

Someone You Should Know: Leigh Goldie

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Leigh Goldie

As a young child, Leigh Goldie started experiencing seizures that made her feel self-conscious, scared and alone. After years of dealing with the illness, she was diagnosed with complex partial epilepsy. In April 2014, she launched Empowering Epilepsy, a nonprofit organization offering support groups both for people with epilepsy and parents of children with epilepsy. Goldie hopes to provide the services necessary so those dealing with epilepsy never feel alone.

What prompted you to create Empowering Epilepsy?

When I was 8 years old, I experienced traumatic brain injury due to a car accident while walking home from school. Soon after, I started getting these feelings in my chest that I could not describe to anyone. My pediatrician referred me to a neurologist who diagnosed me with complex partial epilepsy. That means when I would have a seizure, I would stare like I was daydreaming, smack my lips and swallow and not always understand what others were saying to me. After a minute or two, the feeling would end.

As a child, seizures were scary for me, as I didn't know when they would happen and felt very embarrassed by them since I would lose control. They affected my

ability to process or remember information I learned in school, made me feel extremely self-conscious around my friends, and since I didn't feel anyone else understood them, made me feel isolated and alone.

What was your previous occupation?

I was a teacher. My goal has always been to help others.

How did you turn your idea for an organization into a reality?

In the summer of 2013, I posted a message on Facebook: "If anyone knows someone who experiences epilepsy, please message me. I have a new project and would love their help." Forty of my friends responded that they knew of someone who experienced epilepsy. I sent blind questionnaires to those friends to forward on to the people they knew.

Almost all the questionnaire responses shared the same message – that due to epilepsy, they felt isolated and alone and were disappointed because they felt that outside of their neurologist's office, there was no one to talk to about their chronic condition. They verified that they wanted others to share their stories with, talk about handling medications and their sometimes-overwhelming side effects, find ways to lessen the seizures they experience, and educate others about epilepsy and seizures so people were not afraid. I shared those answers with an amazing group of people who understood epilepsy, some of whom currently serve on our board of directors, and Empowering Epilepsy was born.

What motivates you to do what you do?

What motivates me the most is talking to people who find it unbelievable that someone else understands what they are going through. The lack of public awareness and acceptance of epilepsy is a huge hurdle to face, and the negative stigma affiliated with epilepsy is ongoing. This was the main cause of my feelings of isolation growing up. Providing the help to others that I so desperately needed but couldn't find when living with seizures means a lot to me. While I no longer experience seizures due to successful brain surgery in 1993, I want to be able to help people living with epilepsy realize they are not alone.

What are your goals for the future?

Creating annual Empowering Epilepsy conferences, the first one coming up this April 18, with amazing neurologists, neuropsychologists and attorneys speaking on topics related to epilepsy and empowering your life. I also plan to continue to expand our support groups so that we can begin reaching out to children, teens, seniors, veterans and all people experiencing epilepsy, as well as discussing

women's health issues. One day, I would love to open a facility for people with epilepsy to engage in a variety of activities we have planned to help them effectively manage seizures and empower their lives. The goal is to realize what they can do. People with epilepsy need to be shown that epilepsy is something they have, not something to keep them from setting and attaining goals to empower their life.

Are you hosting any upcoming events?

On March 26, we are holding our first Purple Day Party at Freeway Lanes of Solon to honor Purple Day — an international Epilepsy Awareness Day that is celebrated across the globe. For \$15, attendees can enjoy two hours of bowling, all-you-can-eat pizza, wings, soft drinks and the chance to meet others who understand epilepsy.

WHO: Leigh Goldie

OCCUPATION: Founder, Empowering Epilepsy

AGE: 44

RESIDENCE: Solon

SYNAGOGUE: Temple Emanu El in Orange

OTHER JEWISH AFFILIATIONS: I have been a Sunday school teacher at Park Synagogue Wolf Religious School for more than 15 years. I am a founding board member of the Siegel and Shuster Society, a nonprofit, all-volunteer organization dedicated to honoring the creation of Superman in Cleveland (my cousin, Joe Shuster, was the artist who created Superman).

Do you know somebody we should know? I may want to profile that person in this feature. Send the details of that certain someone to jmitchell@cjn.org and place "Someone you should know" in the subject line.