



## Guest Editorial

# A Brother's Perspective

Chase Kensil

**H**aving a sister with as many medical issues as my sister, Meghan, can be a challenge as well as a great opportunity. My sister was born with Down syndrome, she was diagnosed with Type 1 diabetes when she was 8 years old, and at age 12, she was diagnosed with Celiac disease. These three diagnoses have an effect on my life every day, both negative and positive.

I face many challenges every day as a result of my sister, Meghan, and her medical issues. Diabetes has probably had the most challenging impact on my life. Before going anywhere, even if it is only five minutes away, my family has to make sure that she has all of her diabetes equipment. There have been many times, too numerous to count, where we have had to turn around and go home because someone forgot her meter or her pump supplies. These occasions have made me late for activities and different events. I have grown accustomed to it, and it is something that I am used to now. Another challenge regarding my sister's diabetes is her blood sugar. When her blood sugar is either too high or too low, her meter beeps to alert us. I would say that every other night the meter goes off, waking at least one other member in my family. This person then has to give her orange juice or insulin to raise or lower her blood sugar.

The struggles facing my sister's allergy to gluten and wheat are much different. Celiac disease has an effect on the foods that Meg is able to eat, and often

times, myself and others around us. When we go out to dinner, my sister receives a special allergy menu to account for her Celiac disease. She cannot eat anything with wheat or gluten in it. Often times, to be nice and polite towards my sister, my family and I do not eat anything that she cannot. This is a struggle for me because I occasionally cannot order what I want. Another issue with Meghan's Celiac disease is when she accidentally eats something that has wheat or gluten in it. When this happens, Meg gets really sick, and my family and I must care for her and help her.

Meghan's Down syndrome to me is probably the least challenging of all her diagnoses. I do not know if this is because I have become so used to it or I have just not noticed the many challenges that relate to it since it is all I have ever known. My sister needs help with her homework every night, and my parents are usually the ones to help her. Occasionally, I will have to help her with an answer or two.

Because my parents have to help her with many things, not just her homework, most of their attention is spent on her. I have become so used to it that I barely even notice anymore. As a result of Meghan's Down syndrome, it takes her longer to do things. Tying her shoes and brushing her teeth are both ten-minute activities for her, which is much longer than most people take to do these things. She often stresses about things that to me do not even seem that big of a deal. Overall, Meghan's diabetes, Celiac disease, and Down syndrome have caused many challenges in my life.

Although there are many challenges regarding my sister Meghan's diseases, there are also many upsides. Having a sister with diabetes, although it may not seem to, has had a positive impact on my life in many ways. One way is enhancing my knowledge. If my sister did not have diabetes, I would know next to nothing about the

disease. If there was ever an emergency and someone besides my sister needed help regarding diabetes, I would know what to do. This is because of the knowledge that I now have of diabetes. Another positive influence that my sister's diabetes has had on me is learning how to stay calm in traumatic situations. When I was 8 years old, my sister's blood sugar dropped too low, and she had a seizure. An ambulance had to come and take her to the hospital. Because of this situation and many others, I have learned how to stay calm during traumatic events. One last example of Meghan's diabetes having a positive effect on me is the opportunity to participate in the Juvenile Diabetes walk each year. This opportunity has helped my family and me meet new people and make new friends that are in similar situations regarding diabetes.

Meghan's Celiac disease has also had a positive impact on me. It helped me learn how to eat healthy. Because she cannot eat wheat, I have learned to not eat bad foods to help stay healthy. I have modeled the way that I eat after her. Another positive side to my sister having Celiac disease is expanding my knowledge on foods. As a result of her disease, I have had to read various ingredients and nutrition facts on different food products. This experience has helped me learn what certain foods are made of and also how healthy or unhealthy they are. Doing this so many times has helped me learn to check all the information about the food that I am eating before I eat it.

My sister's Down syndrome has probably had the most positive impact on my life. I cannot imagine what life would be like if my sister did not have Down syndrome. One positive aspect regarding my sister having Down syndrome is being able to participate in the Trisomy 21 Buddy Walk. The Buddy

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**Editor's Note:** *With the holiday season upon us, our thoughts turn to family. Pediatric nurses know that there are all kinds of families—large ones, small ones, multigenerational ones, and so on. As a holiday gift to our readers, we continue our annual tradition of turning over the November/December editorial pen to a child or teen. This year, 15-year-old Chase Kensil shares the challenges and joys of family life with his 18-year-old sister Meghan. Happy holidays!*

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Walk is a walk that Children's Hospital of Philadelphia runs to help support its Trisomy 21 clinic, which is used to treat people with Down syndrome. At the Trisomy 21 Buddy Walk, like the Juvenile Diabetes Walk, my family and I have met other families that have people close to them who also have Down syndrome. Here, we have met people that my family would probably even consider our closest friends. Another positive outcome to my sister having Down syndrome is being able to see her experience CampPals. CampPals is a week-long summer camp where people with Down syndrome can hang out with others like them and also typical kids. My family has been a huge part of this organization for many years, and we all love it. The most important aspect to me of Meghan's Down syndrome is her everyday life. My sister is the happiest person anyone could meet. She has a smile on her face and can make anyone happy in a second. She is always positive and finds the good in everything and everyone. My sister's Down syndrome has made her an amazing person. Meghan's diabetes, Celiac disease, and Down syndrome have all created positive opportunities for me that have made me a better person.

Overall, I would say that my sister Meghan's diabetes, Celiac disease, and Down syndrome have made my life better. The challenges that come with these three medical diagnoses have helped shape me into the person I am. The most important thing that I have learned from these is patience. Waiting for her to check her blood sugar, checking which foods she can or cannot eat, and taking longer to do things have all increased my level of patience. The challenges that come with these three medical issues have helped me to be a better person. If Meghan did not have even one of these diseases, my life would be completely different and not for the better. My sister brightens my day and is my inspiration in life. Even though it would seem to be difficult dealing with Meg's three medical conditions, they have changed my life for the better. 