Gianna in a Place of Grace and hope

By Natalie and David Dragotto

Natalie and David Dragotto are mom and dad to Gianna. David is a firefighter. Natalie, whose business degree led her to become a company controller, left her career to become a stay-at-home mom caring for Gianna. When Natalie is not at the clinic with Gianna, she is spending her day at Gianna's school providing continuity for her suit therapy. David and Natalie give Gianna much love and praise, which Gianna soaks up happily.

Gianna is 5 years old and has a severe seizure disorder. She has an underlying genetic metabolic disorder called CDG: congenital disorders of glycosylation (type 1/subtype unknown). Formerly, this disorder was called carbohydrate-deficient glycoprotein syndrome. We received this diagnosis when she was 2.5 years old.

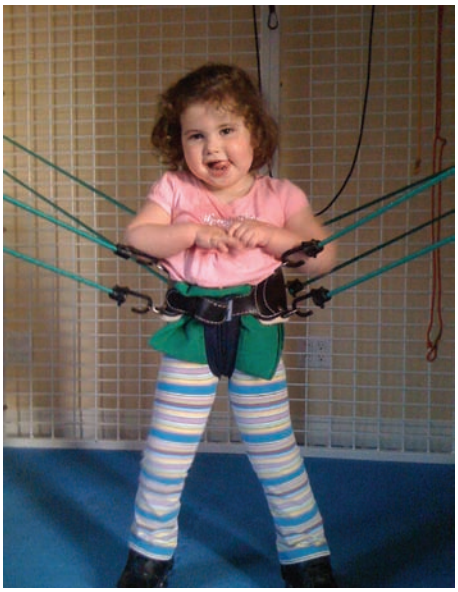
But first …

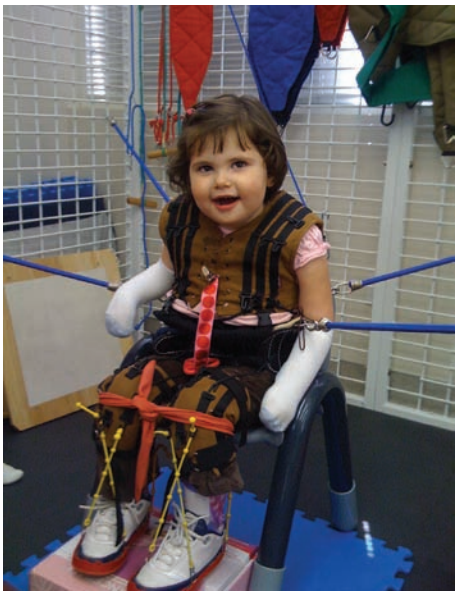
Gianna's was a normal delivery. She was attentive to voices and had no feeding problems the day she was born. Before being released from the hospital the next day, a routine hepatitis B shot was given. She developed jaundice the day after this shot; she stopped latching on for breastfeeding and became colicky with constant crying and screaming. The crying and screaming lasted for five months. We were in and out of the doctor's office due to gastroesophageal reflux disease (GERD), the constant crying/colicky behavior, and feeding issues. At Gianna's 3-month checkup, her developmental assessment was normal. She was attentive to voices, tracked objects, reached for toys, and lifted her head and chest off a surface. At that same appointment, she still had symptoms of colic and GERD; nevertheless, a cocktail of vaccines was administered. The day after the 3-month visit, we noticed that Gianna was eye rolling. In contrast to the 3-month assessment, at Gianna's 4-month checkup, it was noted that her head lagged, she did not reach for objects, and her hands were always clenched into fists. We told Gianna's pediatrician that she wasn't rolling on the floor anymore since our last visit, her head was floppy, and her limbs twitched. The doctor was concerned that her arms were continuously in extension (a straightening movement that *increases* the angle between body parts). The doctor also explained that some children develop later than others. But that didn't answer the question of why Gianna *regressed*. So, we assumed that since Gianna was swaddled during a majority of her four months due to being colicky, she needed more time to develop to compensate for the swaddling. Consequently, Gianna received a second cocktail of vaccination shots at her 4-month checkup. We now feel convinced that it was imprudent to give vaccinations on top of the underlying genetic metabolic disorder.

To reiterate: gastrointestinal problems, eye rolling, and twitching started after vaccination and before we introduced food.

At 6 months, we introduced pureed food – sweet pototoes – and the following day Gianna had her first grand mal seizure.

Gianna's first birthday, 06-29-05





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The ER said it was a febrile seizure. (We now believe it was not febrile because it seemed that certain foods – particularly certain carbohydrate-containing foods – triggered seizures, which led us to the CDG diagnosis.) At her follow-up appointment with her pediatrician two days later, he ordered an EEG and CT scan, **the results of which came back as normal** two weeks later. Within those two weeks, we still noticed eye rolling and twitching, but not a major seizure. At the appointment that was two weeks following the first grand mal seizure, a third series of vaccinations was given. In the days immediately following, we began to see more frequent seizures that also were longer in duration. Six weeks after the first grand mal seizure, another EEG was performed and Gianna was diagnosed with epilepsy. Gianna was in and out of the hospital every few weeks from uncontrolled seizures and pneumonia due to saliva, milk, and pureed food aspiration issues. Consequently, at 10 months, she was being fed only by a G-tube. She had a variety of seizure types lasting 30 seconds to 2 minutes at up to 500 seizures a day, and would become lethargic after each seizure. Around this time, we noticed that limiting foods high in carbohydrates was helpful to the number of seizures, but seizures continued. Any bodily stress such as illness, being overly tired, or even an environmental temperature change would increase her seizure activity. Having a cluster of seizures would make Gianna feverish and create a grand mal type seizure.

At 1 year old, Gianna was shown to have a broad range of seizure types. The majority of her seizures were atypical absence seizures associated with Lennox-Gastaut syndrome, which brings with it a variety of seizures, and which is diagnosed by an EEG pattern. This was said to be a rare situation for children under 2 years of age. We switched pediatricians and discontinued her vaccinations. Although we now know that the vaccinations were not the cause of her original disorder, CDG, we feel that shots caused and/or contributed to the severity of some of the symptoms and/or comorbidities that followed.

Between 10 months and 2 years old, we went to every specialist imaginable with no luck in finding a diagnosis. Since Gianna didn't show any characteristics of any known disorder, they suspected that she "created" her own disorder unique to her. Gianna had severe developmental delay, could not eat by mouth due to aspiration issues, was subject to reoccurring illness, was hypotonic, had reflux, would not use her hands, did not engage in eye contact, and had no head control. At about 1 year old, doctors told us that Gianna would never be "normal" and most likely would not live past 5 years old.

Again, Gianna was now a 1-year-old, and we were still on a mission to find her diagnosis. As her parents, having this mission helped our healing process of getting through knowing our little girl wasn't getting better and might not make it. As you can imagine, having a child with disabilities is very overwhelming. You have your family, friends, and even strangers telling you to see this specialist or that doctor or try some therapy. With the cost of insurance, co-pays, time away from work, and loss of work, doing every recommendation is impossible. We listened and researched every piece of advice given to us. When we heard about hyperbaric oxygen therapy (HBOT), we read more but did not see that it helped children with seizures or metabolic or genetic disorders. We asked Gianna's doctors and none of them knew much about hyperbaric oxygen and said that it probably would be a waste of money. Like many of the recommendations we received, we put this aside and focused on the

traditional therapies and recommendations from mainstream doctors. We later heard about a story of a little girl with a very rare condition affecting her mitochondria whose mother was also on a mission to help her daughter. We were told her story was similar to Gianna's and that we should get a copy of an episode of the *Montel Williams Show*. The show details supplied the name of Shannon Kenitz, mom to Grace, who later became our inspiration. We were able to look up Shannon's Web site (www.ihausa.org) and watch the segment of *Montel Williams* that featured Grace's story. After virtually living the first three years of her life in the hospital and considered in a vegetative state, doctors refused to continue measures to prolong Grace's life. Shannon took her daughter to receive hyperbaric oxygen therapy – the only thing that was changed – and Grace progressed to, among other things, being off seizure and gastrointestinal medicines and her feeding tube, walking, thriving, and receiving normal EEG and muscle biopsy results.

So, at 2.5 years old, Gianna was not showing any sustained progress and was diagnosed with CDG. As soon as Gianna would make progress, she would get sick and lose new skills that she had acquired. Based on learning about Grace's success, we decided to try hyperbaric oxygen therapy, making sure we did not change any variables during the three-month period during which we did the 40 recommended treatments at 1.3 atm (mild hyperbarics). After one month and 29 treatments, we almost stopped the treatments because we did not see any improvements in her behavior. However, within the next few weeks, Gianna created her own sign for "no," would track objects, and started noticing things in her environment. Gianna started to be motivated and played with toys for the first time! We then learned that a new clinic was opening, the California Integrative Hyperbaric Center (CIHC) – "A Place of Grace" – in Irvine, California, which Shannon Kenitz was helping with. Additionally inspired by this, we continued doing hyperbaric treatments with Gianna. We were encouraged by the fact that Shannon's daughter had been doing this for so long and was doing well.

Due to the severity of Gianna's seizures and the fact that any bodily stress or increased heat caused her to have increased seizures, we never worked with her physically more than a few hours a day. Our daily exercise routine was putting her in her stander for at least an hour a day and her gait trainer for one hour. But now, Gianna wasn't getting sick every week, and she was becoming motivated without experiencing setbacks. She started "asking" for particular toys, enjoying television, using her hands, and eating chopped food by mouth. In 2007, we enrolled Gianna in an intensive suit therapy program at Napa Center for five weeks at four hours per day. To our surprise, Gianna was able to tolerate the four hours of therapy. With such an improvement in a short period of time, we realized we had to continue at this pace in order not to lose all the progress she had made in little over one month's time. We purchased our own equipment in order to start a maintenance home suit therapy program. We went to another suit therapy training session in combination with HBOT treatments at CIHC in May 2009. The intensive therapy sessions have built up her endurance, and Gianna now can tolerate six hours of physical therapy per day.

Gianna hates to be in her wheelchair and will whine for us to work with her. Looking back, we feel that after doing HBOT, Gianna was not getting sick as often and not having setbacks. We were then able to get her on a new diet and off some of her medications and able to start working with her aggressively in physical therapy. All of this has contributed to her overall success. Doing intensive suit therapy has contributed to her upper-body strength and has helped improve swallowing and upper-respiratory problems. In August 2008, Gianna was discharged from feeding therapy and can now safely swallow thin liquids. Intensive therapy was something we never thought could be possible with a child having intractable seizures.

Gianna's seizures have changed, and in July 2009, we learned Gianna is having only one type of seizure (tonic-clonic) with the EEG pattern of infantile spasms. Although she is still having frequent seizures, her seizures now last only 2-5 seconds, she does not get lethargic, and she remembers and completes a task after each episode.

Gianna just turned 5 years old. She can spoon-feed chopped food herself, can get up from the floor to a sitting position, can sit unassisted for up to 5 minutes, and can weight bear for up to eight minutes. Two years ago, Gianna would get excited as she watched us flip flash cards and turn pages in her book. Her hands would reach out as if she were going to flip the pages but would then quickly retract back. We could see that she wanted to turn the pages but just could not physically do it. She can now turn pages and flip flash cards over. Within the last two years of doing over 250+ hyperbaric treatments, Gianna has amazed all of her doctors.

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It's hard to believe that just a little over two years ago, we were wearing a stopwatch to time Gianna's seizures. We weren't able to leave her to go to the mailbox or even the restroom. Now that she has improved, we are no longer timing her seizures and have been videotaping her progress. It's really unfortunate that we have no videos of her when she was little. Who videotapes when their child is having a seizure for over two minutes, unable to hold her head up, can't manage her own saliva, and cannot even hold an object or play with a toy?

Although Gianna is improving, she is still having a seizure every 2-4 minutes. We are continuing with her therapy treatments and hope she will continue to progress. We have come far, but we know that we still have obstacles to tackle. We started to post videos of Gianna on YouTube (www.youtube.com/nataliedragotto). We feel it is important to share our story so that other parents know that anything is possible and to NEVER give up. We feel that one day nobody will believe Gianna had over 500+ seizures a day. Gianna is a totally different child – healthier and engaged. Due to the miraculous improvement of the nature and effects of each seizure, we are optimistic that her seizures will go away ... Just like Grace, Gianna has outlived the doctors' predictions ... Gianna is in a place of grace and of hope.