Sofie's journey

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Until our only child, Sofie, developed epilepsy, Brad focused on his consulting and children's retail business while I worked representing composers and volunteering with our local special needs group and Holocaust survivor programs. Sofie was 5 and a half years old when we noticed her first seizure; we are not sure how many went undetected, as they were pretty mild in the beginning.

Sofie's first identified seizure was on Friday, May 20, 2005 just before 6 a.m., a day we will never forget. Sofie woke up and her speech was "stuck" (for lack of a better word). At first we thought she was playing around, but then we panicked. Like any scared parent, we called 9-1-1. By the time they arrived, 3 (of the longest) minutes later, she was yapping up a storm and questioning us about the paramedics in the house! Sofie continued to have seizures despite many medications and many (mis)diagnoses. We sought several opinions and consulted renowned neurologists and neurosurgeons nationwide, including UCLA/Mattel Children's Hospital, which was practically in our backyard at the time. Sofie had numerous electroencephalography (EEG) and magnetic resonance imaging (MRI) studies at different hospitals. One of the first misdiagnoses was that we were told that she had a cancerous tumor and we were immediately being sent to speak to a pediatric oncologist to discuss radiation. REALLY? Well, after more testing, we learned it was not a cancerous tumor, but in fact a lesion. We saw more doctors and tried more medications but seizures were getting worst, and her quality of life was not what she deserved at her age.

Three and a half years later, we were presented with the opportunity for Sofie to have a neurosurgical evaluation to see if she was truly a surgical candidate. The evaluation included neuropsychological testing, as well as the Wada test. In order for Sofie to go through surgery, she had to be able to get through the Wada; not a fun test, and if you ask her today what the worst part about her brain surgery was, she'll tell you the Wada! She did it, she got through it (with a lot of help!) and passed with flying colors. Passing meant her language had switched sides and there was no worry (well, we worried, but her surgeon didn't!) that her language would be compromised. We always thought that surgery was a last option, not understanding that sometimes it's just an option, not always the last one. Now it was time to explain how fortunate she was to be a surgical candidate, that she wound up a lucky one to have a surgically treatable disorder! Once we understood, our focus changed to doing whatever we had to do to fix Sofie, and now, others like her with epilepsy. We didn't realize what stigma epilepsy carries; looking back we are guilty of it too by telling people she had "seizure disorder." What is often called seizure disorder is really EPILEPSY, but it doesn't sound as bad!

Friday, February 27, 2009, became the scariest and at the same time, the best day of our lives. Sofie had a left temporal medial lobectomy; her "troublemaker" was removed, and it was the lesion that was the cause of her focal dyscognitive seizures that she used to call her "crookies." We had agreed the surgery was the best chance for Sofie to be a "regular" kid, but it was still hard to grasp that she was having brain surgery. We had plenty of friends and family question our decision; some thought we weren't making the right choice, and to them I can only say we followed our heart; we trusted the tests and the doctors didn't let us down. When the surgery was described as "just another day at the office" we were in awe. We brought our Rabbi and Doc to

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the hospital (along with family and friends) on the big day and prayed for this surgery to be Sofie's cure. Brad added the promise to ensure others would have opportunities like our daughter, including building our local private neurologists medical practice. Both of these things happened. Brad has become the practice manager for our referring neurologist, as well as general manager of a full service ambulatory video telemetry monitoring EEG lab catering to kids with special needs.

We are ecstatic and ever so grateful that Sofie is 5 years seizure-free!! Each year on the anniversary of surgery, we celebrate with Sofie, by adding a numerical charm to her bracelet, which now has the numbers 1, 2, 3, 4, and 5 dangling from it as a constant reminder of how lucky she is. Sofie is currently in 8th grade, working on student council, and has become a very typical teenager; she loves her iPhone, swimming, and the beach (and sleeping in!). She volunteers by delivering food to the elderly twice a month, and she has been a part of a unique group that pairs up special needs children with a big buddy—SHE is the big buddy. We are truly blessed. Sofie has a unique connection with younger kids and plans on being a pediatric neuro EEG technician, as she understands and can relate to what the young patients are going through.

As a family, we focus our passion on epilepsy awareness, volunteering with youth and elderly, and ensuring others obtain opportunities for great epilepsy care. We created EPILEPSY AWARENESS DAY AT DISNEYLAND RESORT (EADDL). Our first event, on November 7, was an amazing day uniting 972 people together for the same reason, wearing their EADDL purple T-shirts, to help raise awareness and end the stigma related to epilepsy. On November 8, 2013, Candy volunteered to continue as the coordinator of EADDL for 2014 and beyond. We are determined to make this event the biggest gathering of epilepsy support groups anywhere! Last year people came from as far as the United Kingdom and Canada; this year we are working on getting folks from as far away as Australia as well as representation (hopefully!) from all 50 states at EADDL 2014, on November 6, 2014. We are able to gather kids with epilepsy, adults with epilepsy, and trained dogs that work for people with epilepsy all together to find friends and support. It has been AMAZING.

People do what they have to in order to help their kids. We did it; a lot of people do it. We are just trying to give back to those who need some guidance, or handholding. When we started on Sofie's journey, we did not know about support groups, there were not a lot of "Brain Surgery" Facebook pages, but those times have changed! PLEASE look us up, pass the information on to someone you know that is affected by epilepsy, or knows someone who is. It can be the best thing you do for them! Please come and support someone you love!

Epilepsy Awareness Day 2014
at
Disneyland Resort
Nov. 6, 2014

Disclosure

The author has no conflicts of interest to disclose. We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

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