

The Pierce Peddy Story . . .

It was a beautiful weekend. We had so looked forward to a fun family getaway to the beach. The pictures of the weekend are etched in my mind still so clear, it's like watching a slide show over and over again in my head. Our 2 year old son Pierce is laughing, throwing sand and chasing his big sister Gracie around the beach. My husband David and I are enjoying watching them play, feeling blessed to be together for such a wonderful weekend.

That night Pierce began feeling ill and eventually vomited but otherwise seemed fine and we didn't worry much else about it. He went peacefully asleep and remained that way until morning. When we heard him wake up shortly after sunrise I picked him up and put him in bed with us for a cuddle. His messy blonde hair disheveled over his angelic face, he was beautiful. As we watched him, half asleep something strange began happening. Pierce's body stiffened, his eyes shifted to one side and his breathing slowed to the point that we were terrified he stopped breathing. We immediately called 911. I knew as I watched him this was a seizure. He had never had one before, but I recognized what it was and it rocked me to the core. His lips were turning blue we were panicking. The entire event lasted about 3 minutes but felt like 3 days in slow motion.

After an evaluation at the hospital it was determined that the seizure was probably a onetime occurrence. All his tests came back normal; the doctors sent us home and told us not to worry. We were barely getting the first experience out of our mind when 3 weeks later Pierce had another seizure. This time Pierce was started on daily anticonvulsants to control his seizures. The medicine seemed to work wonders – Pierce was seizure free for 8 months! We were finally beginning to relax a bit and wondered if he really needed the medicine after all.

Then wham! Completely out of the blue Pierce had 8 seizures in one week. Additional tests were ordered which came back abnormal. We couldn't believe it. Our normal, healthy, beautiful boy with his mop of blonde hair and his wide sunny smile was sick. How sick? What kind of sick? We didn't know, but were about to begin a long process of trying to figure that out. A process which has changed our lives and continues to this day.

Pierce was immediately given an EEG test. *1. An EEG can diagnosis abnormal brain activity. Small electrodes are attached to a person's head to record different patterns of activity in the brain.* Pierce's was highly abnormal. To look at our son and interact with him you would never know that there was anything "abnormal" about him, whatever that means ~ now I realize it's all relative.

After these tests concluded Pierce was officially diagnosed with Epilepsy. We didn't know much of what that meant at the time. We were grossly uninformed and felt ignorant about our lack of knowledge. There was a monster affecting our son and we didn't know how to fight it. We began scouring the internet and reading all the books we could find on epilepsy.

1. Epilepsy is a neurological disorder which briefly interrupts the normal function of the brain. These brief interruptions or seizures are characterized by a sudden change in movement, behavior, sensation or consciousness produced by an abnormal electrical discharge in the brain. Epilepsy has a variety of

*causes. The leading cause of known epilepsies is a major head trauma. Other causes can include stroke, infectious diseases such as encephalitis and meningitis, diseases that cut the flow of blood to the brain, tumors, alcohol, and drug abuse, birth trauma and high-risk pregnancies. Some epilepsies are genetic. Many causes of epilepsy can be avoidable.** None of these causes occurred to our son prior to his first seizure.

Most of the information we read was encouraging. The majority of people who have Epilepsy have “controlled epilepsy” meaning that medicine works to control these events and they lead “normal”, healthy lives. Many children even outgrow epilepsy and can discontinue medicine after a lengthy seizure-free period. Okay, I thought, this isn’t as scary as it was in the beginning, Pierce is going to be fine – we just need to find the right medicine.

Pierce’s seizures began presenting themselves differently. Sometimes he would stop breathing and stiffen while his lips turned blue, other times as he was running swiftly across the yard he would suddenly drop to the ground seemingly mid-run. His eyes darted left then right, back and forth, he spun around in circles, he was unresponsive. Pierce had so many different kinds of seizures now that it was difficult to describe them all.

We took Pierce to Gainesville to the University of Florida and began something called the ketogenic diet. *This unusual diet is one low in proteins and carbohydrates and very high in fats. No one knows for sure why this diet works but it has shown some short-term benefits of seizure control in some children. One thought is the diet may change the body chemistry in ways that have a positive effect on seizure control.** Looking back it’s difficult to decide if there was much of a positive effect on Pierce. We think it helped but was definitely not our answer.

Pierce began another sharp decline during the summer of 2006. He was airlifted to Shands for treatment, was back home for two weeks then readmitted. He followed that stay with an airlift to Miami Children’s Hospital where we stayed for 1 month. Most of the treatment in Miami was a revised ketogenic approach. I remember being elated as we drove out of the hospital upon his release. We had come so far, he rebounded after each setback – I was sure our son was Superman. He leaped the hurdles in front of him and kept on smiling. Pierce’s spirit was miraculous; in spite of it all he was a happy 3 year old boy. And we were so thankful to be bringing him home.

Our happiness lasted about a month then more problems erupted. While we were home I took Pierce in for a check-up and he was brought up to date on his vaccinations. I remember at the time wondering if vaccinating him so close to his last hospital visit was such a good idea. He was still in a fragile state. I briefly talked about my concerns with our pediatrician and although I was not well informed, I trusted that he knew what was best for our son and we proceeded with the shots. My heart was telling me otherwise; every day I wish I could turn back time.

Shortly after the vaccinations Pierce's seizures worsened and he was now experiencing what specialists call "catastrophic epilepsy". While the vaccination is in question as the culprit, David and I can't help but wonder due to the timeline of the shots and the almost immediate downturn of Pierce's condition. Allowing the vaccination is something that still haunts me today.

So with a heavy heart less than two months after we came home from Miami our suitcases were packed once again, we tearfully said goodbye to our sweet daughter Gracie, and got in the car to drive the 4 hour path back to Miami Children's Hospital. I was sick, physically sick at the prospect of what awaited us, but scared of what would happen to Pierce if we didn't.

The decision was tough but our medical team encouraged us to try a different approach with Pierce. They wanted to administer a powerful drug called *pentobarbital* to slip our son into a sedated coma to give his brain rest from the constant seizures and try and break the cycle of these events. Machines would breathe for him, he would be at rest and this would give his brain time to heal. We were scared out of our mind but felt we had no choice.

Watching our beautiful boy peacefully asleep without a seizure was heaven. Knowing his mind was far away in another land was frightening. Would he be okay? Would he wake up? Would these horrible seizures stop for good? I pushed myself to keep my mind on task, not allowing it to wander a path of "what if". Pierce needed to have a feeding tube surgically implanted in his stomach to accommodate medicine and food while he slept. I remember thinking *what next?* David and I held each other in PICU and prayed, reminding ourselves that Pierce always persevered; he was our strong, brave boy.

And he did! After 5 days in the coma his medicine was tapered down and Pierce's beautiful blue eyes slowly began to open and eventually began to sparkle again. Our daughter Gracie who at 5 was the ultimate big sister and reveled in helping her baby brother as he grew stronger each day. Having Grace visit us on the weekends gave us a bit of "normalcy" that we longed for so much. We desperately missed being with her everyday but she seemed to understand Pierce needed us more. Pierce's trip to Miami lasted about 6 weeks that time.

Pierce was then transferred to Tampa General Hospital for inpatient rehab for 6 weeks. Then discharged home for only 3 days before the seizures became unbearable and was then readmitted to Lakeland Regional Medical Center Intensive Care Unit. Within 24 hours Pierce was airlifted back to Miami Children's Intensive Care. Immediately the neurology/ critical care team decided to induce Pierce back into the Pentobarbital coma. Nothing gave Pierce rest from the wave of seizures that knocked him down over and over again. While we hated seeing our son so far from this world we knew it allowed his brain and body to have a much needed break from the near constant seizing. So we proceeded as before thinking he would peacefully sleep again for a *few days* and come out with flying colors.

7 months later . . .

Pierce was still in the sedated coma. Our precious baby boy had experienced nearly every complication possible without dying. The hills and valleys Pierce experienced were more like mountains and ditches – a cycle of *hope then despair* that continued for 7 months. Pierce endured biopsies of his brain, muscles, and skin in a desperate attempt for our medical team to determine what was causing Pierce’s life to decline out of control. After all the tests, scans, and biopsies came back the results all returned within acceptable ranges – *all normal!!* “How is this possible” we screamed. “Look at him – he’s been asleep for 7 months, he’s needed a tracheotomy, a shunt (to relieve fluid from his brain) and his bones are turning to paper. He’s had pneumonia, collapsed lungs, a blood clot and countless infections. He’s definitely *not very normal right now*”. We felt like we hit a brick wall. All of these months without our son and still no answers? How is that possible? Our life had become a nightmare we couldn’t wake up from.

It was then that we decided no matter what was causing our son’s seizures, what complications he might have now we wanted him awake! We desperately needed to see our son’s eyes open again. Obviously medicine was not going to “fix” him, he was no better than before but now with a load of complications. We had faith if our son woke up we could help him. We felt we could help rehabilitate our sweet, strong Superman; we just needed him to wake up.

After a very slow weaning period Pierce began to wake up. But not peacefully like before. He had been given so much pentobarbital that his body craved it – he was addicted to this twisted, nasty drug. Withdraw was horrific, we watched him suffer through the agony of trying to overcome this hurdle when he still had so many others to jump.

How much suffering can a mother watch her child go through? My heart was broken. I missed Pierce so much. My body ached to feel him jump into my arms and wrap his pudgy hands around my neck. I longed to hear him giggle. I found myself grieving for the child I missed so desperately all while needing to make necessary plans for his recovery. Trying to stay focused on the tasks at hand was nearly impossible, but David and I worked as team to cover as many bases as we could.

It became startlingly obvious that Pierce would have a very lengthy, bumpy recovery. No one could tell us how many functions Pierce would regain. They still can’t. So let me get this straight I thought. Nobody has any idea what’s wrong with our son. No idea what to do to help him or how much he’ll improve from his “post coma” state. Why in the world did we ever put him in the coma? We second guessed ourselves hundreds of times daily, wondering what would have happened if we had chosen another path for him. Would he still have been so sick? Would he have been worse? Did the complications from the amount of pentobarbital make him worse? We didn’t know the answers to our questions, we still don’t. And neither does our medical team. I used to look at doctors for all the answers, now I realize how much is out of their control.

The glorious day finally came when Pierce was released from the hospital after 9 months. The staff threw a party, helped us pack, and wished us luck. And off we drove with our son . . . but only about 3 miles. We had enough foresight to realize that Pierce needed major rehabilitation and we needed to be close to his doctors and therapists at the hospital. We weren’t going home to our cozy, familiar home in Lakeland we were pulling into the driveway of an empty rental house in Miami. Our families showed up

with the contents of our house in Lakeland and began the laborious task of helping us set up our new residence. We scrambled to find a nice school for Gracie and registered her for the new school year. We searched for nursing care for Pierce and began taking care of our little boy 24/7 until we could find help.

Pierce's care is immense. He is not the little boy who closed his eyes and drifted off to sleep in PICU. He is a different boy now. We pray and have faith that he will become a different boy yet. We will never give up the positive possibilities that we think our son can become. We have to hope, we are his parents – it is our job.

Pierce has been out of the coma for 11 months now. He is no longer having seizures; the coma seemed to accomplish that goal. But he still struggles with neurological events called "storms" These are not as damaging as his seizures were but are disturbing episodes to him and us. He still has the tracheotomy, the shunt, and the g-tube in his stomach. He cannot sit up without assistance, he doesn't stand and cannot walk. We don't know if Pierce can see; he doesn't talk. Our Superman has a lot of hurdles to leap yet, but we have faith he will make progress. When his beautiful blue eyes are open we can see them sparkle and they seem to dance in the sunlight. He smiles and stretches like he did when was a baby in my arms. Sometimes he laughs and likes to hear his own voice which sends us into hysterics.

Small things make us happy now. Being back together as a family of four. Everyone under the same roof at the same time. After living in the hospital for over a year these are the pleasures we relish. Going grocery shopping, taking Gracie to birthday parties and after school activities, waking up together and working as a team to raise our family and help our son.

As anyone can imagine we have encountered many financial hardships during this medical nightmare. Our business suffered greatly as David spent any moment he could at the hospital with Pierce and I. He couldn't travel, it was difficult to make sales calls and continue working when your baby was slipping further and further away from you. Pierce has maxed out his private health insurance and we now continue to reapply for government healthcare to meet his needs. A very kind hearted friend created a website for people to remain updated regarding Pierce's condition and many generous friends and family members have given monetarily to a fund developed to help Pierce's rehabilitation. Many of his therapies are not covered and it has been quite useful to aid in his recovery. We are very humbled and grateful beyond words for these acts of kindness. We had always enjoyed helping others and now our life has become one of accepting help from friends and strangers alike.

There are many families who face medical tragedies. We have been side by side with many in PICU and in the main hospital. We have comforted each other and cried together. We have shared tears of joy. We have learned from each other. We understand now that help comes from unexpected places and people. You can step up to a challenge or crisis if you believe in yourself and your faith. Never lose hope, medical advances are being made daily, someone just might find your answer.

This is definably not the life we expected or would wish on anyone. But it is our life - our path to lead Pierce in a way that allows him to maximize his potential and become a happy, healthy adult.

If your child or someone you know is suffering from uncontrolled seizures and is in need of direction and help, I urge you to contact your local Epilepsy chapter – www.epilepsyfla.org or contact Pat Dean, President of Florida’s Epilepsy foundation. Pat is also the coordinator of the Comprehensive Epilepsy Program at the Brain Institute located within Miami Children’s Hospital.

Resources:

1 One Hundred and one Questions and Answers About Epilepsy, Epilepsy Services of West Central Florida, Inc.

Epilepsy, Florida’s Hidden Healthcare Crisis