romances, Contemporary Problem Novels." *International Companion Encyclopedia of Children's Literature*. Edited by Peter Hunt. Routledge, 2005, 2nd ed., pp. 542-555.

Elman, Julie. *Chronic Youth: Disability, Sexuality, and U.S. Media Cultures of Rehabilitation.* NYU Press, 2014.

Ferguson, Kevin L. "The Cinema of Control: On Diabetic Excess and Illness in Film." *Journal of Medical Humanities,* vol. 31, no. 3, 2010, pp. 183-204. doi: 10.1007/s10912-010-9110-8.

Feudtner, Chris. *Bitter Sweet: Diabetes, Insulin, and the Transformation of Illness*. The University of North Carolina Press, 2003.

Gammeltoft, Tine. "Everyday Attentiveness: Understanding Diabetes in Vietnam through Literary Displacement." *Journal of the Royal Anthropological Institute*, vol. 28, no. 2, June 2022, pp. 595-612. https://doi-org.ezproxy.emich.edu/10.1111/1467-9655.13710.

Glenn Marsh, Sarah. *The Girls Are Never Gone*. Razorbill, 2021.

Garland-Thomson, Rosemarie. "Preface." *Extraordinary Bodies : Figuring Physical Disability in American Culture and Literature.* Columbia University Press, 2017. EBSCOhost, https://search-ebscohost-com.ezproxy.emich.edu/login.aspx?direct=true&db=e000xna&AN=1821397&site=ehost-live&scope=site.

—. "Feminist Disability Studies." *Signs*, vol. 30, no. 2, 2005, pp. 1557-1586.

Grossman, Marni. "Die, Die My Darling." *Bust*, 21 Jan. 2010, pp. 56-59.

https://issuu.com/celinahex/docs/bust_issue_61_small_hope.

Hardin, Amy and Jesse Hackell. “Age Limit of Pediatrics.” *Pediatrics*, vol. 140, no. 3, 2017, pp. 1-3, doi: 10.1542/peds.2017-2151.

Harling, Robert. *Steel Magnolias*. USA, Fireside Theatre, 1986.

Hautman, Pete. *Sweetblood*. Simon Pulse, 2004.

Hazell, Anne. “Meals in Minutes: Food in Contemporary Australian Adolescent Fiction.” *The Australian Library Journal*, vol. 49, no. 2, 2000, pp.. 151-158, doi: 10.1080/00049670.2000.10755916.

JDRF. “Diabetes Basics.” *JDRF.com*. www.jdrf.org/t1d-resources/about/.

Joachim, Gloria and Sonia Acorn. “Stigma of Visible and Invisible Chronic Illnesses.” *Journal of Advanced Nursing*, vol. 32, no. 1, 2000, pp. 243-248.

“Just Diagnosed with Type 1 diabetes.” *Centers for Disease Control and Prevention*, Centers for Disease Control and Prevention, 25 Mar. 2021, www.cdc.gov/diabetes/basics/diabetes-type-1-diaghosis.html#:~:text=Did%20You%20Know%3F,older%20(even%20over%2040).

Kafer, Alison. “Introduction.” *Feminist, Queer, Crip.* Indiana University Press, 2013.

Katz, Alexandra et al. “Media Portrayal of Type 1 Diabetes in North American Television and Film.” *Canadian Journal of Diabetes*, 2022, pp. 1-3.

Keith, Lois. *Take Up Thy Bed and Walk: Death, Disability and Cure in Classic Fiction for Girls*. Routledge, 2001.

Kent, Deborah. “Disabled Women: Portraits in Fiction and Drama.” *Images of the Disabled, Disabling Images*, edited by Alan Gartner and Tom Joe, Praeger Publishers, 1987, pp. 47-65.

Kesavadev, Jothydev et al. “Evolution of Insulin Delivery Devices: From Syringes, Pens, and Pumps to DIY Artificial Pancreas.” *Diabetes Therapy : Research, Treatment and Education of Diabetes and Related Disorders,* vol. 11, no. 6, 2020, pp. 1251-1269. doi:10.1007/s13300-020-00831-z.

Koltin, Dror and Denis Daneman. “‘Dead in Bed Syndrome’—A Diabetes Nightmare.” *Pediatric Diabetes*, vol. 9, 2009, pp. 504-507, doi: 10.1111lj.1399-5448.2008.00404.x.

Kriegel, Leonard. “The Cripple in Literature.” *Images of the Disabled, Disabling Images*, edited by Alan Gartner and Tom Joe, Praeger Publishers, 1987, pp. 31-46.

“Kristy’s Great Idea.” *The Baby-Sitters Club*, season 1, episode 1, NBC, 3 July 2020. Netflix, www.netflix.com/title/81005407.

Kumar, Kevita. “Target Expands Adaptive Clothing and Products for People with Special Needs.” *Star Tribune*, 17 April 2020, www.startribune.com/target-expands-adaptive-clothing-and-products-for-people-with-special-needs/569732532/#:~:text=In%20the%20summer%20of%202017,irritating%20for%20children%20with%20autism.

MacDonald, Paul. “The Good, the Bad and the Ugly? Looking at What 2014 has to Offer for Teen and Younger Readers.” *Scan: The Journal for Educators*, vol. 33, no. 2, 2014, pp. 29-33.

Mantilla, Stephanie. “Interrogating (In)visibilities: Invisible Disabilities and Their Economies in the Australian Soap Opera *Home and Away*.” *Journal of Literary & Cultural Disability Studies*, vol. 15, no. 4, 2021, pp. 419-435.

Marsh, Sarah Glenn. *The Girls are Never Gone*. Razorbill, 2021.

Martin, Ann M. *The Baby-Sitter’s Club #1: Kristy’s Great Idea*. New York, Scholastic Inc, 1986.

—. *The Baby-Sitter’s Club #43: Stacey’s Emergency*. New York, Scholastic Inc, 1991.

—. *The Baby-Sitter’s Club: The Summer Before.* Scholastic Press, 2010.

—. *The Baby-Sitter's Club #3: The Truth About Stacey*. New York, Scholastic Inc, 1986.

—. *The Baby-Sitter's Club #3: The Truth About Stacey*. New York, Scholastic Inc, 1995.

McDaniel, Lurlene. *Will I Ever Dance Again?* Willowisp Press, 1982.

McEntyre, Marilyn Chandler. "Friends in Need: Illness and Friendship in Adolescent Fiction." *Literature and Medicine*, vol. 21, no. 1, Spring 2002, pp. 132-146.

Melvin, Alexi. "How Turning Red Brings Diabetes Representation to Pixar." *Beyond Type 1*, 12 Dec. 2022, https://beyondtype1.org/turning-red-diabetes-insulin-pump/.

Mintz, Susannah B. "Introduction: Sleuthing Disability." *The Disabled Detective*. Bloomsbury Publishing, 2020, pp. 1-23.

Mitchell, David T. and Sharon L. Snyder. "Mapping Identity: Disability and Other 'Marked' Bodies." *Narrative Prosthesis: Disability and the Dependencies of Discourse.* The University of Michigan Press, 2000.

Nykvist, Karin. "In the Kingdom of Cancer: Dying Children Living Their Own Lives in the Contemporary YA Novel." *Child Autonomy and Child Governance in Children's Literature: Where Children Rule.* Routledge, 2016, pp. 120-133.

Olmstead, Kathleen. *The Girls' Guide to Tarot.* Sterling Publishing Company, 2002.

Pals, Regitze Anne Saurbrey et al. "A Delicate Balance Between Control and Flexibility: Experiences of Care and Support Among Pre-Teenage Children with Type 1 Diabetes and Their Families." *Sociology of Health and Illness,* vol. 43, no. 2, 2021, pp. 369—391, doi: 10.1111/1467-9566.13223.

Pate, Tanja et al. "Fear of Hypoglycemia, Anxiety, and Subjective Well-Being in Parents of Children and Adolescents with Type 1 diabetes." *Journal of Health Psychology*, vol. 24, no. 2, 2019, pp. 209-218, doi: 10.1177/1359105316650931.

Pugh, Catherine. "Beautiful Monsters: Sickness, Disability, and the Extraordinary Body." *Studies in Gothic Fiction*, vol. 6, no. 1, 2018, pp. 54-61, doi: 10.18573/sgf.19.

Resene, Michelle. "From Evil Queen to Frozen Teen: *Frozen* Introduces Disney's First Disabled Princess." *Disability Studies Quarterly,* vol. 37, no. 2, 2017, doi: 10.18061/dsq.v37i2.5310.

Robertson, Debra. *Portraying Persons with Disabilities: An Annotated Bibliography of Fiction for Children and Teenagers*. R.R. Bowker, 1992.

Roy, Ron. *Where's Buddy?* Clarion Books, 1982.

Saad, S. Chris. "The Portrayal of Male and Female Characters With Chronic Illnesses in Children's Realistic Fiction, 1970-1994." *Disabilities Studies Quarterly*, vol. 24, no. 1, Winter 2004, doi: 10.18061/dsq.v24i1.848.

Samuels, Ellen Jean. "My Body, My Closet: Invisible Disability and the Limits of the Coming Out Discourse." *GLQ: A Journal of Lesbian and Gay Studies*, vol. 9, no. 1-2, 2003, pp. 233-255.

—. "Six Ways of Looking at Crip Time." Disability Studies Quarterly, vol. 37, no. 3, summer 2017, https://doi.org/10.18061/dsq.v37i3.5824.

Scheiner, Gary. *Think Like a Pancreas: A Practical Guide to Managing Diabetes*. Philadelphia, De Capo Press, 2011.

Schalk, Sami. "Ablenationalism in American Girlhood." *Girlhood Studies*, vol. 9, no. 1, 2016, pp. 36-52.

Siebers, Tobin. "Disability as Masquerade." Literature and Medicine, vol. 23, no. 1, spring 2004, pp. 1-22, doi: 10.1353/lm.2004.0010.

Smith, Phil. "Whiteness, Normal Theory, and Disability Studies." *Disability Studies Quarterly,* vol. 24, no. 2, 2004, doi: 10.18061/dsq.v24i2.491.

Soloski, Alexis. "'The Baby-Sitters Club' is Back: Help Yourself to the Fridge." *The New York Times*. 27 May 2020. www.newyorktimes.com.

Stasiewicz-Bienkowska, Angieszka. "Vampire Fiction, Girls and Shame: Introduction," *Girls in Contemporary Vampire Fiction*, Palgrave Macmillan, 2021.

Telgemeier, Raina. *The Baby-Sitter's Club #2: The Truth About Stacey*. Based on the novel by Ann M. Martin. GRAPHIX, 2015.

"The Truth About Stacey." *The Baby-Sitters Club*, season 1, episode 3, NBC, 3 July 2020. Netflix, www.netflix.com/title/81005407.

United States, Department of Health and Human Services (HHS). "National Diabetes Statistics Report 2020: Estimates of Diabetes and its Burden in the United States." www.cdc.gov /diabetes/pdfs/data/statistics/national-diabetes-statistics-report.pdf.

United States, Department of Education. *Portrayal of Handicapped/Disabled Individuals in Children's Literature: Before and After Public Law 94-142,* Educational Resources and Information Center, 1993.

Valeras, Aimee Burke. "We Don't Have a Box: Understanding *Hidden Disability* Identity Utilizing Narrative Research Methodology." *Disability Studies Quarterly*, vol. 30, no. 3, 2010, doi: 10.18061/dsq.v30i3/4.

von Engelhardt, Dietrich, editor. *Diabetes: It's Medical and Cultural History.* Berlin Heidelberg, Springer-Verlag, 1989.

Weil, Julie Zauzmer. "Lurlene McDaniel Has Made a Career of Making People Cry." *Washington Post*, 10 Aug. 2018, www.washingtonpost.com/entertainment/books/lurlene-mcdaniel.

Weiss, Emily. "The Baby-Sitters Club: Where are They Now?" The Hairpin. 18 Jan. 2011.

https://www.thehairpin.com/2011/01/the-baby-sitters-club-where-are-they-now/

White, Sarah. *Let Me List the Ways.* HarperTeen, 2018.

"World Famous Heroes Magazine Issue 2." *View Comic Online*, n.d., https://viewcomiconline.com/world-famous-heroes-magazine-issue-2/. Accessed 13 Dec. 2022.

"Young Adult." American Library Association. 2006. www.ala.org/ala/protoolsbucket/usersvcs bucket/youngadultbucket/youngadult.htm (Accessed 12 Sept., 2022).

Zheng, Katherine et al. "Illness Acceptance in Adolescents: A Concept Analysis." *Nursing Forum: An Independent Voice for Nursing*, vol. 54, 2019, pp. 545-552, doi: 10.1111/nuf.12368.

# APPENDICES

## Appendix A: A Bibliography of Diabetic Children's Literature

This appendix is a bibliography of books with Type 1 diabetic characters, separated according to reading level: picture books, middle-grade chapter books, and YA novels. This list is not definitive (new texts are still being added, and some previously published are hard to find), but I hope that this list will be a resource for others looking for representations of Type 1 diabetes in fiction.

Although not a common format, I chose to write this list in chronological order in order to demonstrate the evolving nature of Type 1 diabetes in fiction through the last several decades. I believe that by viewing this list in the order that texts were published, we can better observe changing notions of how diabetes is discussed within North American culture (via the book titles), and we can also more clearly observe periods of time when Type 1 topics were "trending."

At the end of this bibliography, I have also included a short list of adolescent books written about Frederick Banting and Charles Best, the Canadian researchers who discovered insulin.

### Picture Books

Althea, Angela Owen. *I Have Diabetes.* Dinosaur Publications, 1983.

Moulton, Grace. *Life is Not So Sweet.* E.J. Arnold, 1987.

Pirner, Connie White. *Even Little Kids Get Diabetes*. Albert Whitman & Co., 1990.

Laskowski, Gail. *Teddy Ryder Rides Again.* American Diabetes Association, 1990.

Mulder, Linnea. *Sarah and Puffle: A Story for Children About Diabetes.* Margination Press, 1992.

Gosselin, Kim. *Taking Diabetes to School.* JayJo Books, 1994.

Haines, Sandra. *Donnie Makes a Difference.* Writer's Press Service, 1994.

Mazur, Marcia. *The Dinosaur Tamer: And Other Stories for Children with Diabetes.* American Diabetes Association, 1998.

Dennis, Anne. *Taming the Diabetes Dragon*. JayJo Books, 1998.

Gosselin, Kim. *Rufus Comes Home*. JayJo Books, 1998.

—. *Trick-or-Treat for Diabetes*. JayJo Books, 1999.

Coleman, Owen. *Matthew Takes His Shot.* Ivy House Publishing Group, 2001.

Robert, G. *Sillwee Wobbert: Diabetes and Jose at School and Play*. Dream Publishing Co., 2002.

Stern, Rochelle L. *Can Mom Have a Piece of My Birthday Cake?* Word Association Publishers, 2002.

Olson, Michael. *How I Feel: A Book About Diabetes*. Lantern Books, 2003.

Shepard, Dana. *Life with Diabetes: Lacie the Lizard's Adventure.* Critters Inc., 2004.

Lang, Rocky and Sally Huss. *Lara Takes Charge.* HLPI Books, 2004.

Troutt, Eleanor. *The Little Red Sports Car: A Modern Fable About Diabetes.* Illustrated by Chris Price, Eleanor Troutt, 2006.

Ganz-Schmitt, Sue. *Even Superheroes Get Diabetes.* Dog Ear Publishing, 2007.

Thomas, Pat. *Why Am I So Tired?* Barrons, 2008.

DeLand, M. Maintland. *The Great Katie Kate Discusses Diabetes*. Illustrated by Jennifer Zivoin, GreenLeaf Group Book Press, 2010.

Chilman-Blair, Kim. *What's Up with Ella?* Rosen Publishing Group, 2010.

Amerikaner, Susan. *Coco and Goofy's Goofy Day.* Lilly Disney, 2011.

—. *Coco Goes Back to School.* Lilly Disney, 2011.

Grimes, Nikki. *Halfway to Perfect*. G.P. Putnam's Sons, 2012.

Amerikaner, Susan. *Coco's First Sleepover*. Lilly Disney, 2013.

Gaynor, Kate. *The Bravest Girl in School.* Special Stories Publishing, 2013.

Deland, M. Maintland. *Be a Hero! Help Prevent Diabetes with the Great Katie Kate*. Illustrated by Jennifer Zivoin, GreenLeaf Group Book Press, 2014.

Paradis, Anne. *Caillou: Emma's Extra Snacks.* Chouette Publishing, 2015.

Amerikaner, Susan. *Go, Team Coco!* Lilly Disney, 2015.

Sotomayor, Sonia. *Just Ask.* Philomel Books, 2019.

Tubb, Kristin O'Donnell. *Zeus, Dog of Chaos*. Katherine Tegen Books, 2020.

Marsh, Sarah Glenn. *Diabetes Doesn't Stop Maddie*. Albert Whitman & Co., 2020.

**Middle-grade Chapter Books**

Roy, Ron. *Where's Buddy?* Clarion Books, 1982.

Dacquino, V.T. *Kiss the Candy Days Goodbye*. Yearling, 1983.

Taylor, Theodore. Sweet Friday Island. Scholastic, 1984.

Talbert, Marc. *Thin Ice*. Little Brown Books for Young Readers, 1986.

Roberts, Willo Davis. *Sugar Isn't Everything*. Aladdin Books, 1987.

Bates, Betty. *Tough Beans*. Holiday House, 1988.

Miller, Judy. *Grilled Cheese at Four O'Clock in the Morning*. American Diabetes Association, 1988.

Aiello, Barbara. *A Portrait of Me: Featuring Christine Kontos.* Twenty-First Century Books, 1989.

Sinykin, Sheri Cooper. *The Next Thing to Strangers*. Lothrop, Lee & Shepard, 1991.

Harris, Dorothy Joan. *Don't Call me Sugarbaby!* Scholastic, 1991.

Christopher, Matt. *Shoot for the Hoop*. Little Brown Books for Young Readers, 1995.

Loski, Diana. *Zack Attacks*. Winter's Press Service, 1995.

Harrison, Sue. *Sisu*. Illustrated by Jennifer Thomas, Thunder Bay Press, 1997.

Tate, Nikki. *Return to Skoki Lake*. Stable Mates #6. Sono Nis Press, 1999.

Schultz, Lorna Nicholson. *Roughing*. James Lorimer & Co., 2004.

—. *Interference*. Lorimer Children & Teens, 2004.

Morgan, Melissa J. *Alex's Challenge*. Grosset and Dunlap, 2005.

Olsen, Leight. *ESPN: Up for the Challenge*. Lilly Disney, 2011.

West, Tracey. *ESPN: Power Forward*. Lilly Disney, 2011.

Olsen, Leigh. *ESPN: Covering the Bases*. Lilly Disney, 2012.

—. *Running Interference*. Lilly ESPN, 2012.

Alexander, Heather et al. *Hannah Montana: Uptight (Oliver's All Right)*. Disney Press, 2012.

Mack, Winnie. *Bittersweet*. Scholastic Canada, 2016.

Buyea, Rob. *Saving Mr. Terupt*. Yearling, 2016.

Butcher, Kristin. *Winter Road*. Orca, 2018.

Buyea, Rob. *Goodbye Mr. Terupt*. Delacorte Books for Young Readers, 2020.

Olsen, Leigh. *Superstar Dreams*. Lilly Disney, 2013.

West, Tracey. *Bull's Eye*. Disney-Hyperion, 2019.

Belford, Bibi. *Another D for Deedee*. Sky Pony Press, 2019.

Hernandez, Carlos. *Sal and Gabi Break the Universe*. Rick Riordan Presents. Disney Hyperion, 2019.

—. *Sal and Gabi Fix the Universe*. Rick Riordan Presents. Disney Hyperion, 2020.

**Baby-Sitters Club Novels Narrated by Stacey McGill**

Martin, Ann M. *The Truth About Stacey*. Scholastic, 1986.

—. *Boy-Crazy Stacey*. Scholastic, 1987.

—. *Good-bye Stacey, Goodbye!* Scholastic, 1988.

—. *Stacey's Mistake*. Scholastic, 1988.

—. *Welcome Back, Stacey!* Scholastic, 1989.

—.*Stacey and the Mystery of Stoneybrook*. Scholastic, 1990.

—. *Stacey's Emergency*. Scholastic, 1991.

—. *Stacey's Ex-Best Friend*. Scholastic, 1992.

—. *Stacey's Choice*. Scholastic, 1992.

—. *Stacey's Ex-Best Friend*. Scholastic, 1992.

—. *Stacey's Big Crush*. Scholastic, 1992.

—. *Stacey and the Cheerleaders*. Scholastic, 1993.

—. *Stacey's Lie*. Scholastic, 1994.

—. *Stacey vs. the BSC*. Scholastic, 1995.

—. *Stacey and the Bad Girls*. Scholastic, 1995.

—. *Stacey McGill, Super Sitter*. Scholastic, 1996.

—. *Stacey's Broken Heart*. Scholastic, 1996.

—. *Stacey the Math Whiz*. Scholastic, 1997.

—. *Stacey's Secret Friend*. Scholastic, 1997.

—. *Stacey's Ex-Boyfriend*. Scholastic, 1998.

—. *Stacey McGill…Matchmaker*. Scholastic, 1998.

—. *Stacey's Movie*. Scholastic, 1999.

*BSC Mysteries*

—. *Stacey and the Missing Ring*. Scholastic, 1991.

—. *Stacey and the Mystery Money*. Scholastic, 1993.

—. *Stacey and the Mystery at the Mall*. Scholastic, 1994.

—. *Stacey and the Mystery at the Empty House*. Scholastic, 1994.

—. *Stacey and the Haunted Masquerade*. Scholastic, 1995.

—. *Stacey and the Fashion Victim*. Scholastic, 1997.

—. *Stacey and the Stolen Hearts.* Scholastic, 1998.

*BSC Friends Forever*

—. *Stacey vs. Claudia*. Scholastic, 1999.

—. *Stacey and the Boyfriend Trap*. Scholastic, 2000.

—. *Stacey's Problem*. Scholastic, 2000.

*BSC Portrait Series*

—. *Stacey's Book*. Scholastic, 1994.

### YA novels

Branfield, John. *Why Me?* Littlehampton Book Services, 1973.*

McDaniel, Lurlene. *Will I Ever Dance Again?* Willowisp Press, 1982.**

Giff, Patricia Reilly. *The Gift of the Pirate Queen*. Doubleday, 1982.

Ferris, Jean. *The Stainless Steel Rule*. Farrar, 1986.

Williams, Barbara. *Beheaded, Survived*. Franklin Watts, 1987.

McDaniel, Lurlene. All the Days of her Life. Bantam, 1995.

Carter, Alden R. *Between a Rock and a Hard Place*. Scholastic, 1995.

Kent, Deborah. *Living with a Secret*. Simon Pulse, 2001.

Hautman, Pete. *Sweetblood*. Simon and Schuster, 2003.

Morrison, Grant. Joe the Barbarian. Vertigo Comics, 2013.

Perry, Jolene B. The Summer I Found You. Albert Whitman & Co., 2014.

Ormsbe, K.E., Lucky Few. Simon and Schuster, 2016.

Norwood, Travis. *Sugar Scars*. Dragon Moon Press, 2016.

White, Sarah. *Let Me List the Ways*. HarperTeen, 2018.

Reed, Jamie. *Sorry Not Sorry*. Point, 2019.

Marsh, Sarah Glenn. *The Girls are Never Gone*. Razorbill, 2021.

*Released in the UK as *Sugar Mouse* (1973)
** Re-published as *Last Dance* (1982, 2005) and as *When Dreams Shatter* (1988)

## Children’s Books About Frederick Banting and Charles Best

Walters, Eric. *Elixir*. Penguin Books Canada, 2005.

Kerbel, Deborah. *Fred and Marjorie: A Doctor, a Dog, and the Discovery of Insulin*. OwlBooks Inc, 2021.

## Appendix B: Selected Covers of Baby-Sitters Club Books that Feature Diabetes

This appendix features a side-by-side comparison of several book covers used for *The Truth About Stacey*, as well as a single cover image for *Stacey's Emergency*. I discuss both of these books in Chapter 1 of this thesis. These cover designs show that sugary food is often a focal point in cover designs for Baby-Sitters Club books where Stacey's diabetes is crucial to the plot.

Figure 1. Stacey appears behind a candy store counter on original cover art for *The Truth About Stacey*, Apple Paperbacks, 1986.

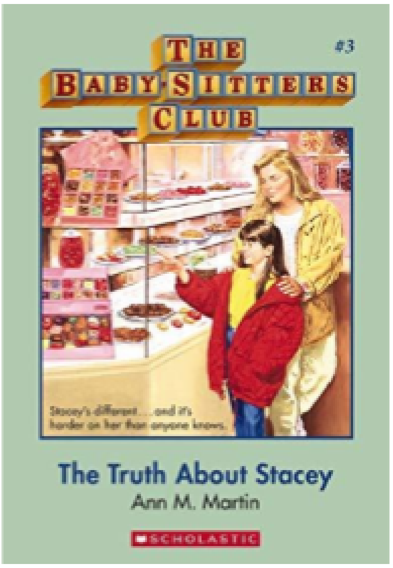

Figure 2. A glass case separates Stacey from candy store treats on the Scholastic cover art for *The Truth About Stacey*, 1995.

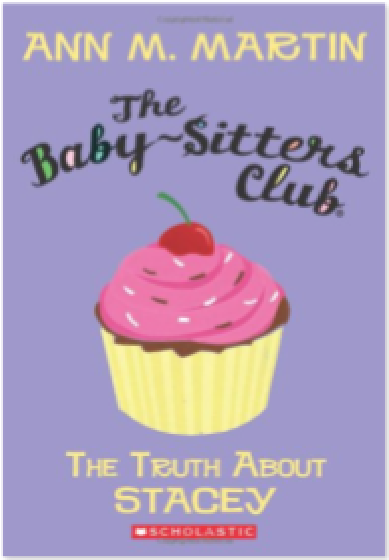

Figure 3. The Scholastic cover art for *The Truth About Stacey*, 2010, emphasizes sweet food with a solitary cupcake.

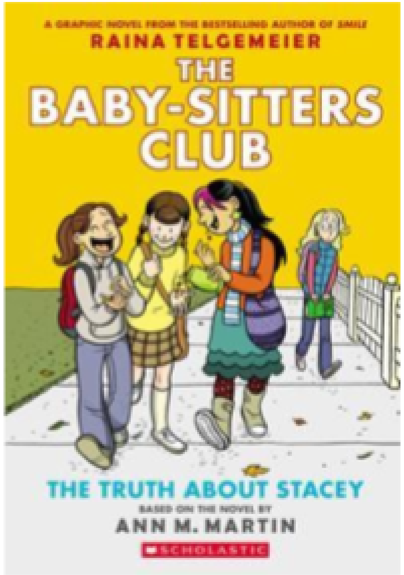

Figure 4. Stacey looks on from a distance as her friends enjoy snacks without her. The cover for the Graphix adaptation of *The Truth About Stacey,* illustrated by Raina Telgemeier, 2015.

Figure 5. Stacey appears out of control in a baking scene on the cover for BSC book #43, *Stacey's Emergency,* published in 1991.

## Appendix C: Depictions of Diabetes Paraphernalia in Baby-Sitters Club Graphic Novels

This appendix includes interior pages from various books in the Graphix *Baby-Sitters Club* books where Stacey is featured with her diabetes paraphernalia.

Figure 6. Stacey wears an insulin pump in the graphic novel adaptation of *Goodbye, Stacey, Goodbye!*, pg. 12. This book was published in 2022 and illustrated by Gabriela Epstein.

Figure 7. Stacey describes using multiple daily injection therapy in the graphic novel adaptation of *Boy-Crazy Stacey*, pg. 3. This book was published in 2019 and illustrated by Gale Galligan.

Figure 8. Stacey's diet exchange meal plan is diagrammed in the graphic novel adaptation of *The Truth About Stacey*, pg. 18. This book was published in 2015 and illustrated by Raina Telgemeier.