

# Storytelling: Collaborating with Patients and Parents to Create a Children's Book Representative of Their Experiences

Lindsay Partin, Steven Chapman, MD

# **BACKGROUND**

- Children's literature can supplement the care of children living with chronic illnesses, has been shown to promote mental health and facilitate coping with hospital stays, and can be used as a key resource to help educate young patients, families, and communities about the illness experience.
- Children experiencing disease or disability are rarely depicted in children's literature and are often overlooked or presented inaccurately in children's books.
- There is an unmet need for resources which accurately reflect the experiences of children in these circumstances and could explore what may lie ahead, normalize experiences, and provide a sense of comfort during times of stress and uncertainty.

### **METHODS**

- 1. Informal discussions with multidisciplinary providers within the Endocrinology Department of the Children's Hospital at Dartmouth Hitchcock (CHaD) occurred June — August 2021 to identify potential participants and literature gaps.
- 2. Semi-structured individual interviews were conducted August October 2021 to gain insight of the experiences of those with Type 1 Diabetes in the Upper Valley.
- 3. Feedback sessions were initiated in October 2021 and have been ongoing to discuss the children's book development, plot, illustrations, and additional information.

#### INTERVIEW PROBES

- ➤ What does Type 1 Diabetes look like for ➤ What is the best way to incorporate **AOO**S
- Describe a typical day
- What are things you like to do as a family? What are things you like to do for you?
- Where do you find support?
- management of Type 1 Diabetes in a children's book?
- Should the book focus on a normal day (at school) or an adventure (like a field trip)?

## PARTICIPANT INFORMATION

Participants	Patients (n=4)	Parents (n=2)
Male sex (patient), n (%)	1 (25)	1 (50)
Patient age at time of interview, mean (median, range)	12.3 (12.5, 6-18)	9.5 (9.5, 6-13)
Patient age at time of diagnosis of Type 1 Diabetes, mean (median, range)	7 (6, 3-13)	8 (8, 3-13)

# COMMON QUESTIONS & PARTICIPANT THEMES

- "Things I get asked often in my daily life as [someone with diabetes]: does it hurt when I test my sugar, if my insulin pump is a phone, what can your friends or parents do to help, what's the best part of diabetes" (Patient 2)
- "Some kids asked if [diabetes] is contagious, but my friends were really supportive" (Patient 4)
- "A peer was like, 'that's really annoying' when he heard the CGM alarm" (Parent 1)
- "[Classmates] ask 'what is that' when she's wearing her pods or sensors" (Parent 2)
- "It's not really talked about...if you're growing up [as someone with diabetes] you don't see anyone who's doing anything outstanding who has diabetes" (Patient 2)
- "My classmates were not really [supportive]" (Patient 1)
- "He lost the ability to be free" (Parent 1)
- "Shouldn't [diabetes] be represented in books that everybody is reading?" (Parent 2)

Page 17 Page 16

"Lyla! How are you feeling? I got your low blood sugar notification after you all had run off and then Nathan came and found me. Did you test?" Lyla's dad asks, out of breath after running down the mountain to meet Lyla, Mia, and Zach

"I'm doing much better now! My blood sugar was 40 (remember that's low!) but now it's 80 and going up! Thanks for helping me, you guys" Lyla announces to the crew.

The gang continues down the trail, they only have a mile left of the hike!

"What's it like to have diabetes, Lyla? Is it hard to deal with?" Nathan asks

"It can definitely be tough sometimes, and I remember when I was first diagnosed I was scared that I wouldn't be able to do everything I used to do. I've learned that as long as I'm prepared with enough food and supplies that I can handle anything that comes my way. Sometimes I wish I didn't have diabetes, but I'm lucky to have friends and family that support my like all of you guys"

