

Becca

Our daughter, Becca, was damaged by her initial DPT vaccine at 3 months of age. She was progressing well and had her first two well-baby visits prior to immunization. Becca had several seizures the first day of immunization beginning only hours after the vaccine was administered. By the second day, I knew something was wrong. The initial episodes were so minute and brief one might have missed them or written them off, but I knew in my heart of hearts something was definitely NOT right. She would turn her head to the left slightly, click her tongue, avert her eyes also to the left, and clench her fists. All of this activity lasted perhaps 15 seconds. Then she would resume whatever activity she was attending to. We know now these were complex partial seizures. She did have a high fever and redness and slight swelling at the site of the shot also. When I took her in to the pediatrician the second day and tried to describe what Becca was doing, he dismissed me as being a "new nervous mother," even though I had a seven-year old daughter already. He suggested I video tape "whatever this is you say she's doing". At the time, I was on maternity leave from the Children's Hospital where she was born. I was headed out the door of that office and I was taking Becca to the chief of pediatrics for CH, whom I knew personally, when Becca had another "episode." One of the nurses happened to witness it and called us back in. Then the nurse, the doc, and I all sat in his office for 45 minutes while his other patients backed up, and we waited for Becca to perform again. Finally she had another seizure. Boy, did that doc ever change his tune! He sent us immediately to a neurologist as Becca continued to seize, and they seemed to be getting closer and closer together. She was tested and put on phenobarbital. The seizures finally stopped, thank God. Becca was given an EEG which was normal. The neurologist that day wrote in his notes that there was a direct correlation between the seizure activity and Becca's DPT vaccination. Little did we know that this would prove to be a very valuable notation later when we filed for compensation thru the Vaccine Compensation Program. He also wrote and verbally instructed us that Becca was to have no more pertussis, but just a DT in the future. By the way, we changed pediatricians immediately to my friend who was chief of pediatrics!

Everyone kept saying she was to have no more pertussis but that Becca would surely grow out of the seizures by age five and kindergarten. No one EVER used the word epilepsy during that five-year period. Of course, we all know now that one seizure is not epilepsy, but subsequent seizures do classify it as epilepsy. So we waited for five years and kindergarten. Becca would only experience a seizure perhaps once a year when her weight would catch up to the dose of phenobarb. It was increased each year to compensate for these seizures, which had changed to drop attacks.

Well, at five and one-half years, well into her kindergarten year and after learning her ABC's, how to write, and generally running around on target with all her other peers, the bottom literally fell out of our lives. Her seizures went intractable and we have never since regained control. We slowly over the next six years watched the Becca we had known get lost within herself. She very very slowly developed speech problems and began losing her skills, one by one. She missed so much of the remainder of that school year that she had to repeat kindergarten. By the middle of the next year, everyone knew something was terribly wrong. The regression was taking our Becca so slowly it was almost unnoticeable--but we could see it happening right before our eyes. Today, at age 11, Becca is nonverbal and cannot walk without great assistance. She is for all intents and purposes wheelchair-bound. Her diagnosis now is Lennox-Gastaut Syndrome, a rare form of childhood epilepsy, which is key-noted by varying degrees of mental and physical disabilities and intractable seizures of various types. These brain storms have taken their toll on Becca, and she can no longer read or write or sing. She is having great difficulty eating now, and I must chop or on occasion puree her food so that she gets the proper nutrition. Becca has been on the ketogenic therapy for seizure control for 29 months now, under which she has gained appreciable seizure control but not total control, albeit more control than all the drugs and combinations of drugs afforded her prior to inception. She has been weaned down during this period from four concurrent drug therapies to one now. Just in the past month, Becca stopped having day-time seizures and only has them at night during sleep! We are so thankful for this latest development. It has helped her to function better during the day not having to deal with upwards of 15 hard seizures daily. We are glad to have found this life-changing keto therapy for her to use in place of anti-epileptic drugs. It has allowed Becca to be who Becca is now instead of being drugged up and completely

unaware of her surroundings. She can smile now, occasionally laugh, and express her feelings instead of being on the verge of overdose thru multi-drug intake.

Most of Becca's great activity occurs only at night for some reason which we haven't been able to put our finger on yet. Even though all meals and drugs are completely evenly spread out through the day and night, when 10 p.m. rolls around, you will find Becca wide-eyed and able to giggle, laugh, clap, squeal, and yes, even try to run and gallop like a filly being set out to pasture! There is also an occasional night when she can even call "mama" or "dad" out loud. Virtually NONE of these emotions or abilities are part of her regime during daylight hours---it DOES take its toll on us, but we try to keep up with her and not stifle these most wondrous moments as we celebrate Becca's life!

We too went thru the vaccine compensation program when Becca was turning five, prior to any and most all of the above damages. Boy, if we only knew then what we know now! The attorneys on both sides actually joked that Becca might even be in college before the matter was resolved. Hmmmmm. Obviously, yet again, no one had any idea what was to lie ahead for us. It took us five long years, but we finally agreed on a settlement and are so thankful for the help the program has afforded us to give to Becca. It was a very arduous, long five years, though.

Becca is the light of our lives, our hero, our comforter, and my side-kick! We have removed her from public school and I am homeschooling her now. I am able to take advantage of her windows of opportunity for teaching, even if it is at 1 a.m.! She is flourishing now that we made this decision in December of 1997, and I must say I am much more at ease knowing Becca is getting what she needs when she needs it from me. Becca's little sister, Sarah, is age 7, and has taken over the job of "big sister" since Becca's older sister, Angie, is 19 and away attending college studying to be a music therapist. Their help has been tremendous to me, but Becca's disability has taken its toll on her siblings too. It truly is a family affair.

In June of 1997, a cyst was discovered on Becca's cerebellum during an MRI. This resulted in a second diagnosis of Dandy Walker Syndrome. Apparently this is the reason for her poor mobility skills. It is inoperable but is not expected to increase in size. Just another hurdle to deal with and get over.....

Becca has been such a blessing to our family, and we feel so fortunate that God chose to leave her in our care. I don't know what avenue our family would have taken had we gone to "Italy instead of Amsterdam", but I do know that we would not be near the close and loving family that we are now--all because of the pure form of love which emanates from Becca every moment, despite all the trials and hardships she endures, day in and day out.