Annie Galloway’s Testimony

April 2, 2014

I am a parent of a child with Intractable Epilepsy. I never thought that I would know what that means. I am one of many parents who have watched my child have unrelenting seizures that have robbed her of skills, time, strength, health, joy, and many of the “firsts” in childhood. I am standing up for these children that we know deserve to have treatments that will allow them to reach their full potential. Can you imagine your own child suffering this condition?

My daughter Maitri is 10. She loves pink, ponies, and playing a good trick. She hit all her developmental milestones until age 5 ½, then she began having increased anxiety, waking at night first once a month which then increased to 4 times/night. In the spring of 2010 we were exploring a meadow, Maitri ran off and she wouldn’t come back when I called her, she just kept running. She was waving her arms. I thought maybe a bee was chasing her. When I caught up to her, her pupils were dilated, her heart was racing, and she could not speak. It took 45 minutes before she could tell me what happened. She said sobbing, that the tree was chasing her and going to eat her. I was baffled and very concerned. The pediatrician thought she was having panic attacks. Over the next three months these episodes increased until she was having 60 seizures each day. One day I found her curled up in the fetal position on the bathroom floor. She was shaking and said, “Mama what is happening to me, make this stop.”

In June 2010, Maitri was diagnosed with severe life threatening epilepsy. Her seizures are primarily in her frontal lobe, but also her temporal lobe. She has more than 10 focal points. The seizures affect her behavior, her ability to regulate some of her body function, her executive functioning, her fine and gross motor ability, her coordination and her personality.

The next four years was a roller coaster, a crash course in neurology, pharmaceuticals, nursing, insurance, IEPs, service providers, learning about VNA, CSHN, and PPCP …. BUT most of all how to grieve and how to learn to let go of what I thought was going to be my daughter's childhood.

Maitri tried 7 seizures medicines in 4 months. They all failed her. The side effects were horrible. When she tried Topomax, she became nonverbal and screamed for 4 weeks. When she tried Keppra, she ran into walls and knocked out her front teeth. She fought and kicked and hid in corners. When she tried Depakote she gained 17 pounds, became lethargic and depressed. When she tried the Ketogenic Diet she had increased seizures and developed Pancreatitis and was hospitalized for 10 days. When she tried Lamictal she developed a rash all over her body. When she tried Zonegran she lost her appetite and had to be fed by syringe for 3 months, she lost 15 pounds and spent the summer with no energy. When she tried Onfi, she could not control her behavior and ran into traffic. These 4 years Maitri went to the hospital over 30 times for various illnesses and tests related to her epilepsy.

In the last year, the medicines that she was on were controlling her seizures so she had two status seizures/week and 15 smaller seizures/week. The thing that parents know who have children with Intractable Epilepsy is there is always going to be a time when the medicine stops working and then what do we do next? We are always looking for the next possible medicine to help our children.

Maitri had been to see 3 different neurologists before switching to Dr. Holmes. Two of them had said to me there is nothing else we can so for your daughter.

How can this be true?

Last spring I learned about Charlotte Figi's story. I learned about this brave amazing mother who like us had tried so many pharmaceuticals looking for the medicine that would stop or even reduce the seizures. Paige gave her daughter Cannabis and it worked! Paige was fortunate to have met the Stanley Brothers who owned a dispensary and at the time were developing a high CBD strain. This is plant that is now named Charlotte's Web. I began to learn as much as I could about this treatment option. I discovered Realm of Caring and reached out to Paige Figi. We had a few conversations by phone and soon she had me in contact with the Stanley Brothers.

At the same time I began to reach out the Vermont Dispensaries to Shayne Lynn and Alex Ford. I decided that Maitri needed to be on the registry in Vermont in case there was a medicine available that could help her with her seizures. I met with Shayne and we began talking about how we could make this possible for the children in Vermont with Intractable epilepsy. Shayne was very interested in finding a way to make this happen for the children in Vermont who could benefit. Though there were parts of the process that still needed to be set up… a lab to test the medicine and the processing equipment to make it. And of course the right strain of Cannabis, a high CBD, low THC strain that would be like Charlotte's Web. There was still a lot of work that needed to be done.

And the question in the mind of a mother of a child with Intractable Epilepsy… how long does my child have to live?

In November, I helped to organize for Paige Figi, Joel and Josh Stanley to speak to Vermonters. In the days after the Talk, I became overwhelmed with the urgency to have Maitri try this medicine. Dr. Holmes and Maitri's pediatrician were on board and felt that this could be a viable option for her. Many families were moving to Colorado to see if Charlotte's Web would help their children. I could not sleep for days. With the support of my family, I decided I needed to go to Colorado and at least get things started so that if Maitri's health took a turn for the worse that I would have the option to get her the medicine quickly.

While we were in Colorado Maitri's medicine became available. Now I had to choose….. Do I stay in Colorado and give Maitri the chance to try this medicine right now? Or do we return to Vermont and wait until we can have this medicine in Vermont? It was an obvious and heart wrenching choice. When I told Maitri that we were staying Colorado so she could try CW, she said, "Remember Mama, keep your eye on the prize!" I knew in that moment we made the best choice for Maitri.

The decision to come to Colorado impacted our family in immeasurable ways.

The Care Team that I had developed to support Maitri had taken years to set up. The thought of moving us away from our family and friends who supported us with all the challenges that we had faced the past 4 years was terrifying. It took years to develop this team because of the intensity of Maitri's illness, her anxiety disorder made it so that getting to know providers took months for her to establish a connection. Maitri's support team is our family, our friends, our Quaker Meeting, her neurologist and pediatrician, the Schoolhouse where she finally began to attend school full time just last January, her 1:1 Caitlin, her Visiting Nurse, her PT, OT, the wonderful Bonnie Benson who helps her with swimming, Stern Center, Monica from PPCP and CSHN social worker and her therapist. So when we left Vermont, we came for the medicine but we left our team behind. I resigned from my work at VFN. We left our home.

Since starting the Charlotte's Web treatment, Maitri has had fewer seizures then she has had in the past four years. Her seizures have been reduced by 80 %. Last week she went a whole week with NO seizures. I have titrated down her pharmas by 1/3 of her total dose and she is still having less seizures. Many families here have brought their children with support from doctors completely off of the pharmaceuticals and the children are doing better.

One thing I learned about CBDs is that we all have an endo-cannabanoid system in our bodies. Many of the receptors are in our guts as well as our brains. CBDs can be found in human breast milk and in Cannabis. It is exciting to think of all the research that will happen in the next few years and how in learning more about this system we have the potential to help many people who are suffering from neurological conditions like epilepsy.

We want to come home. We need you now to help us.

Wish List for what I hope for Vermont

Find a way; create a path so that Charlotte's Web can be grown in Vermont.

Compassion Use Law

Please consider writing a compassionate use Law that would allow children in need to access the medicine as quickly as possible. Some children have passed away before they could try this new found treatment. This is a crime.

Reciprocity Law

In Utah the Governor is signing a law that will allow for cannabis medicine to be shipped from Colorado to Utah for children in need. The more states that follow suit and sign these laws the more pressure this will put on the Federal Government to change Federal Laws.

Qualifying Medical Conditions

There are many people in Colorado and California who are being helped who suffer from Parkinson's, Autism, Migraines, PTSD and other neurological conditions. I think it is in the best interest of the people of VT that the list of Qualifying conditions be expanded so that more people can be helped by these new therapies. I especially think that Chronic Lyme Disease needs to be considered as we live in New England any many people are suffering from this illness.

Regarding the 6 month waiting period with a new doctor.

The records of a patient should be enough for a person to obtain a doctor's signature for the Registry Application provided that the doctor has reviewed the records and agrees the patient has a qualifying condition. If a person has suffered for 4 years it does not seem necessary to he or she would have wait 6 more months in order to obtain relief of a debilitating condition. Some patients will not have 6 months to wait.

We will walk to the ends of the earth to find the medicines that will help our children.

THANK YOU FOR THIS OPPORTUNITY TO SHARE OUR STORY