



The Blessings of Being Jonathan's Mom

Almost 16 years ago, my husband and I gave birth to a beautiful baby boy who we named Jonathan. Ten days after his birth, he had his first seizure. Through the evaluation process at Saddleback Hospital, we found out that our son was born with a rare brain birth defect called hemimegalencephaly which basically means that one side of his brain was slightly larger than the other side. In Jonathan's case, it was the left hemisphere that was slightly larger. This birth defect caused him to have uncontrollable seizures that the medication at that time had little impact on.

When Jonathan was almost three years old, we decided to have him evaluated at UCLA to find out whether or not brain surgery would be an option for him to stop the seizures. We found out that he was a good candidate, so on September 2, 1994, he had the majority of the left hemisphere of his brain removed. The day before surgery, he had so many seizures that we lost count and the day after surgery – he had no seizures. Jonathan remained seizure free for approximately six years and then he started having some very mild seizure activity for which he is currently taking medication.

After surgery, he returned to therapy three to five times a week. It was as if the lights had come on and were burning brightly. Jonathan started to talk (which is unusual in itself because you talk from your left brain and he didn't have one). He walked by the age of four. We had fantastic therapists who worked diligently and patiently with him for many years.

Once Jonathan learned to walk, we enrolled him at the Providence School for Speech and Hearing in Orange. He attended school there for three years until he completed kindergarten. At this time we decided that it was time to enroll him in first grade at our local elementary school. Jonathan started first grade at Viejo Elementary in Mission Viejo. I wish I could say that it was an easy transition and that everything was fine. But when faced with the challenge of teaching a child with half a brain, it takes some creative thinking and lots of different methodologies. The first year was very challenging for all concerned but we made it through.



The Blessings of Being Jonathan's Mom

The remaining years in elementary school were faced with ups and downs, but we weren't overly frustrated at this point because we didn't expect it to be perfect. We had a supportive school staff and principal and Jonathan made good progress.

When he entered middle school, we learned that Jonathan's best modality of learning was through a one to one process. He has been working with a tutor since before he started first grade and by the end of sixth grade, he was reading at about a third grade level. We felt that he would make more progress in both reading and math if he had a one to one teacher for these subjects. We requested this through the IEP process and we were given a wonderful teacher for Jonathan's seventh and eighth grades.

Now Jonathan is a sophomore in high school and continues to make good progress. We are facing some difficulty with the school district as to his appropriate placement in the high school, but hopefully these issues will be resolved soon so that he will continue on the path towards high school graduation.

Never give up hope of what is possible. Never let someone else tell you what is not possible for your child.

Julie Redmond, Jonathan's mom