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Delilah the Dinosaur with Type 1 Diabetes: Addressing the Social-Emotional Needs of the Young Child Diagnosed with Type 1 Diabetes

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By

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Abstract

This independent study is intended to support very young children, ages 4-8, who are diagnosed with type 1 diabetes and their families. The following work provides a thorough examination of literature regarding the social-emotional effects of type 1 diabetes on the young child and his or her family; the specific developmental challenges that can arise due to an early type 1 diabetes diagnosis; and a detailed review of the current fictional children's literature available to this population. Finally, as a culmination of this research, this project includes an original, fictional story intended to address the social-emotional needs of the young child with type 1 diabetes and his or her family.

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Rationale

The diagnosis of type 1 diabetes at an early age, defined as 0-6 years old, can be a shocking and devastating occurrence. The diagnosis and how it is addressed by the medical team can have a momentary or lasting impact on the psychosocial state of the child and their family. Through this project, I set out to examine the specific impact a type 1 diabetes diagnosis has on the young child and his or her family and whether or not the current children's literature addresses any of the issues encountered.

The main drive for choosing this particular topic for my thesis is that I was diagnosed with type 1 diabetes 29 days before my fourth birthday. While I have lived with this chronic illness now for over 25 years, it is still a daily struggle that is only made easier by surrounding myself with supportive people. Two of my favorite memories surrounding diabetes from when I was growing up are the book *Grilled Cheese at Four O'clock in the Morning* (Miller, American Diabetes Association, 1988) and attending diabetes camp. The book is about a sixth grade boy who was juggling school, sports, and a new diagnosis of diabetes. I had already had diabetes for three years when this book came out, but it resonated very deeply with me. I went to diabetes camp from ages 6-12 and then also worked at camp as a counselor. Camp allowed me to see that I was not alone in my struggle and that there were hundreds of other girls like me from all over the country. We were all unique, but we shared the bond that having type 1 diabetes brings. Both literature and a supportive environment helped me to make sense of this chronic illness.

Through my research I have discovered that the current children's literature fails to address the social-emotional needs of young children diagnosed with type 1 diabetes and their families. The current literature mainly addresses the diagnosis itself, but not the social-emotional aspects for the child or the family. It also fails to address the importance of a diabetes community such as camp, the online community, or support groups, which help the child and family feel as if they are not alone in this struggle. With the rise in prevalence of type 1 diabetes in very young children, there is an even greater need for this type of literature.

I am a firm believer in the ability of literature to be a springboard for discussion and inspire people to make changes or seek help. Because of the impact *Grilled Cheese at Four O'clock in the Morning* had on me, I recognize that literature has the power to validate children's feelings and to help them see that they are not alone. *Delilah the Dinosaur with Type 1 Diabetes* is a tool for parents and caregivers to read with their young child to help them all recognize that there are many positive ways to cope with the day-to-day struggles of type 1 diabetes.

Literature Review

When a young child, ages 0-6 years, is diagnosed with type 1 diabetes mellitus (T1DM), it is not solely their own psychosocial well-being that is impacted, but the psychosocial well-being of the family. This review aims to examine the literature regarding the psychosocial effects of T1DM on the young child and his or her family and to show why more resources than currently exist are needed to help support children and their families. This review is broken down into three sections: the impact of diagnosis on the child; the impact of diagnosis on the family; and the necessity of a multidisciplinary team approach when caring for a young child with diabetes. Psychosocial supports that exist for newly diagnosed young children and their families include support groups, summer camps, playgroups, and literature. However, there is a lack of research on these existing psychosocial supports.

The number of diagnoses of T1DM are increasing, with the greatest rise in very young children, ages five years or younger (Anderson, 2009; Gregory, Lowes, & Lyne, 2004; Kiess, Kapellen, Siebler, Deutscher, Raile, Dost, Meyer, & Nietzschmann, 1998; Lowes, 2008). When children are diagnosed with T1DM, they are at risk for developing problems with psychosocial adjustment and the risk increases when children are diagnosed at a younger age (Anderson, Loughlin, Goldberg, & Laffel, 2001). Some of the issues that young children face are depression, disordered eating, family conflict, and difficulty with medical adherence (Fogel, & Weissberg-Benchell, 2010). As with other chronic illnesses, it has been found that pre-school age children diagnosed with diabetes are at risk for social adjustment and behavioral problems at a higher rate than their healthy peers (Kiess, et al., 1998). Young children with diabetes are also found to be at increased risk for developing psychological problems because they are unable to follow self-care regimens on their own, and often succumb to peer pressure and the social environment. This limits their ability to mesh the demands of the social environment with their prescribed treatment regimen (Schiffrin, 2001).

Because of the increased occurrence of T1DM and the susceptibility to psychological issues in the very young child, it is essential that young children with diabetes receive psychosocial support. Children who do not receive adequate psychosocial support can fail to thrive in some developmental domains (Anderson, 2009). Young children with diabetes cannot carry out the required medical regimen on their own. They need family support in order to attain good medical and psychological health. The family is paramount in assisting the child with daily health-care regimens and helping the child cope with the psychosocial issues that may arise from the diagnosis and ongoing care of this chronic illness.

When a young child is diagnosed with diabetes, it can prove to be a very challenging venture for the family. According to the literature, parents and siblings can have a variety of responses associated with a diagnosis of T1DM, including but not limited to: guilt, anger, shock, anxiety, depression, isolation, grief, a feeling of loss, fear, sadness, despair, and uncertainty (Lowes, 2008; Schiffrin, 2001). As soon as a child leaves the hospital after diagnosis, which is typically less than a week, parents have to assume full responsibility for the child's day-to-day care. Unlike many other childhood illnesses or disorders, which require less day-to-day management, the demands of diabetes are nearly constant. In essence, the parents must become 'the patient', always thinking about blood glucose checks, insulin injections, food intake and exercise. If these areas are not managed well, the child's behavior, mood, growth, and development may be affected (Anderson, 2009; Anderson, et al., 2001; Pediatric Diabetes, 2007). Particularly in the pre-school years, parents have an increased fear of hypoglycemic, or low blood sugar, episodes. Parents often feel isolated and unable to share their feelings with others. This can lead to parents restricting the time their pre-school child is away from the home, whether in daycare, with a babysitter, or having a play date with another child. On the other hand, it may also lead to parents allowing their child's blood sugar levels to run higher than suggested by their healthcare team so they will not have a hypoglycemic episode while away from home. Either of these circumstances can be damaging to the child's psychosocial and physical development and growth. Children who fare best with their diabetes management and control are those who have stable families with good psychosocial support and positive attitudes towards the chronic illness (Anderson, 2009; Kiess, et al., 1998; Schiffrin, 2001).

The current trend in the management of pediatric diabetes is using a multidisciplinary team approach (Anderson, 2001; Anderson, 2009; Anderson, et al., 2001; Lowes, 2008; Pediatric Diabetes, 2007; Schiffrin, 2001). The ideal medical team consists of a doctor, diabetes educator, nutritionist, and mental health professional. This combination of medical providers and a mental health professional leads to more positive medical outcomes and reductions in complications than solely providing physical care for the child. Additionally, parents should be provided with educational materials and opportunities to participate in support groups, especially in the early developmental periods. Support groups may help minimize feelings of isolation, anxiety and depression.

There is a significant lack of research in the area of psychosocial interventions for young children with diabetes and their families, as well as a significant lack of services for this group. While the incidence of diagnosis of T1DM in children under the age of five is on the rise, most diabetes clinics have few very young children with diabetes in their practice, which makes it challenging to allocate resources for comprehensive programs (Anderson, et al., 2001). The only U.S. program that has focused solely on young children with diabetes and their families has been very successful. Joslin Diabetes Center's Young Children's Program was launched in 1992. It was a comprehensive program of outpatient care that integrated the psychosocial care of parent and child with regular medical follow-up (Anderson, et al., 2001). Joslin researchers have concluded that the feelings of isolation experienced by families of young children with diabetes are the greatest opponent in the family's adaptation to coping with this chronic illness. To address this, Joslin offered multi-family support groups while simultaneously providing activities for children with diabetes and their siblings. The major goal of the children's group was to create a positive medical environment for the child who will be a lifetime consumer of healthcare. Parents who attended these groups were consistently more likely to seek additional medical care, have children with better diabetes control and were less likely to be 'burned-out' from the daily stressors of managing diabetes (Anderson, et al., 2001). More programs like the one at Joslin are needed to promote psychosocial well-being for young children with diabetes and their families.

Despite the increase in the rise of T1DM diagnoses in children under the age of five, little is being done to increase the amount of psychosocial support available to both families. Support can come in many forms, including support groups, summer camps, and literature. Good mental and physical health for young children with diabetes requires the development and implementation of more support during the time of diagnosis and throughout childhood. This review supports the effort to create children's literature that seeks to make children and their families feel less isolated with a diagnosis of type 1 diabetes.

The Effects of a Type 1 Diabetes Diagnosis on Development

Each child with T1DM is an individual who may face different psychosocial and developmental challenges after diagnosis. Research focuses on several themes that emerge with an early (prior to age six) diagnosis of this chronic illness. These themes include: cognitive challenges, emotional and psychological challenges, physical challenges, and conflicts of self-reliance. For the purpose of this thesis, this portion of the paper is focused on children who are four years old. The reasoning behind that focus is two-fold; the author was diagnosed with T1DM twenty-nine days prior to her fourth birthday, and the children's book portion of this thesis is focused on children ages 4-8. The author wanted to make sure the information was as relatable as possible to the youngest child who may come across the book.

Cognitive Challenges

At the age of four, children are in the midst of what noted developmental theorist Jean Piaget called the *preoperational stage* (Crain, 1992). This second stage of development as defined by Piaget occurs between the ages of 2-7 years. During this stage, intelligence is increasingly demonstrated through the use of symbols and internal images; however, the child's thinking is unsystematic, illogical, and very different from that of adults. The emergence of symbolic play is evident in this stage, and memory and imagination are developed as use of language matures. Preoperational children are often egocentric and have a difficult time seeing things from others' viewpoints. They are also at a stage when they believe in animism, the belief that objects, such as cars, couches and teddy bears, have feelings (Crain, 1992). One might see a four-year-old scolding a couch for being naughty when the young child ran into it, or believing that a car won't start because it is tired or sick. Children at this age learn best through sensory input. They need to hold objects and manipulate them in order to best understand the object and to have a lasting impression of the object (Miller, 2001).

Brain functioning is another very important area when it comes to cognition. From 1 ½ - 4 years of age is deemed as the most vigorous activity period in brain development and includes growth, pruning, and connecting. "Neuroscience is telling us that *this may be one of the most important periods* for developing self-regulation, problem-solving, social-emotional, and language/communication behaviors" (Fruend, 2008, power point presentation). By four years of age, children have acquired the basic structures of their native language (Johnson, 2008). However four year olds, "…can use words and verbal expressions that are far beyond her level of comprehension. This verbal sophistication can be, and often is, mistaken for conceptual understanding by grown ups" (Elkind, 1994, p. 80).

The four year old who is diagnosed with T1DM can have a variety of different problems associated with cognition. If a young child has chronic hypoglycemia (low blood sugar) he or she may be impaired in planning tasks, have problems with visual scanning and reading, have difficulty attending to detail, or have slower response time. If a young child has acute hypoglycemia, he or she may be plagued with fatigue or confusion. If the child has chronic hyperglycemia (high blood sugar), it may impair his or her spatial abilities or cause eye damage. These issues suggest that "…critical periods may occur during development when the brain is sensitive to fluctuations in blood glucose…" which can have short or long term effects on the young child (Thies, 1999, pp. 394-395). Recent data emphasizes that an early diagnosis of T1DM can have long-term effects. Children who are diagnosed earlier in life with diabetes perform worse in overall cognition when compared to children diagnosed later, and to their typically developing peers (Chen, Gaudieri, Greer, & Holmes, 2008).

Emotional and Psychological Challenges

Typical four year olds are extreme emotional beings (Ames & Ilg, 1976). One minute they will love something or someone and the next minute they will hate that exact same person or thing. One common issue among typical four year olds is that they can have unreasonable fears. They look at the larger world around them and begin to realize their vulnerability. These fears may show up as the child becoming fearful of dark areas in the house or having monsters in the closet. Older fours, especially, may have nightmares (Wood, 2007). Children at this age will often become fearful of new situations, such as going to the doctor or going to a birthday party. They will often act out these fearful situations over and over though dramatic play until they are resolved in their own mind (Miller, 2001). The typical four year old also shows a great deal of curiosity. This is the time in a child's life when you will often hear them asking, 'why?' about every new experience they encounter. According to noted educational theorist Erik Erikson, this stage in a child's life is called *initiation vs. guilt*. In this stage, the child deeply identifies with the parents. The child feels a need to constantly be "doing" or "making." With increased mobility and language abilities the child is increasingly curious, very physical, speaks constantly, and is always on the move. The child ranges along a continuum from initiation to guilt. The guilt stemming from "an overly severe conscience that punishes sexual fantasies and immoral thoughts or behavior" (Miller, 2002, p. 154). While parental relationships are the main focal point of the four year old, this is also the age when peer relationships grow in significance. Children begin to negotiate over toys and space and delight in each other's company (Koplow, 2007).

With a diagnosis of T1DM comes a whole host of related psychological and emotional challenges. Children who are diagnosed at an early age with chronic illness have a greater risk of developing mental health or social adjustment problems (Clark, 2003). They tend to experience more depression and anxiety than their peers (Cunningham & Wodrich, 2006; Thies, 1999). This tendency towards depression and anxiety coupled with the four year old's inclination towards extreme emotions can lead to some very troubling psychological problems for the young child. Accordingly, when parents and caregivers place increased pressure on a child to achieve "normal" blood sugar levels it can lead to feelings of hopelessness, anxiety, failure, and depression (Eiser, 1990). Children diagnosed at a young age can also feel incredibly isolated, particularly if they do not know others with the disease (Diabetes Research Institute [DRI], 2009). This isolation can lead to increased feelings of anxiety and depression. In some instances, the young child with diabetes is unable to engage with his or her peers in socially normative ways, such as on Halloween, which isolates the child even further. "Even on occasions that might be carefree for other children, diabetic children (and their caretakers) never leave cares behind" (Clark, 2003, p. 10).

A constant struggle in the young child's life with T1DM is low blood sugar reactions. These reactions can occur because the child either has too much insulin in his/her system, has exercised too much, or has not matched his or her insulin needs with the food being eaten. When young children have low blood sugar it can be very traumatic for them and for their family. According to Clark (2003), "If trauma is 'a sudden, extraordinary, external event' that 'overwhelms an individual's capacity to cope and master the feelings aroused,' an insulin reaction can be a kind of recurring trauma (albeit a reversible one) in the lifeworld of diabetes" (p. 39). These reactions, while fixable, can be excruciatingly frightening for a family. Some insulin reactions can be immediately reversed with the ingestion of a small amount of sugar such as glucose tablets, juice, or regular soda. However, very severe reactions can send the child into an unconscious state or seizure, revived only with an intramuscular shot of Glucagon. While low blood sugars are fleeting events, they leave behind traces of unsteadiness in the life of the child. This, compounded by the typical four year old's tendency to be fearful, can lead to increased levels of trauma where the young child with diabetes becomes fearful to leave the caregiver for fear of low blood sugar.

Physical Challenges

Typical four year olds are constantly on the move. They are natural explorers who love new adventures, enjoy going out on excursions, excitement, and fun (Ames & Ilg, 1976). Most four year olds cannot wait for their caretakers to bring them out to the store, to the playground, or to a friend's house. They are filled with boundless energy that is waiting to get out. By the age of four, children have a newfound confidence in their gross motor abilities, such as jumping and climbing, and a bold initiative to try new things (Elkind, 1994). You will see them on the playground, climbing tall structures and fearlessly jumping off, then scurrying right back up to do it again. They are at a point in their lives where they have become more self-reliant. They want to go out on their own to explore and discover what their own physical limits are. Four year olds typically learn best through play. According to Wood (2007), one fourth of the day should be spent in some sort of physical activity. Not only are four year olds happiest when they are active, they learn best this way.

Children who are diagnosed with T1DM do not have any visual physical impairment. They look just like their peers on the outside and still have that same voracious energy as their typical counterparts. However, there are two major issues in regards to physicality with children who have diabetes. The first is that their "childhood play is punctuated by interruptions to stop, shift attention and check blood, eat a snack, finish a meal, or get a shot" (Clark, 2003, pp. 9-10). While children may want to continuously play, they are often unable to do so, due to the constraints of blood sugar control. Children with T1DM typically have different schedules than their peers, especially if they are on injections, rather than an insulin pump. While on injections, children with diabetes have to keep a strict eating schedule of meals and snacks that contain the proper amount of carbohydrates to correlate with their insulin needs. This strict schedule can many times get in the way during a play date or while at school. Children with T1DM will have to interrupt their play if their blood sugar level is dropping in order to check their blood sugar level and eat a snack. They then have to wait to see if their levels are returning to normal before returning to play. The four year old with diabetes therefore may not be as adventurous as his/her typical peers because of the repercussions of their actions. If they play too hard or too long, they will ultimately need to stop and this may lead to a child who is more reserved about play.

The second issue is closely tied in with the first. When children with diabetes experience hypoglycemia or low blood sugar they become fatigued (Thies, 1999). This can interrupt their ability to play and ultimately to learn about themselves in the physical world. As previously stated, while the hypoglycemic episode may be fleeting, the fatigue can stay with the child for a significant time after. The energy level of a child with T1DM can be compromised and not in step with their typical peers.

Conflicts of Self-Reliance

Around age four, you will often hear children saying, "let me do it myself!" They have come to a point in their lives when they are becoming much more self-reliant and would prefer to clothe and feed themselves in lieu of adult help (Elkind, 1994). Four year olds feel like they are ready to conquer the world on their own. They are ready to be "big kids" and do not ask for help from their caregivers as much as they did when they were three. Children may start to push away slightly from their parents in order to become their own independent selves. There is, however, a natural conflict between wanting to be grown up and wishing to remain a dependent child that is evident at this age. Particularly when children are frustrated or tired, they become more reliant on their caregivers (Elkind, 1994)). According to attachment theory as proposed by Mary Ainsworth and John Bowlby, by the child's fourth year of life, he or she has reached the final stage of the attachment process. At this point "the child is able to function within a relationship that is less dependent upon proximity to the caregiver, and more based on shared goals, plans, and the exchange of feelings. Although children continue to enjoy and need close contact with their parents/caregivers, they have come to understand that they share a continuing relationship with these special caregivers whether or not they are in close contact" (Culbertson, Newman, & Willis, 2003, p. 746). Securely attached children will not be distressed by separation if they and their caregiver have already negotiated a plan for their separation and reunion (Britner & Marvin, 2008).

Self-reliance is a very complicated issue when it comes to young children with T1DM. Often, young children with T1DM feel a closer bond to their caregivers than their typical peers at this age. Even if a child with T1DM is securely attached, he or she may feel an increased level of distress with separation due to their need for help with all daily diabetes management. According to Clark (2003) some children with diabetes feel that having their parents help them with their diabetes management is "another way of loving" (p. 21). There are many complicated daily procedures one has to deal with when diagnosed with T1DM, including but not limited to: blood sugar checks, drawing up insulin in a syringe, injecting insulin, rotating injection sites, insertion of insulin pump sites, carbohydrate counting, meal planning, calculating insulin-to-carbohydrates ratios, and managing insulin sensitivity factors. While four year olds are ready to assert their independence in many ways, they are not able to manage diabetes independently. Children with T1DM often feel as if they have lost dominion over their own body. There is very little they can do to regain this control. According to Clark (2003), many children "develop a preference for a particular injection site" which is a "means of keeping dominion over their own body" (p. 34), even though physicians advise against this due to tissue build up and uneven insulin absorption. Four year olds with T1DM are not able to do everything on their own in the way they would want. Caregivers must be understanding of this natural conflict and allow the child with diabetes to be in control of as much as possible. This could include giving the child a choice of which finger to prick in order to check blood sugar, where to do the insulin injections, or giving the child a choice in treatment for low blood sugars (juice, glucose tablets, hard candies, etc.).

Children's Literature Review

This literature review is a critical analysis/annotated bibliography of the literature available for young children with T1DM. The available literature surrounding the topic of T1DM for young children is quite limited. There are several books for adolescents, ages 9-12, both fiction and non-fiction, some even written by adolescents with diabetes, such as *Sugar was my Best Food: Diabetes and Me* (Peacock, Gregory & Gregory, 1998). However, many of the books written for young children with T1DM, ages 4-8, are not readily available at local libraries or bookstores. All of the books reviewed, except for the unpublished master's thesis, can be purchased from websites such as www.amazon.com.

The books reviewed are from a variety of sources. Some were purchased on www.amazon.com, a small percentage were found at local libraries, and a few were made available to me through inter-library loan. None of the following books paints the full picture of what life can be like for a young child who is diagnosed with a chronic illness.

Clark, R. (2006). *Taking Care of Ourselves and Still Having Fun: Developing an original story for children with diabetes*. Unpublished master's thesis, Bank Street College of Education, New York.

Clark, who has T1DM herself, revised her previously written children's book for her thesis. She included both the original and revised stories in the thesis. Her story, *Still Having Fun*, is geared towards children ages 6-9, a slightly older age group than this thesis focuses on. The book is well written and includes hand drawn color pictures. The main character is a white female who has two friends, one boy and one girl, of different races. The book addresses the emotional aspects of having diabetes as a young child including the feeling of being isolated. For the most part, the story uses the correct language for diabetic supplies, however, on the last page, lancets are labeled "finger pokers." Clark also uses the terminology "test" rather than "check" when the child does a finger stick, which can lead children to feel they are being judged based on the numbers from the "test," rather than just having a data point from a "check." One aspect of the book that is especially beneficial for all children is the comparison made between the main character having diabetes and her two friends, one with a lactose allergy and one with asthma. Near the end of the book, the main character's father says, " 'When your body tells you it needs a break, then you've got to listen. If we can each learn to take care of ourselves, we can all still have a lot of fun!' " This notion is one that all children, regardless of illness or disability, should heed.

Ganz-Schmitt, S. (2007). *Even Superheroes Get Diabetes*. Indiana: Dog Ear Publishing. The reviews for this book suggest it is written for children ages 4-9; however, I would caution against reading it to children younger than seven. Children ages 4-6 may have difficulty relating to this text because of some of the language and the length. For example, when the main character is brought to the hospital the text reads, "We parked and moved through a never-ending hallway. It was brighter than a supernova." The book is twenty-eight pages long with up to sixteen lines of text per page. However, this is an excellent book for slightly older children. The idea of using a superhero theme is a relatable subject and makes those with T1DM feel brave and powerful. The images are bright and inviting. During the portion of the text where the main character, Kelvin, a white boy, is diagnosed, the author uses onomatopoeia and lays the images out on the page in a way to suggest time moving much more quickly than in the rest of the book. This allows the reader to feel as if they are rushing around with the family, moving from place to place in a hurry, a very relatable feeling. This book is filled with positive messages. The main character asks if he will still be able to do things like ride his bike and eat birthday cake and without pause, his father tells him yes. The book discusses carbohydrate counting and that children all over the world have diabetes, making the character feel less isolated. A wonderful component of this book is that Kelvin is fitted with an insulin pump and has a superhero doctor who also has T1DM and an insulin pump. This book empowers children and their parents.

Gosselin, K. (2001). *Rufus Comes Home: Rufus the bear with diabetes.* New York: JayJo Books.

The inspiration for this book came from a woman name Carol Cramer, who created a stuffed animal known as Rufus, The Bear with Diabetes. The Rufus bear has patches to help children learn where they can give themselves injections, heart patches on his paws for blood sugar checks and a medical identification bracelet to show that he has diabetes. All of the proceeds from the sale of the bear and the book go to the Juvenile Diabetes Research Foundation. This is the story of a young white boy named Brian who is diagnosed with T1DM. Brian has many typical symptoms a child experiences pre-diagnosis, such as feeling sick, weak, tired, thirsty and frequently urinating. Brian is brought to the hospital and diagnosed right away with diabetes. His mother realizes that Brian feels alone and isolated because of his diagnosis. She goes out and creates a Rufus bear for him to have a friend to talk to who also has diabetes. This is one of the only books reviewed that shares a solution to the isolated feelings that some children with diabetes may experience. The story refers to many brand specific products and has advertising throughout. The author also chose to place certain words in quotation marks throughout the book such as "diabetes," "sugar," "highs," "lows," "something" and "good-bye." This use of quotation marks is somewhat confusing and adds nothing to the book's relevance or content.

Gosselin, K. (2004). *Taking Diabetes to School (Special Kids in Schools Series, No 1).* New York: JayJo Books.

Geared towards school-aged children, this is the best picture book I have found to explain diabetes to a child's peers. The author of the book has a son with T1DM and wrote this book in response to the lack of literature available to explain diabetes to children. The story is told from the perspective of a young white boy with diabetes. Gosselin uses clear and concise language to explain what happens in the body of a child with diabetes. The text also explains that diabetes is no one's fault, it is not contagious, why it is important to wear a medic alert bracelet, what a meal plan is for, why a child with diabetes may have to leave the room or eat snacks and how shots become a part of one's regular routine. The images in the book are cartoonish but contain important information as well. There are images of the young boy's meal plan on the fridge, of the boy with his friends, with his medic alert bracelet, checking his blood sugar and giving an injection, and of his friend who wears an insulin pump. The structure of this book is less story-like and more an explanation of the daily life of someone with diabetes.

Morris, C. (2007). *I'm A Perfectly Normal Kid Who Happens to Have Diabetes!* Florida: The Peppertree Press.

The author of this book writes about her young grandson who was diagnosed with T1DM. Geared towards children ages 4-8, the story line is easy to follow; however, it has a few elements that may not be relatable for all children. This story is centered on a young white boy who loves to play golf. He was diagnosed with diabetes at 3.5 years old. While the story does not focus exclusively on golf, it is a central theme of the boy's life, and many young children may not relate to this theme. When the boy is diagnosed, he has the classic symptoms of frequent urination, excessive thirst, and vomiting. The author uses the term "Juvenile Diabetes" when the boy is diagnosed which is an outdated term for T1DM (not only children are diagnosed with this form of the disease). Some of the wording in the story may be confusing for young children. After the boy explains that his body does not make insulin in the way that it should he says, "Insulin turns sugar into energy. The wrong amount is hard on my body and organs." This is confusing without further explanation. When the young boy is first diagnosed he takes insulin injections and explains that he needed to learn which foods were good for him to eat and which foods he has to stay away from. It is always necessary to maintain a balance of food intake, however there are no foods that are completely forbidden when one has T1DM. When the boy is slightly older, at age 6.5, he gets an insulin pump. This is a great addition to the story, although again, there is some misinformation. The author writes about the pump, "It has my insulin in it and it can tell when I need, when I need it." This is not 100% accurate. A pump can only do what you tell it to do. It gives a certain amount of insulin automatically based on the amount a doctor prescribes, but then the patient has to manually tell the pump to give additional insulin based on the amount of carbohydrates consumed. Now that he has the pump the boy claims, "I can eat anything I want, anytime I want." While a pump does give more freedom, the patient still has to be aware of the foods that are going into his or her body and how they affect the body. Moderation should be practiced regardless of the pump. This story ends with the main character speculating about what he wants to be when he grows up. He says that he thinks he wants to be a doctor and take care of others with diabetes but his doctor tells him that by the time he finishes college, they will have found a cure for T1DM. While a cure may be a possibility in the future, there is no guarantee. The book unfairly leaves the reader feeling that the only way the boy will truly be happy is when there is a cure. This book outlines the basics of diagnosis and management, but contains inaccurate information.

Mulder, S. (1992). *Sarah and Puffle: A story for children about diabetes*. New York: Magination Press.

This picture book, geared towards children ages 4-8, is a fabulous tool for children with diabetes, their parents, teachers, siblings, and peers. The fictional story introduces the concepts of dealing with diabetes and the frustrations of the disease through a story of a young white girl and her talking lamb stuffed animal. The book begins with an introduction for parents and includes accurate facts about diabetes in general and diabetes management. Mulder writes that, "The management of diabetes involves more than taking shots and watching what you eat. It is a complex balance of three things: insulin dosage, exercise, and food." While the book alludes to the psychological management of diabetes, this is not referenced in the introduction. Mulder writes using child-friendly language, but includes the correct terminology for diabetic supplies. The book helps to express the isolated feelings that a child with diabetes may experience, but also balances those feelings with the notion that sharing your disease with others will help them better understand you. It is a wonderful read for young children with diabetes and their parents.

Olson, K. (2003). *Cooper Has Diabetes.* Georgia: Pritchett & Hull Associates.

Geared towards children ages 4-8, mainly focusing on the hospital aspect of diagnosis, this is a lovely story of a young white boy named Cooper with T1DM. This story has a very clear focus, using cheerful text to describe all of the details of the Cooper's hospital stay. Once in the hospital Cooper meets an endocrinologist, a CDE or certified diabetes educator, and a dietician. Since he loves to play baseball, he makes the comparison between a baseball team that works hard together and all the people who help take care of him, which he calls his diabetes team. Olson writes using accurate medical terminology but in a way that makes it easy for children to understand. To explain the lack of insulin production, the illustration on page 14 shows multiple body parts and what each does for the body. The text beneath the picture explains that the pancreas is the body part that does not function properly when someone has diabetes. When Cooper meets with the dietician, she shows him how to choose foods that will keep him healthy, but also says he can have treats once in a while like chocolate cake. Once back at home, Cooper is able to complete his diabetes team with his school nurse and teacher who also help to keep him healthy. This book shows that a young child can be diagnosed with diabetes and still lead a very fulfilling life. It is also unique in that it focuses on the hospital stay of the child and puts it in a very positive light. The one major problem with this book is that it fails to address the social-emotional effects of a T1DM diagnosis in the young child.

Pirner, C. (1991). *Even Little Kids Get Diabetes*. Illinois: Albert Whitman & Company.

This picture book is geared towards young children ages 4-8. It uses child friendly language; however, it is outdated. The book shows the young white girl needing a feeding tube in the hospital when she is diagnosed. This is an unusual situation, and could be very scary for the young reader. The main character is never allowed to eat candy or ice cream, which is not how diabetes is currently managed. The book addresses many emotions from the perspective of both the parents and the child. It also contains a letter to parents at the back of the book that addresses the psychological issues intrinsic to diabetes. The author chose to use the word "test" instead of the less judgmental word "check" for finger-sticks. The final line of the book reads, "We do all this stuff so I can stay healthy until they find a cure." This line incorrectly portrays the notion that diabetes should solely be managed until a cure is found, rather than embracing the disease and making it a lifestyle.

Robert, G. (2003). *Sillwee Wobbert: Diabetes and Jose at school and play.* Maryland: Dream Publishing Company.

This book, geared towards children ages 4-8, is part of a series of books about a character, Sillwee Wobbert, and his friends who have challenges such as diabetes or asthma. The book is written in a rhyming pattern, although many of the rhymes are almost-rhymes and do not sound right to the ear. The main character Sillwee Wobbert has a heart shaped head, which could be confused with a large blood drop, atop a child's body. Jose, the young boy who gets diagnosed with diabetes and is friends with Sillwee Wobbert, is a light skinned Hispanic character. The illustrations in the book are very simplistic and cartoon-like. The book contains many extremes and does not include certain pieces of information necessary to explain diabetes to a young child. Prior to being diagnosed, the story reads that Jose was sick and down for a whole year and that "…his face had looked tired, haggard, and grim…" (p.7). Most parents take their children to a doctor before a whole year has passed if their child is feeling ill. On page 8 the picture of the insulin looks like a bottle of pills, which a T1 would not take, and the image of the syringe has an enormous, scary needle. Jose has one episode of low blood sugar in the book while he is playing sports, which is accurate, but his friends do not know what is wrong with him. The book also uses incorrect terminology for a blood glucose meter, calling it an "instrument" to be used on Jose's finger to check his blood sugar. The story contains no information about high blood sugars. By the end of the book, all we know is that Jose eats better and feels better now that he is taking insulin. This inconsistent story is not an optimal choice for a family with a child who has been recently diagnosed with T1DM.

Thomas, P. (2008). *Why Am I So Tired? A first look at childhood diabetes*. New York: Barron's Educational Series.

This book, part of the *A First Look At…Book* series, teaches about T1DM in young children. Unfortunately, the book contains a significant amount of inaccurate data. Thomas writes that there are two types of diabetes and that people are born with the first type. Both of these statements are inaccurate. There are more than two types of diabetes and one is not necessarily born with T1DM, it can develop throughout life, up through middle-age or later. Thomas also writes that when you are exercising and tired, you should rest. The book insinuates that exercise makes people with diabetes have low blood sugars (which can be true) but calls this "being tired" rather than having a low blood sugar. It does not discuss how to properly treat the low blood sugar. Throughout the book there are images of young boys and girls, of various races, feeling sad that they have diabetes. The cover image is a young girl sitting away from the group, later in the book is an image of a huge needle that appears to be injecting a child in the forearm, and further in the book is a picture of a girl crying with text that reads, "You may wonder if one day you will grow out of your diabetes. This won't happen. Whatever type of diabetes you have will stay with you for life." The text is accurate in that diabetes will be with you for life; however, there are many ways to live a happy and healthy life with diabetes. Rather than portray the characters as sad, the characters could be shown with a group of friends interacting and doing typical activities. This is a depressing tale of diabetes and is inappropriate and potentially frightening for young children.

Parent Resources

Books

McAuliffe, A. (2002). *Growing Up With Diabetes: What Children Want Their Parents to Know*. NY: John Wiley & Sons.

Plunkett, L. & Weltner, L. (2006). *The Challenges of Childhood Diabetes: Family Strategies for Raising a Healthy Child.* NY: iUniverse, Inc.

Scheiner, G. (2004). *Think Like a Pancreas.* NY: Marlowe and Company.

Websites

American Diabetes Association
http://www.diabetes.org

Children with Diabetes: The online community for kids, families and adults with diabetes
http://www.childrenwithdiabetes.com/

Diabetes Education and Camping Association
http://www.diabetescamps.org/

Diabetes Research Institute
http://www.diabetesresearch.org

Diabetes Squared: Raising Two Kids With Type 1 Diabetes
http://www.diabetessquared.com/

Diabetes Support Groups Listed by State

http://www.elviradarknight.com/diabetes/supportgroups.html

DLife: for your diabetes life
http://www.dlife.com

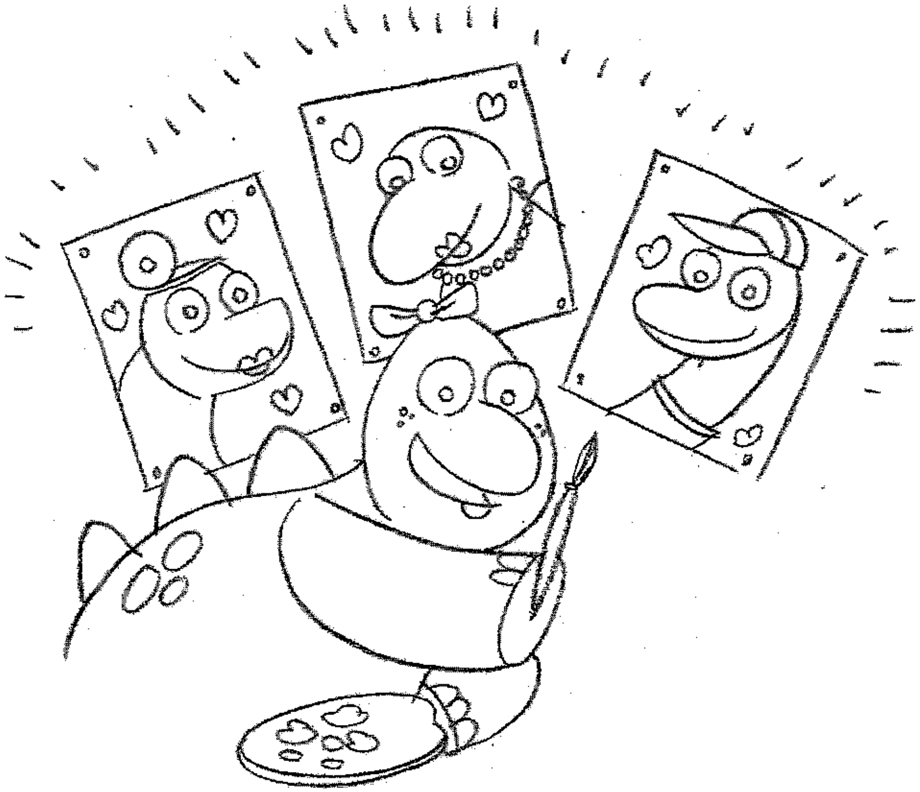
Juvenile Diabetes Research Foundation International
http://www.jdrf.org

Parenting Diabetic Kids
http://www.parentingdiabetickids.com

National Diabetes Education Program
http://ndep.nih.gov/hcp-businesses-and-schools/Schools.aspx

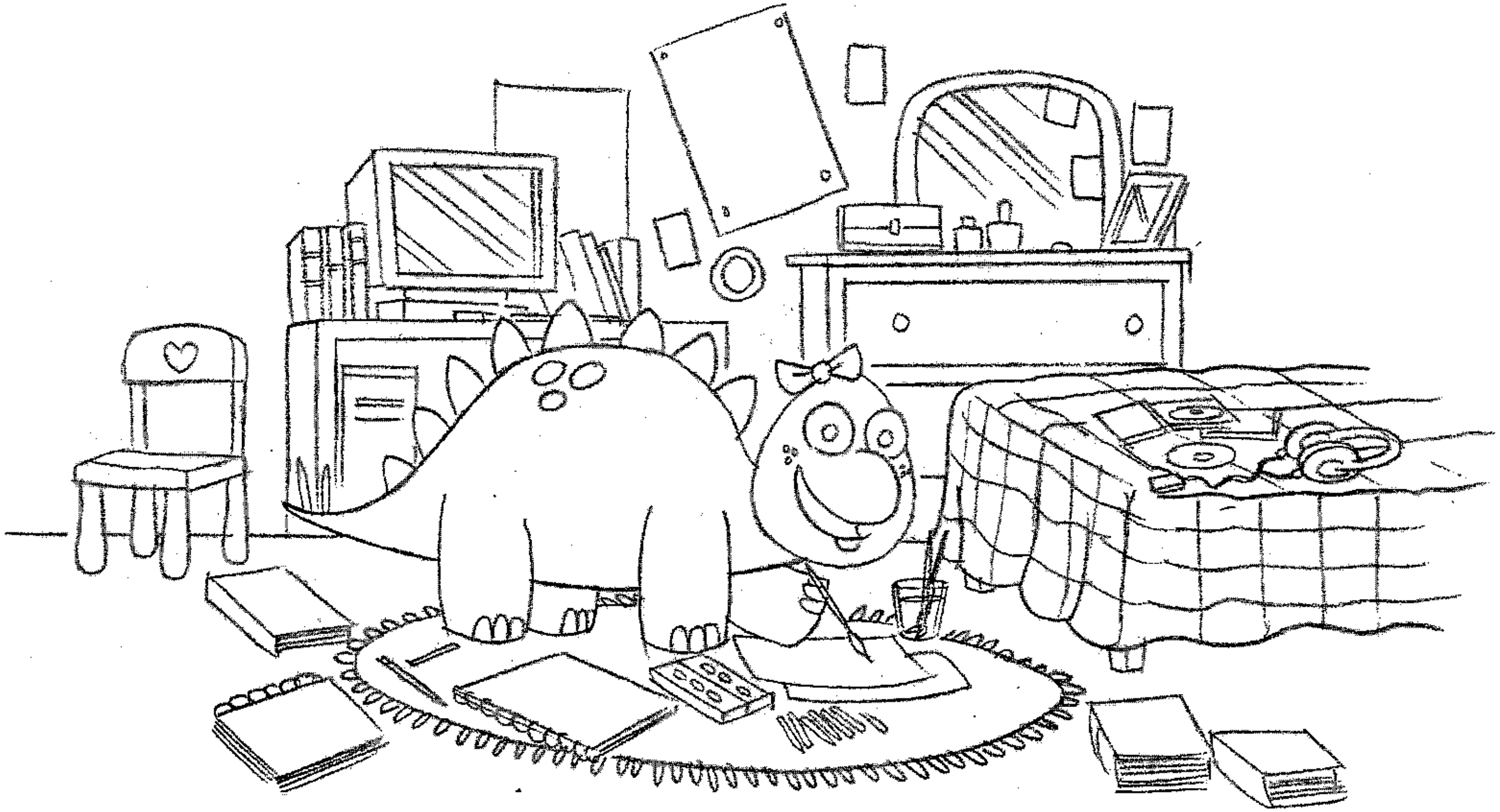
Tudiabetes: a community of people touched by diabetes, run by the *Diabetes Hands Foundation*
http://www.tudiabetes.org

Delilah the Dinosaur with Type 1 Diabetes



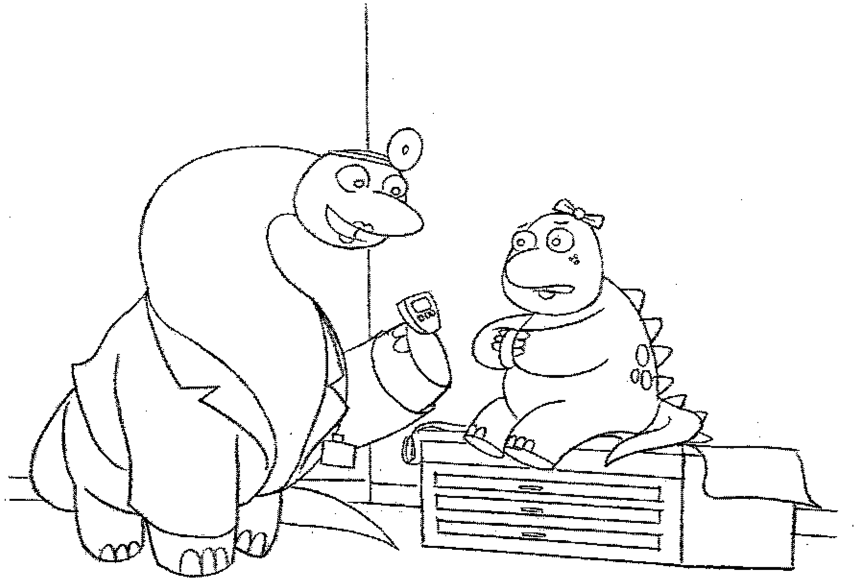
Written by Andrea Tuttman Gellerstein

Illustrated by Brian Smith



Hi! My name is Delilah the dinosaur. I love to dance and paint and ROAR! I want to tell you about something BIG that happened to me when I was four years old. I'm six now, so that was a long time ago.

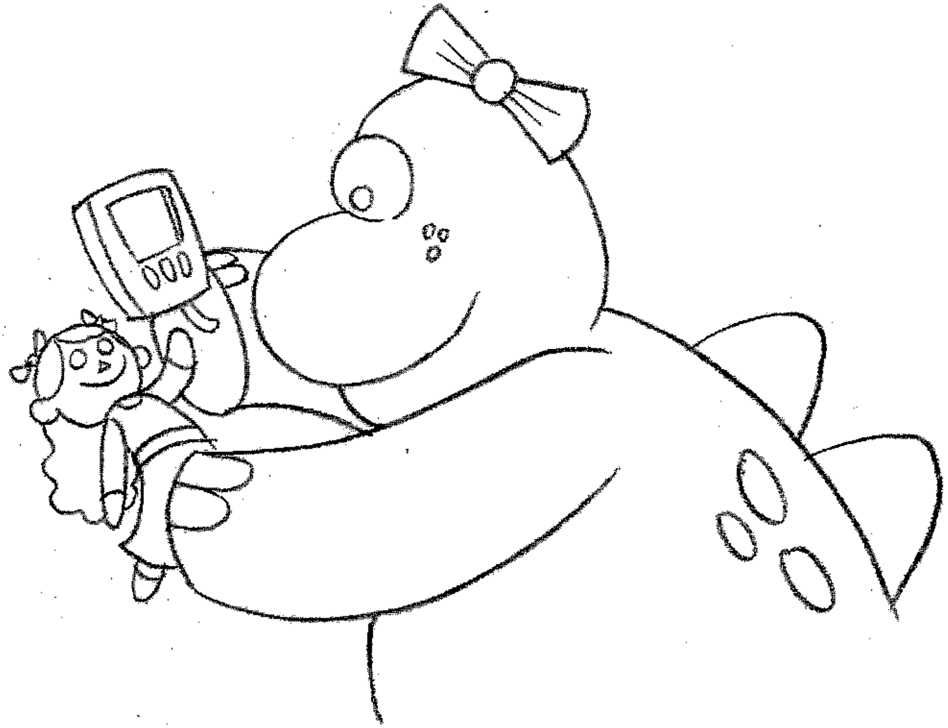
Right before my fourth birthday I started to feel yucky. I was thirsty and hungry all the time and I had to go to the bathroom A LOT. I even wet the bed a few times.



My mom got worried and called my doctor. That's when the BIG thing happened. I went straight to the hospital. When I got there, the nurses and doctors were all really nice. They tested some of my blood and told me I had Type 1 Diabetes.

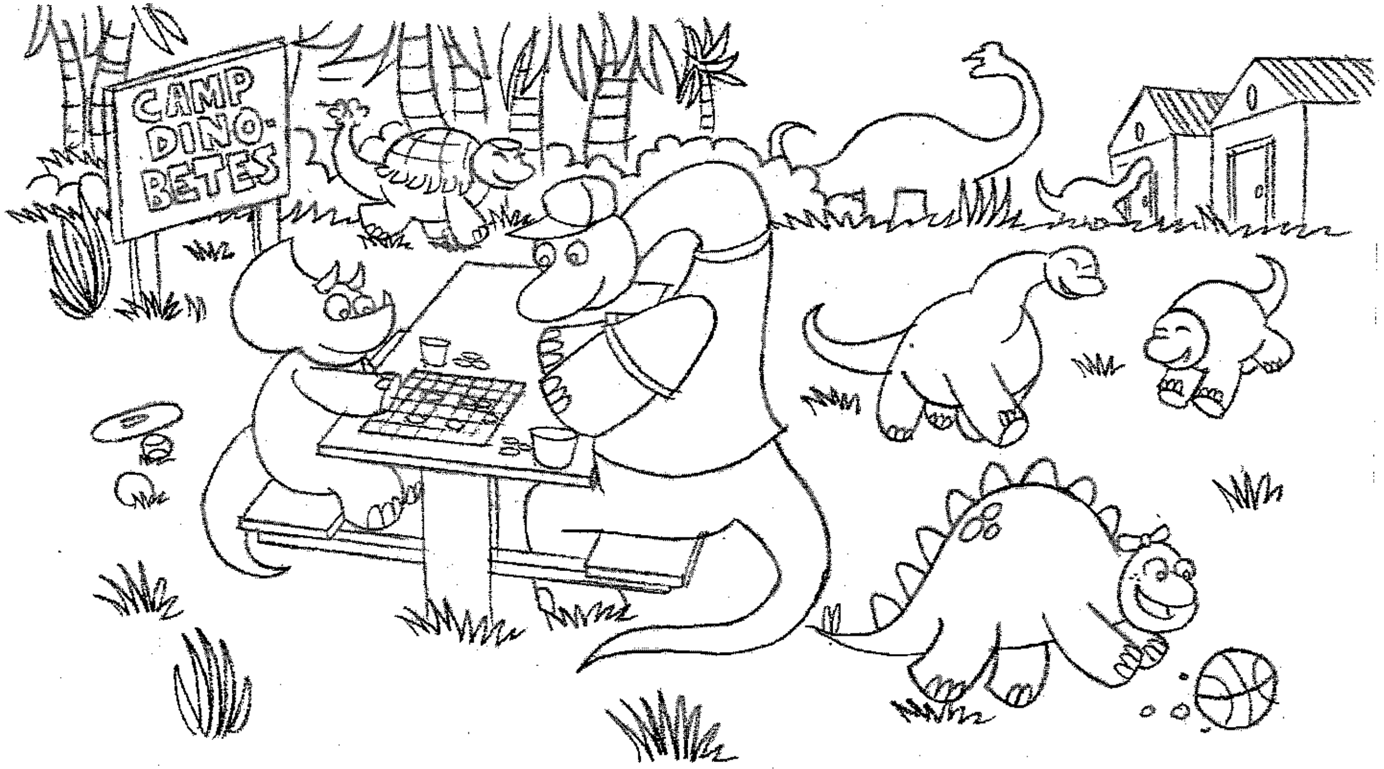
Dia-bee-sting? Diet-beets? Dia-what? I was really confused! The doctors and nurses explained to me that my body had stopped making insulin. Insulin is a really important thing that your body makes. When you eat food, insulin helps your body turn the food into energy so you can dance and paint and ROAR.

The doctor told me I would have to take shots of insulin when I eat and check my blood sugar with a small machine. I got to choose the color of my machine and I chose purple! She also told me that my whole family would start counting the carbohydrates in the food we eat.

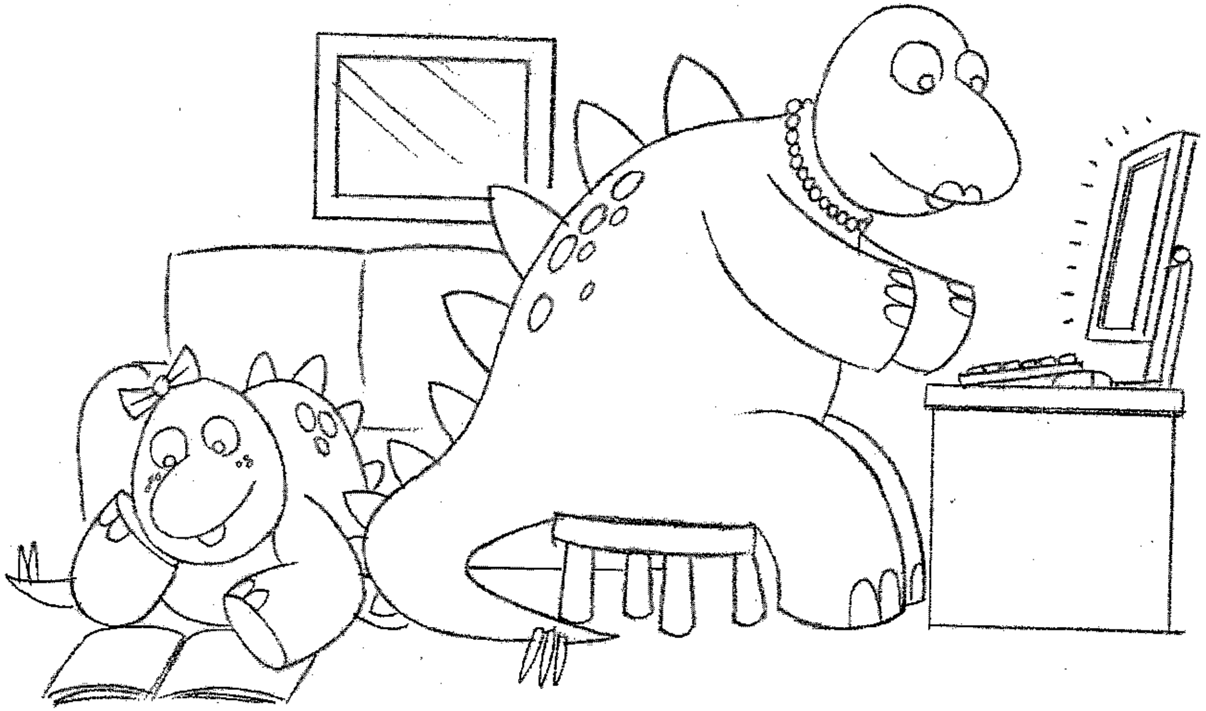


I was really nervous about checking my blood sugar and taking shots. I had a lot of questions! Would I still be able to eat Halloween candy? What about birthday cake? Could I still play with my friends? What if I didn't feel well when I was at school? Were there other dinos like me?

My doctor introduced us to a diabetes educator and a child life specialist. They were very nice to me and answered all my questions. I even got to practice pricking a doll's finger just like I would be pricking my own when I check my blood sugar.

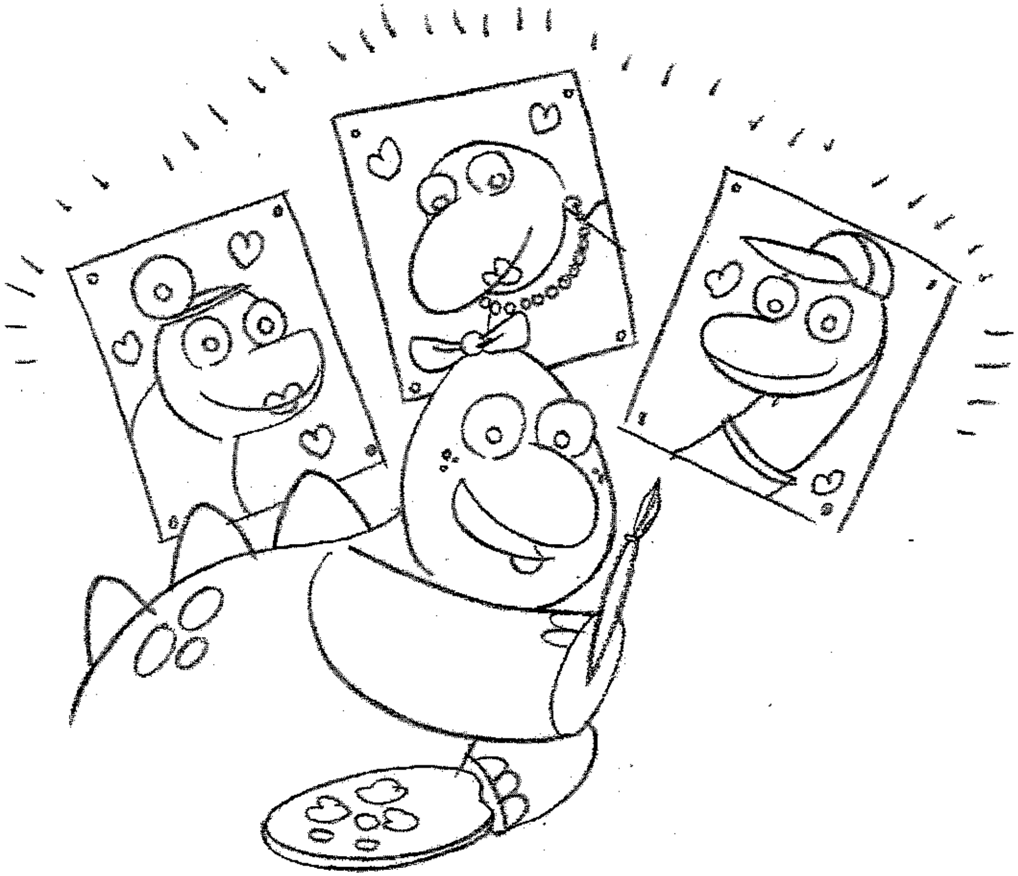


Now I'm six. I still love to dance and paint and ROAR! But some other things have changed. I check my blood sugar and take shots before I eat. I still don't love pricking my finger and taking shots, but it has gotten easier. Also, every summer I go to Camp Dino-betes with other dinos like me. They are from all over the place, but we all have diabetes! It's really fun and I don't feel alone when I'm there. We can talk about EVERYTHING!



My mom talks to other parents on the computer. She says that talking to other parents of dinos with diabetes really helps her to feel better.

As a family, we go to dino diabetes support group meetings once a month. The meetings are really fun! I get to play and laugh with all the other dinos with diabetes. We play games and tell stories about diabetes while our parents talk to each other. Then we all check our blood sugar, take insulin and sit down for a delicious meal. It's great!



Even though things are different now that I have diabetes, I still get to do all the fun things I did before. I play with my friends, I eat dinner with my family, and I love school. Diabetes is hard, but my family takes care of me and I am still Delilah the dino and I love to dance and paint and ROAR!

References

Ames, L.B., & Ilg, F.L. (1976). *Your four-year-old: Wild and wonderful*. New York: Delacorte Press.

Anderson, B. (2001). Children with diabetes mellitus and family functioning: Translating research into practice. *Journal of Pediatric Endocrinology and Metabolism, 14,* 645-652.

Anderson, B. (2009). Psychosocial care for young people with diabetes. *Pediatric Diabetes, 10(Suppl. 13),* 3-8.

Britner, P.A., Marvin R.S. (2008). Normative Development: The Ontogeny of Attachment. In Cassidy, J., Shaver, P.R. *Handbook of Attachment: Theory, Research and Clinical Applications* (269–294). New York and London: Guilford Press.

Anderson, B., Loughlin, C., Goldberg, E., & Laffel, L. (2001). Comprehensive, family-focused outpatient care for very young children living with chronic disease: Lessons from a program in pediatric diabetes. *Children's Services: Social Policy, Research and Practice, 4(4),* 235-250.

Chen, R., Gaudieri, P., Greer, T., & Holmes, C. (2008). Cognitive functioning in children with type 1 diabetes: A meta-analysis. *Diabetes Care, 31(9)*, 1892-1897.

Clark, C.D. (2003). *In sickness and in play: Children coping with chronic illness*. New Brunswick, NJ: Rutgers University Press.

Crain, W. (1992). *Theories of development: Concepts and applications* (3rd ed.). Prentice Hall: NJ.

Culbertson, J.L., Newman, J.E., Willis, D.J. (2003). Childhood and adolescent psychologic development. *Pediatric Clinical North America, 50*, 741–764.

Cunningham, M.M., & Wodrich, D.L. (2006). The effect of sharing health information on teachers' production of classroom accommodations. *Psychology in the Schools, 43(5)*, 553-564.

Diabetes in children: Psychosocial aspects. (2007). *Pediatric Diabetes, 8(Suppl. 8),* 26-31.

Diabetes Research Institute. (2009). *Diabetes at school*. Retrieved from http://www.diabetesresearch.org/Document.Doc?id=262.

Eiser, C. (1990). *Chronic childhood disease: An introduction to psychological theory and research*. Cambridge: Cambridge University Press.

Elkind, D. (1994). *A sympathetic understanding of the child: Birth to sixteen.* Needham Heights, MA: Allyn and Bacon.

Fogel, N. & Weissberg-Benchell, J. (2010). Preventing poor psychological and health outcomes in pediatric type 1 diabetes. *Current Diabetes Report 10,* 436-443.

Freund, L. (2008). *Nurturing the developing brain in early childhood.* [PowerPoint slides]. Retrieved from http://webcache.googleusercontent.com/search?q=cache:-iK1pUL7q4IJ:www.smartstartga.org/_images/pdf/eec_pdf/nov_freund_docs/freund.ppt+typical+brain+development+for+4+year+old&cd=11&hl=en&ct=clnk&gl=us&source=www.google.com

Gregory, J., Lowes, L., & Lyne, P. (2004). Newly diagnosed childhood diabetes: A psychosocial transition for parents? *Journal of Advanced Nursing 50(3),* 253-261.

Johnson, M.H. (2008). *Brain development in childhood: A literature review and synthesis for the Byron Review on the impact of new technologies on children.* London: Centre for Brain & Cognitive Development.

Kiess, W., Kapellen, T., Siebler, T., Deutscher, J., Raile, K., Dost, A., Meyer, K., & Nietzschmann, U. (1998). Practical aspects of managing preschool children with type 1 diabetes. *Acta Paeddiatr Suppl 425,* 67-71.

Koplow, L. (2007). *Unsmiling Faces: How preschool can heal.* New York: Teacher's College Press.

Lowes, L. (2008). Managing type 1 diabetes in childhood and adolescence. *Nursing Standard, 22(44),* 50-56.

Miller, Karen. (2001). *Ages and stages: Developmental descriptions and activities, birth through eight years.* West Palm Beach, FL: Telshare Publishing Co,

Miller, P.H. (1993). *Theories of developmental psychology* (3rd ed.). New York: W.H. Freeman.

New York State Department of Health. (2000). *Children with diabetes: A resource guide for schools.* Albany: NY.

Rovet, J.F., Ehrlich, R.M., Czuchta, D., & Akler, M. (1993). Psychoeducational characteristics of children and adolescents with insulin-dependent diabetes mellitus. *Journal of Learning Disabilities, 26(1),* 7-22.

Schiffrin, A. (2001). Psychosocial issues in pediatric diabetes. *Current Diabetes Reports, 1,* 33-40.

Thies, K.M. (1999). Identifying the educational implications of chronic illness in school children. *Journal of School Health, 69(10)*, 392-397.

Wood, C. (2007). *Yardsticks: Children in the classroom ages 4-14.* Turners Falls, MA: Northeast Foundation for Children, Inc.

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