THE ANDREW KRIEBEL STORY

It took seven years to get pregnant. Finally, our first child was born, Andrew Jacob Kriebel. He was 9lbs, 6oz and 21 inches long and he was beautiful.

The first 9 months of his life everything appeared normal, and then we noticed that Andrew would stare off into space several times a day. The staring spells got more intense and longer until one year of age Andrew had his first seizure. We were freaking out and immediately called our doctor and rushed Andrew to his office. The family doctor was not sure what to make of it so he sent us to Geisinger's Janet Weis Children's Hospital where he was later diagnosed with a seizure disorder. He was placed on a seizure medication and sent home. As time went on the seizures kept getting worse so a second and third drug were added. Andrew was having as many as 26 seizures a day and he was a Zombie. He had no idea what was going on around him. We missed a lot of work and our healthy boy, so we thought, was not so healthy anymore.

We took him to Pittsburgh Children's Hospital and Philadelphia Children's Hospital for second and third opinions. The consensus was he had a seizure disorder and global developmental delay and recommended he stay on the medication, however, no one could pin point the cause. We decided to keep going to Janet Weis Children's Hospital as it was only 45 minutes away.

Another year went by and Andrew's seizures started going away. He was going some days without any. We notified the neurologist at Geisinger and told him what was going on. He said that it was impossible for Andrew's seizures to be gone. We took Andrew to see the doctor and EEG's were performed. The brain scan did not detect any seizure activity. We told the doctor we wanted Andrew off the drugs. He decided to let us try it and we weaned Andrew off all the drugs very slowly over several months. Andrew remained drug free for three years and only had seizures when he was ill with a cold or flu. He still was very delayed and had a slew of other medical problems.

On July 6th, 2006 Andrew had a violent seizure while taking a nap. Amy administered the rectal diastat to stop the seizure but it didn't work. 911 was called and the paramedics gave him more drugs and rushed him to the local hospital. He was later life-flighted to Geisinger 45 minutes away as he was seizing for over an hour. While in route he finally stopped. We were so upset. We couldn't understand why this violent seizure happened when he was good for so long.

We had been looking for a diagnosis for several years but no one had any answers. Scott Myers, a Neurodevelopmental Specialist at Geisinger, mentioned to us that Andrew matches a few of the characteristics of Angelman Syndrome. He wasn't really educated on it but heard about it. We went home and started researching this syndrome and to our amazement, he matched an overwhelming amount of characteristics. Andrew displayed the following; severe seizure disorder, sleep disorder, excessive mouthing, non-verbal, easily excited, frequent laughter, wide unsteady gait, severe developmental delay, rarely potty trainable and not heat tolerant. This had to be it. We did more research and noticed the leading specialist/scientist in the country for Angelman Syndrome was located in Charlotte, NC. We contacted Dr. Joseph Wagstaff and requested he meet with our son. The Dr. asked for a video of the following on Andrew before

we made the long trip. He wanted to see Andrew walking, running, eating and taking a bath. The next day the video was in the mail and we eagerly awaited his call. One week later Dr. Wagstaff called and said he wanted to meet Andrew and strongly believed he had Angelman. To this day Andrew is still diagnosed with a "clinical" diagnosis which means it has not been detected in his blood.

We were finally relieved to have a diagnosis to work with so we could give Andrew the best treatment options available. So, for Andrew this means he will never talk, he will be severely mentally retarded, he will not be potty trained, he will suffer from different seizure types and his life will be tainted with hospital trips. Andrew also cannot feed himself, dress himself and has sleep issues.

In 2009, Andrew began having issues with bending over and walking. It got progressively worse until he was totally dependent on people to move him around. He had lost the ability to walk. This went on for 16 months. We consulted a doctor in Boston, Massachusetts on what we should do as she did a lot of research on Angelman Syndrome and Dr. Wagstaff was deceased. She was very interested in Andrew's case but believed an 8 hour drive was too much for the family to handle on a regular basis so she contacted a colleague of hers at Philadelphia Children's Hospital and asked her to see us. We began our regular appointments 3 hours away to see Mrs. B. She ran us through an array of tests. We had bone scans done, several MRI's with and without dye, EEG's for a day and one for a full week. She set up appointments with orthopedic staff and geneticists. She even had the whole team of doctors in the neurology department review EEG's and live video of Andrew to see what they could come up with and everyone was undecided. At this point Mrs. B asked us to try a drug from Canada. We already experimented with seven other seizure drugs in the U.S. and we were willing to try anything. The only catch was we had to pay for it since our insurance would not cover it. We didn't care we just wanted Andrew to have a good quality life. Approximately three weeks after starting the drug Andrew started taking steps. We couldn't believe it. His Physical Therapist was elated as we were. His nurse and PT started pushing him to get his strength back. His legs had atrophied over the last 16 months and he needed to get his muscle tone back. They worked with him on a regular basis and his nurse walked him every day. He is now walking two miles a day with assistance. His nurse holds his hand in case of a seizure. His walking does not look pretty as he is very pigeon toed but he is doing it. In May 2013 during the last week of school Andrew completed a 2 ½ mile walk from his home to school. All of the children in his elementary school lined the streets to cheer him on as they have known him since he was 6 years old. They all knew how hard he has worked because they see him walking the playground and hallways every day. This was a major event with 1200 children, staff, family and friends attending. The news station was on hand that day and they rated Andrew's story the winner for 2013 as their most inspirational story that year.

Andrew currently attends public school in a life skills class at the high school and receives physical therapy, occupational therapy and speech. He is a happy kid. He loves to float in the pool in his adaptive tube. He loves to walk in his trampoline and have people chase him like a monster and occasionally takes a nap in there. The more you interact with him face to face the more he smiles. Although he can't talk his smiles speak volumes. When he smiles his gorgeous blue eyes light up and you know he is having fun.

So, how has Andrew's disability helped others?

We decided to start a motorcycle ride event named the Duboistown Dice Run Fund Raiser to benefit special needs children with disabilities in honor of Andrew. It began in July of 2004 and we wanted it to be the biggest event in Central PA. Numerous local businesses believed in the cause and donated various prizes to auction off or raffle. The donations were unbelievable from hot tubs, above ground pools, computers, big screen TV's, jewelry and gift certificates. The response was fantastic so we decided to start a non-profit organization named, **Andrew's Special Kids Foundation in honor of our son.** It was designed to help local children with special needs. We assist other children in obtaining therapies not covered by insurance, providing special educational opportunities, purchasing adaptive equipment and assisting with out of state travel expenses for doctor's appointments.

In July of 2011 we decided to take on another endeavor and organize a fundraiser called the Fanny Float. The event coincides with the motorcycle rally and occurs on the same day. This event was an even bigger success and we raised $101,000 in two years. In 2013, our biggest year to date, we raised a little over $75,000. More and more people are hearing about us and donations come in from private citizens to corporate sponsors.

100% of all the money raised through these fundraisers is for special needs children. No one in this organization is paid for their services. It is run purely on volunteers. **No child should do without therapy, adaptive equipment or be denied a specialist visit because the insurance company will not pay for it or the parents can't afford it.**

To see what ANDREW'S SPECIAL KIDS FOUNDATION has done for others, view the "**Services We Provided"** link on this page at www.askandrew.org

The ultimate goal for this foundation is to have a residential facility for people with medical frailties, rare syndromes and severe seizure disorders. In this area we have a lot of children and adults that are in need of care that requires a nurse or home health aide. Where can families place their loved one when he or she gets too big to handle or the parents pass away? There are not any facilities in Central Pennsylvania to accommodate this population. The only facilities we have are nursing homes and they are not designed to meet the needs of this special population. They can't provide 24 hour constant individualized care. Currently, the facilities offer intermittent care to individuals who can assist themselves in some way or another.