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## Sweet Siblings: Diabetes Youth Advocates Offer Support

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Melissa Lee | March 22, 2016 Category: Diabetes Advocacy

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We live in a connected world, but for kids and teenagers living with type 1 diabetes, it can be hard to find the resources and communities that click for them, as many sites are understandably geared toward their parents. Facing a new diagnosis, it's especially scary for kids, and they might have questions that are different from the ones their parents have.

Brother and sister duo Mathias and Eliana Salmon, well-known youth advocates in the New York area, dreamed of creating a place where kids with T1D (and their siblings!) could come to find community, answers, and support, particularly in the early days post-diagnosis. The enterprising young teens launched a website called **SweetSiblings.org**, a site for kids and by kids.

With whimsical, colorful imagery, resources in English and in Spanish, and a blog where they cover topics from device reviews to government advocacy opportunities to what's in the diabetes news, they are building the site out to be a friendly, approachable hub for kids with T1D.

ASweetLife had the opportunity to reach out to these two Sweet Siblings and find out a little bit more about their attitudes, their approach, and their aspirations.

Mathias, you were diagnosed with type 1 diabetes pretty young – age 3. What are your memories from that time period? Was it scary? What was helpful to you?

Mathias: My dad was on a business trip when I got diagnosed and when he came to the hospital – he brought me a little set of Delta airplanes, which I still have. Every day my mom's friend would come to the hospital and we played airplanes

while my parents spoke to the doctors. Since I was only three I can't remember feeling scared but looking back I can imagine that I was frightened and feeling very displaced.

Eliana, you were a few years older than your brother and were likely more aware that life was suddenly quite different in your family. If you could give advice to parents who might be reading this for how to help an older sibling navigate a diabetes diagnosis in the family, what would you tell them?

Eliana: I was six years old when my brother was diagnosed with diabetes. I definitely noticed a change in the family and more than anything, I wanted to understand. My brother was hospitalized for six days when he was diagnosed which was slightly frightening for a young child who automatically associated "hospital" with "illness." I would tell families to make sure to explain to a sibling what is happening and to allow them to understand, to the best of their ability, that their sibling has diabetes. It is undeniable that attention will shift to the brother or sister that is diagnosed and understanding the reason why will be helpful for the other sibling. Even as a six-year-old child, I felt that I was learning about diabetes alongside my parents and that awareness has allowed me to be a supportive sister from the very beginning.

You two were doing some impressive youth advocacy work on a local level, speaking at New York area events, helping newly diagnosed families, etc., and had the idea to take it online, right? Were either of you already active online on any social sites? What kind of response have you had from young people finding SweetSiblings.org so far?

Eliana: I personally was active on social media websites, which led me to realize how powerful they can be as a way to reach as many people as possible. The idea behind Sweet Siblings is to spread the knowledge that



my brother and I have gained, having lived with diabetes and a sibling with diabetes for 11 years, to people that do not have access to this form of advice. Overall, there has been a positive response to young people learning of the existence of Sweet Siblings because we really fill a gap in the support system for young diabetics, which is the need for guidance from teens as opposed to simply from doctors or parents.

What kinds of questions have your peers come to you for so far? What are some of the most common concerns you auvs hear?

Eliana: From younger kids, one of the most common questions we get is, "does this hurt?" My brother and I try to promote a positive attitude and we typically answer that although a pump or CGM insertion can hurt momentarily, it will improve your ability to control your diabetes and is 100% worth it. Another common question is "how do I explain diabetes to my friends?" We believe that friends can be a great support system and they need to know how to be able to help you. Therefore, the best approach to telling friends about diabetes is to explain it to them one-on-one and to clarify what they can do to help, such as how to identify a low and what to do in the case of an emergency. Friends are always there for you so it is important that they are informed about your diabetes.

The site you've put together is really visually appealing, with great information for young people on the blog and a growing presence on Pinterest, Twitter, and Facebook. Do you have plans to develop the site further? What do you hope it will be able to accomplish?

Eliana: We will continue to try and make ourselves available on more outlets. What we hope to do is use the online platform that we have built to continue reaching diabetics that are far away while also partnering with organizations like JDRF and DRI to use Sweet Siblings as a support for local diabetics or people in the larger organizations' networks.

Do either of you attend any of the diabetes camps or conferences geared toward young people - particularly the ones like Children with Diabetes Friends for Life Conference or Riding on Insulin's events that encourage siblings to come along, too? Or JDRF events? What has your experience been with those?

Eliana: Since the summer of 2014, I have been working at the Barton Day Camp at Mount Sinai hospital. I started out as a CIT and this past summer I worked as the counselor responsible for the youngest group of girls. I absolutely loved looking after these girls during the summer. I think that having diabetes in my family has equipped me with the proper instincts to be able to pass myknowledge on to others, which is what I am trying to achieve both by working at camp and through Sweet Siblings.

Additionally, my brother and I have attended the JDRF one EXPO for two years now. Our first year, we spoke on a panel alongside other amazing diabetics. This past year, we had a booth where we spoke to the people at the conference about Sweet Siblings and our goal. Being able to interact with people at the conference and spread the word about Sweet Siblings has been a great opportunity because it has allowed us to reach more children in need of guidance.

We'd love for our readers to know a little bit more about each of you. Mathias, has it been tough to navigate diabetes with your friends? Do you have to explain yourself a lot or do they get it? Has knowing your sister's got your back been helpful at all? What kinds of activities do you participate in? What do you like to do?

Mathias: I have been very lucky with my friends and my diabetes. Because of the fact that I have been going to the same school since the age of four, I have been able to avoid having to explain my diabetes to my friends. But, recently since I have entered high school and have met a lot of new friends, I have noticed that people are curious and ask a lot of questions about the devices that are connected to me and what I am periodically doing. I have never been in a situation where I have been criticized or made fun of because of my diabetes, I only find that I sometimes need to have a little patience to explain it to people - they just want to learn.

Yes! My sister absolutely has my back. I know I can always trust her to help me in any situation I am in - whether I am running out of juice or having a low blood sugar and just asking her to keep me company until I feel better. She is always I take part in many extracurricular activities such as Model UN, Debate and Mock Trial, I also enjoy College Bowl and Entrepreneurship club, During the summers I love to play golf. Having diabetes has sometimes made it difficult for me to participate in overnight activities but as I am getting older, I am working through those challenges and taking part in everything! It just requires a little more planning and vigilance.

Eliana, I think most people find your involvement and support of your brother truly impressive. You both clearly have an entrepreneurial spirit and an understanding of how we do better when we have somebody to walk a path with us. Do you worry about your brother a lot? Do you think that's true of most "sweet siblings?" What helps settle your worries? And what are your interests? Your aspirations?

Eliana: Thank you. I think that my brother and I have always been a team. We are close in age and we support one another in school and outside of school. It is a very natural instinct for me to worry about my brother. He is very responsible and good at managing his diabetes but yes, I do get worried occasionally. I do hope that other siblings support one another and part of what we are trying to accomplish with Sweet Siblings is to inspire that sense of responsibility, not only in the sibling with diabetes but in their brother or sister as well. I would say that technological advances have helped settle my family's worries. My brother has been on the pump since months after his diagnosis and the Dexcom has been Mathias extremely helpful and reassuring as he is becoming more independent as a young adult. This is why we update the Sweet Siblings blog with



technology posts and new research breakthroughs. Although we are aware that not every family has access to these resources, we feel that much can be done to ensure that health care covers these devices because they are crucial for diabetics.

In terms of my own interests, I am the captain of my school's Debate team. I am also an editor of the school paper and a member of the Model UN team. I recently travelled to Boston on a Model UN trip with my brother, where he managed his diabetes very elegantly with a few check-ins and reminders from his older sister. In the future, I hope to combine my interest in public policy and debate to be an active advocate for the diabetes community.

Eliana and Mathias, you've helped many kids and their families already. We can't wait to see what you do next. There is nothing more heartening than seeing the rise of a generation of advocates that will take our causes to the next level and there is something exceptionally sweet about siblings who work together to make it happen.



















# A New Diabetes Website for Kids by Kids? How Sweet It Is

Health

Dec 9, 2014



Forget sibling rivalry. Eliana and Mathias Salmon have more important things to do than quibble. They recently teamed up to launch <a href="SweetSiblings.org">SweetSiblings.org</a>, a website for kids with type 1 diabetes.

The site, which is available in English and Spanish, is aimed at mentoring newly diagnosed kids. The two teenagers post advice on kid-friendly topics, such as eating favorite foods, dealing with diabetes during school, and handling holiday diet temptations.

"We came up with the tips through experience — trial, and error," Mathias told Healthline. "By creating the website I wanted to share those tips with everyone so they didn't have to make those errors."

### Let's Chat

Mathias, 13, was diagnosed with type 1 diabetes when he was just a toddler. His sister, 15, has been helping him cope with the condition for a decade. The two have been active in the diabetes community in New York, but they felt they could have a much greater impact if they posted their suggestions online. They've created a space where kids can talk to their peers about their life-changing condition.

"Over the years, I have helped a lot of children who are newly diagnosed transition into a life with diabetes," Mathias said. "When you're first diagnosed you feel like your life is over. I meet with them personally and explain to them that everything will be okay. "

Only 5 percent of diabetics have type 1 diabetes, a condition in which the immune system attacks cells in the pancreas that produce insulin. Insulin is a hormone that regulates your blood sugar levels, which can go up and down depending on what you eat. Type 1 diabetics may experience blood sugar spikes or drops so severe that they end up in a coma.

Growing up with diabetes has been challenging for both children. Diabetes is a 24/7 condition, Mathias said, and it takes a lot of energy and concentration to constantly keep tabs on his health.

### Siblings Need Support, Too

Having a diabetic in the family can also be taxing for siblings, which is why Eliana's perspective is equally important. As a young child, Eliana remembers being frustrated with her brother's restrictive diet, which affected her ability to eat normally. She taught herself to deal with any disappointments so she could better support her brother.

Diabetes affects the entire family, she said. "Oftentimes the advice is directed specifically toward the diabetic child, but I think it's also important to support the sibling, because they're also greatly affected by diabetes," Eliana said.



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The siblings' best advice for newly diagnosed kids is to embrace a positive attitude and stay hopeful that things will get easier in the future.

Eliana and Mathias have posted their contact information on the website, and say they will answer any questions sent their way.

"We want to be role models for children," Eliana

said. "With the right support and the right attitude, we believe diabetics



#### **Brother-Sister Duo Create Website to Help Kids with Type 1 Diabetes**

11/24/14

Children living with type 1 diabetes know it's an unexpected challenge. It can be overwhelming and frightening. Today, coinciding with diabetes awareness month, a brother-sister duo who know firsthand the difficulties of living with the disease, announced the creation of Sweet Siblings, an online support group for children affected by type 1 diabetes.

The website was envisioned and created by 15-year-old, Eliana Salmon and her 13-year-old brother Mathias, who was diagnosed with type 1 diabetes when he was 3-years-old. With ten years of experience living with the disease, they have acquired useful tips about finding the right foods, diabetes equipment and accessories, and other helpful hints that they want to share with other children like themselves.

"What is truly unique about Sweet Siblings is that it is a site run by kids, for kids, which you don't see at all in the diabetes online community," said Eliana Salmon. "Diabetic kids receive advice daily from their doctors or parents, but what has been lacking is advice from their peers. We want to share what we have learned with other children in order to make a difference in their lives."

Each year 15,000 children are diagnosed with type 1 diabetes and the number is expected to grow worldwide by 3 percent next year. Sweet Siblings hopes to help a fraction of these children by serving as role models for healthy living with type 1 diabetes.

"We are here to help through any of the small bumps along the way and show that you can still live an active, happy and healthy lifestyle after diagnosis," said Mathias Salmon. "The main thing we want to promote is positivity. We believe that with a 'can-do' attitude, adequate care and supplies, and most importantly, support, that every diabetic can succeed."

To help others succeed, Sweet Siblings is packed full of tips for children. Browsing the site you will find links to the latest equipment and current news on diabetes. There is also an interactive blog where children and teens can ask questions and receive answers from Eliana and Mathias. The site also has a bilingual element to reach a broader audience and ensure that a language barrier doesn't keep children who need advice from receiving it.

Parents can also find useful information throughout the site including links from babysitters who can care for diabetic children to tasty recipes that are kid-approved.

"When my child was diagnosed I wanted to make sure I knew everything I could to ease his concerns and help him adjust to life with diabetes," said Leslie Salmon, mother of Eliana and Mathias. "It can be difficult, but when armed with the right tools parents can make the transition seamless and inspire their children to continue living their lives and reaching their dreams."

For more information or to connect with Eliana and Mathias visit www.sweetsiblings.org.



## Sweet Siblings: A New Website for Children with Type 1 #diabetes

December 10, 2014





Eliana (age 15) and Mathias (age 13) Salmon have launched a

new website called sweetsiblings.org. Mathias was diagnosed with Type 1 Diabetes 9 years ago. Mathias, 13, was diagnosed with type 1 diabetes when he was just a toddler. His sister, 15, has been helping him cope with the condition for a decade. The two have been active in the diabetes community in New York, but they felt they could have a much greater impact if they posted their suggestions online. They've created a space where kids can talk to their peers about their life-changing condition. The site, which is available in English and Spanish, is aimed at mentoring newly diagnosed kids. The two teenagers post advice on kid-friendly topics, such as eating favorite foods, dealing with diabetes during school, and handling holiday diet temptations.

Eliana Salmon

Mathias Salmon

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As teenagers who understand what it means to have diabetes and to have a family member living with diabetes, both Eliana and Mathias know that it takes a long time to get accustomed to life with T1D. They recognize that there is insufficient funding for endocrinologists and their support teams. Despite patients' need for attention and education, busy medical practices often cannot provide adequate support for children that were recently diagnosed. They hope to be here to address all of your unanswered questions. Being advised by adults and professionals does not have the same impact as getting tips from children who have lived with the disease and their siblings. Sweetsiblings.org hopes to serve as relatable role models for healthy living with Type 1 Diabetes.



## A New Diabetes Website for Kids by Kids? How Sweet It Is

A brother and sister are helping kids tackle type 1 diabetes by launching a new website chock full of advice.

Written by Mollie Bloudoff-Indelicato | Published on December 7, 2014



Forget sibling rivalry. Eliana and Mathias Salmon have more important things to do than quibble. They recently teamed up to launch <a href="SweetSiblings.org">SweetSiblings.org</a>, a website for kids with type 1 diabetes. The site, which is available in English and Spanish, is aimed at mentoring newly diagnosed kids. The two teenagers post advice on kid-friendly topics, such as eating favorite foods, dealing with

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Growing up with diabetes has been challenging for both children. Diabetes is a 24/7 condition, Mathias said, and it takes a lot of energy and concentration to constantly keep tabs on his health.

#### Siblings Need Support, Too

Having a diabetic in the family can also be taxing for siblings, which is why Eliana's perspective is equally important. As a young child, Eliana remembers being frustrated with her brother's restrictive diet, which affected her ability to eat normally. She taught herself to deal with any disappointments so she could better support her brother.

Diabetes affects the entire family, she said. "Oftentimes the advice is directed specifically toward the diabetic child, but I think it's also important to support the sibling, because they're also greatly affected by diabetes," Eliana said.



The siblings' best advice for newly diagnosed kids is to embrace a positive attitude and stay hopeful that things will get easier in the future.

Eliana and Mathias have posted their contact information on the website, and say they will answer any questions sent their way.

"We want to be role models for children," Eliana said. "With the right support and the right attitude, we believe diabetics can have the same lives as people without diabetes."

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healthline.com

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Sweet Siblings

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