

This story was written for the Childhood Brain Tumor Foundation, Germantown, MD.

## Larry and Judith, the Dynamic Duo



Courage, determination and compassion are words that come to mind when thinking about twins Larry and Judith Theriault of Peabody, Massachusetts. Now thirteen years old, Larry and Judith are living with neurofibromatosis (NF 1). Diagnosed at 6 months of age and first manifesting optic nerve gliomas at age 2 and 3 respectively, Larry and Judith consistently make the most of life despite the challenges that each child faces on a daily basis.

Family and friends describe Larry who will start the 7th grade in the fall as a funny kid who likes to talk and make people laugh. Larry confirmed this by saying, “Yes, Judith and I like to make kids smile.” When asked about the things he likes to do for fun, Larry explained, “I am not sports oriented because I can’t see out of one eye, but I can play some sports like baseball, basketball and soccer. I really like to play tag or hide and seek. I also like to read, tell jokes, play video games and the keyboards. And in the summer, we really like to swim. We couldn’t go the summer without swimming.”

Although he has no vision in one eye and very limited vision in his other eye, Larry stresses that he can get around almost “perfectly.” To compensate for his vision, Larry has been learning Braille, for the past four years. Larry explains that learning Braille is a lot of fun, and that he is very grateful to his Braille teacher because she has helped him very much.

Despite his successes compensating for his vision and in learning Braille, Larry often wonders what it would be like to see out of two eyes. With limited vision since he was a toddler, Larry notes that it is very difficult to be blind in one eye. Yet, Larry is quick to point out that his eyes don’t stop him from doing things. At the same time he acknowledges the challenges of compromised vision. As Larry explains, “I can’t see colors and I have trouble distinguishing faces. Sometimes I mix up my mom with other people if I am out in a store and sometimes in a movie, I can’t tell what is going on. The thing that really bothers me is when people don’t understand my vision. Some people think I can see because I can get around perfectly. But I can’t see. A lot of times it doesn’t seem like they want to help.”

Reflecting on the people he most admires in life, Larry is quick to identify those people he considers heroes. “Judith is my hero. I wouldn’t be able to go to school without Judith. She is always there to help me when I am in trouble. My mom and dad are my heroes. My grandmother is one of my heroes. And Helen Keller and Louis Braille are my heroes.”

When asked about the future, it is clear that Larry has plans. “I want to be a librarian, an author, or I want to work at a bookstore. Those are my three top choices. But right now, I am thinking more about middle school. I am going to try out for the chorus.”

Judith, who will start the 8<sup>th</sup> grade in the fall, likes talking on the phone with her best friend, taking dance classes, drawing, reading, riding her bike, and spending time with her family and her dog Maggie, a Beagle, Basset, Pointer mix.

When asked about a particularly memorable experience, Judith recalled a trip with her family to Disney provided by the Make-A-Wish Foundation. “It was the best trip ever. There was a merry-go-round, an arcade, an ice cream store, and a six-foot rabbit that even tucked us in one night. We also met Mickey, Minnie, Donald, and Daisy during a parade and they all said hi to us from a float.” Larry added, “We

laughed and laughed the whole time, it was great.”

Judith completed a second round of chemotherapy about a year ago and has been doing well since. When asked about this experience, Judith explained, “A test of my visual fields test showed, along with an MRI, that the tumor was growing. I didn’t want to do treatment again, but my parents said I had to. I would rather have my vision so I started treatment. At first I didn’t want people to know I was going to go through it again because I didn’t know what people would think. But then they were all really nice. I didn’t want them to know at dance either, but then they found out and they were all fine too.”

When talking about her treatment experiences, Judith explained, “Treatment day is really long. We are there all day. I didn’t usually feel good the next day so I would just sleep. Usually, I felt better by Thursday. It would just depend. I never missed dance though. Dance is on Friday and I am always better by Friday.” Yet, Judith noted that her most recent treatment experience was “really hard.” She explained, “I missed 58 days of school and I was sick a lot. In the beginning I was a lot better and then it just got worse and worse.” Larry added, “It was horrible for me. Coming home everyday and knowing my sister was sick was hard.” Overall, it is clear that Judith is very well versed on her course of treatment and has a sophisticated sense beyond her thirteen years of the intricacies of living with a brain tumor.

Judith clearly reinforces the social support she and her brother receive at the Jimmy Fund Clinic in Boston where they both receive treatment. “I have known everyone there since I was three and Larry was two. It has been about ten years.” Judith added, “When we go into Boston, there are some patients there who are really sick and they are not having fun. So I try to make it a little more fun for them, which makes it more fun for me too.”

In reflecting on the people who are most important to her, Judith explains, “My mom and dad are my heroes, we couldn’t do it without my mom and dad. My grandmother helps me too and, of course, Larry is one of my heroes.”

When asked about what she would like to do for a career, Judith responded quickly, “I want to be a teacher. I have wanted to be a teacher forever. I think maybe I also want to be a dance teacher. After school I could teach dance. I could have two jobs. I think that would be cool.”

The twins are very protective of each other; particularly in social situations when other kids don’t always understand or appreciate the challenges each faces on a daily basis. It is clear that Larry and Judith have an extremely strong bond and that they support each other through good times and those which are more challenging. The strength of the Theriault family should not be understated. This is a team in the truest sense.

In talking about the twins, it is clear that mom and dad are proud of their children. At the same time they are open about the challenges each child faces as a result of NF. Mom explains, “Larry is going to be a politician. He is so open, not shy at all. He will just go out there, put his hand out, and introduce himself. I think this is good for him since things are often so hard for him. His vision makes it particularly hard. No matter how hard he tries, he is not always accepted by the other kids. He can never be involved in outside sports activities. And the fact that he doesn’t look sick makes it even harder. If you don’t look sick, people don’t make allowances for you. Not that I want him to look sick, but I think it is a disservice to him. Because he adapts so amazingly well to his environment, other kids often don’t know how to react to him.”

Dad explains, “Because Judith doesn’t have as many physical limitations especially with the visual piece of the puzzle, I think it is easier for her to socialize and develop friendships with other kids. But Larry is our most outgoing one. He meets everyone. We take the train and we know everyone on the train. It does not matter who it is, we know him. They called him the Mayor at his old school. He knew everyone.”

On Larry’s vision, Dad says, “It is very hard for him. It puts a real damper on his social affairs and makes it very hard for him to play with the boys. They want to play sports or rough games, and he can’t do this because he would get hurt. He can’t defend himself if he needs to. He can’t toss the ball around. He does very well with younger kids and adults. Meeting other kids with similar problems in the clinic has been good for him. But it is a tough road.”

Mom and dad also explain that both twins have learning differences, which have posed challenges in school over the years. Yet, both kids are clearly bright and articulate. Judith is particularly mature for her age and

is good at engaging in conversation. Yet, as mom and dad also note, this is not always easy either as it masks the real difficulties. Reflecting on their hopes for their children, both mom and dad say that more than anything else, they would like Larry and Judith to come away from this phase of their lives with a strong sense of the future.

Without a doubt this is an amazing family who together face the challenges of NF. Larry and Judith are kids who despite significant obstacles focus more on what they can do as opposed to what they can't do. They thrive despite the uncertainties they face and the challenges life brings. They are a true inspiration.

*Kate K. Lund recently completed a doctorate in clinical psychology in Boston and will begin a two-year post-doctoral fellowship at the University of Hartford this summer.*