

Danville: Diabetic student to lobby for cure

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DANVILLE -- Louise Marshall firmly believes one person can make a difference in the world.

The Danville teen is planning to travel to the nation's capital next month to share her story of life with Type 1 diabetes and lobby lawmakers for continued research funding.

"What I want to do with my life is help people," Marshall said. "What I want to do is change people's lives for the better. I'm not really sure how I'm going to do that, but this is a good way to start."

Marshall is one of four Bay Area youths and another 150 children from across the country and internationally who are part of the 2015 Juvenile Diabetes Research Foundation Children's Congress. JDRF, the only global group with a strategic research plan to end Type 1 diabetes, has hosted the Children's Congress every other year since 1999.

"The children have a unique voice," said Gabrielle Brits, JDRF Greater Bay Area chapter's co-vice president of advocacy and government relations. "Children have a very unfiltered voice. They give a unique perspective to our leaders when they're talking about how these technologies affect their lives. The children speak right to the heart of the matter. It's not politicized. It's not a pitch."

Marshall and the other California delegates hope to meet with California's U.S. Sens. Dianne Feinstein and Barbara Boxer as well as state representatives. The youth delegates support the efforts of adult JDRF volunteers who lobby Congress to continue its support of the \$150 million annual special diabetes program to fund research.

"They're saying, 'Thank you for your support,' " Brits said of the youth delegates. "They're there to put a face to a life with diabetes and all the research and advancements that come as a result of the funding from the special diabetes program."

Type 1 diabetes is the less common form of diabetes, affecting roughly 5 percent of people who get diabetes. The majority of people with diabetes have Type 2, which is typically brought on by lifestyle issues such as poor diet and a lack of exercise.

Type 1 diabetes, on the other hand, is an autoimmune disease unrelated to diet or exercise. The disease ruins the pancreas, meaning a person with Type 1 must rely on insulin -- by shot or an insulin pump attached to the body -- to stay alive. Type 1 can strike at any age but often starts in childhood. The cause is not known nor is there a cure. Marshall, 16, who attends Monte Vista High School, was 14 months old when she was diagnosed with the incurable disease.

"I've struggled with diabetes my whole life," she said. "I've lived my life based off of blood sugar checks and insulin doses and the way diabetes affects me as a person. I don't want other people to have to go through that."

As a child, Marshall endured multiple daily shots, as many as eight a day, until she got an insulin pump in first grade. The site that attaches the pump to her body must be changed every three days. She must also prick her finger eight to 10 times a day to check her blood glucose levels.

"I really want nothing more in this world than a cure for diabetes," she said. "It's not just a disease. It's not just about the finger checks or the insulin doses. It's about everything. It's the fact that diabetes does not

leave any aspect of your life untouched. It permeates through every layer of your life and alters you as a person."

That is the message she hopes to convey to everyone she comes across on Capitol Hill.

"If there's one thing that I would want to really express is that while we as people make the choice to be who we are, we are in part made the people we are through our struggles," she said. "I think every diabetic struggles with being a diabetic. I don't know that anyone comes to terms with it. There are days you accept it and feel normal and content. Then there are days when you want to scream out into the sky and be done with it. Diabetes is a constant battle, and I would really like to stop fighting."

Marshall was among 35 Bay Area youths with Type 1 diabetes who applied for Children's Congress. Nationwide and internationally, more than 1,500 children applied, and roughly 150 were chosen for the program. The children, ages 4 to 17, submit an application and an essay explaining why they are passionate about finding a cure.

"If there's anything I would want to talk to Congress about, it would be to give a more in-depth understanding of what it's like to be a Type 1 diabetic," Marshall said. "Support from (Congress) is entirely necessary for new developments in research and ultimately the path to a cure."

The energetic teen is a veteran JDRF volunteer. She has accompanied her mom to many JDRF events, including a fundraising walk shortly after Marshall's diagnosis. She lends a hand and turns on the charm at events to help raise big bucks for research. Last summer, she made an emotional speech at a key East Bay fundraiser, prompting participants to dig deep to make hefty donations.

"We're just beside-ourselves-happy for her," said mom Rachel Haven. "It's an amazing opportunity to go to D.C. and meet with senators. A lot of kids don't think that their voice matters. It's a great way for her to learn that your voice does matter in government."

Haven, who will travel with her daughter on the three-day July trip, believes the program takes the crucial step of personalizing a disease.

"It's important because it puts a face on the disease," she said. "There are so many organizations going for the same (research) dollars that you have to find a way to personalize it. There are adults living with this. This is not something that goes away. You don't get it as a kid and it goes away -- no. She is not going to outgrow this."

Since being chosen earlier this year, Marshall has put in several hours preparing for her trip -- making videos and writing letters that will be shared with lawmakers. And while she admitted she's nervous, she's eager to make a difference.

"What is so important about kids advocating for themselves is it takes away some of the power that diabetes has over you," Marshall said. "Going and being a representative for your state and everyone with diabetes, it really gives you a sense of empowerment like, 'OK, I can do something about this.' "