

After trying to get pregnant for seven years, Amy Kriebel finally conceived her first child. Nine months later a healthy 9lb. 6 oz. 21" baby boy named Andrew Jacob Kriebel was born.

For the first 9 months of his life, everything appeared to be just fine. Then, his parents, Amy & Dean Kriebel noticed that Andrew would stare off in to space for 10 seconds or longer several times per day.

When Andrew was one year old he had his first seizure. He was immediately taken to his family doctor. The doctor sent Andrew to Geisinger Medical Center where he was diagnosed with a seizure disorder. He was placed on a seizure drug. His seizures became more frequent and more violent. Andrew was placed on a second drug and he continued to get worse. A third drug was added and he was having as many as 26 seizures per day. He was a zombie! He had no idea what was going on around him. His parents missed a lot of work & their healthy boy, so they thought, wasn't so healthy. After numerous tests, his parents were told he had brain atrophy, (shrinkage of the brain), and probably wouldn't learn much.

His parents took him to Pittsburgh Children's Hospital & Philadelphia Children's Hospital for second and third opinions. All doctors said Andrew has a severe seizure disorder, global developmental delay, and they recommend that Andrew stay on all three seizure drugs to help control his seizures. After watching their child have twenty six or more seizures a day, all of a sudden the seizures were gone. Dean called Andrews seizure doctor and told him the seizures were gone. The doctor said, That's impossible! They took Andrew to see him and a brain scan did not detect any seizure activity in the brain. The doctor couldn't understand why the seizures appeared to be gone. The parents stated they wanted Andrew off the harsh seizure drugs ASAP! The doctor said they could try it but it needed to be done slowly. After several months, Andrew was free of all drugs. His parents were extremely nervous about this whole situation. For some reason,

Andrew did well and only had 1 seizure each year for the next two years.

On July 6<sup>th</sup>, 2006, Andrew had a violent seizure while taking a nap in his room. He had just got done floating in the pool and running around (didn't start walking until 23 months old) in the sunny driveway. Amy gave Andrew his rectal drug to stop the seizure and it didn't work. 911 was called. The paramedics administered more drugs and it still wouldn't stop. He was taken by ambulance to the local hospital. He was seizing close to an hour!!! He was life flighted to Geisinger Medical center 35 miles away. While en route to Geisinger, he finally stopped seizing. The parents wondered why did he have such a violent seizure after doing so well for so long?

For years, the parents were looking for a diagnosis for Andrew seizures and severe learning disability. Scott Myers, Neuro-developmental Specialist at Geisinger, could not pin point what was the root of all evil. At one appointment he mentioned Angelman Syndrome. We asked him what that was and he said, I'm not sure he has it but some characteristics are similar with what I see in him and the two Angelman kids I have seen. We'll discuss it next time we meet in six months. Both Amy & Dean immediately googled Angelman Syndrome on their home computer. Their jaws dropped as they read the characteristics that matched Andrew. Seizure disorder, sleep disorder, excessive mouthing disorder, non-verbal, easily excited, laughs a lot, loves water, walks with a wide jerky gait, do not like excessive heat and rarely get potty trained. The Kriebel's immediately contacted Scott Myers and told him they strongly believe their son has Angelman Syndrome. After more research on the computer, a doctor named Joseph Wagstaff, the leading scientist / doctor for Angelman Syndrome, who lived in Charlotte NC, was contacted by the Kriebel's. He requested they send him a video of Andrew walking, running, eating, & taking a bath or swimming. The next day the video was in the mail. Dr. Wagstaff called them a week

later and stated that he could not make a diagnosis by watching a video but strongly believed Andrew had Angelman Syndrome. Three weeks later the Kriebels made the trip to Charlotte. After observing Andrew for two minutes, Dr. Wagstaff said, Andrew has Angelman Syndrome. Andrew was diagnosed with clinical Angelman. To this day, they can not find a genetic link in Andrew to Angelman but he matches an overwhelming amount of characteristics to the syndrome.

The Kriebel's were happy to finally have a clinical diagnosis for their 5 year old son but what did that diagnosis mean? Basically, Andrew will never talk, he will be severely mentally retarded, never be potty trained, will have seizures, but will be very happy & should have a normal life span however, his life will be tainted with hospital visits. Andrew currently receives occupational therapy, physical therapy & speech therapy. He attends public school and is in a life skills classroom with six other children.

Andrew loves to float in his pool and play in his trampoline. He loves to take car rides (especially with the windows down.) He loves to ride in the sidecar of Dad's Harley Davidson. He loves for people to chase him and act like a monster and make loud noises. He loves when you get down on the floor and interact with him face to face. Although he can't say anything, his smile speaks volumes. He smiles with his gorgeous blue eyes and you know he is having fun.

**How has Andrew's disability helped others?** Well, his parents started a motorcycle event named, The Duboistown Dice Run Motorcycle Rally Fund Raiser, to benefit Children with Disabilities. It began in July of 2004. Dean & Amy wanted this to be the biggest and best motorcycle event in Central Pennsylvania. Most events you either have to pay for your food or you get a hot dog and soda. How could they make their event the BEST? Well, they charge each registrant \$15 to attend and that includes: the motorcycle ride, live band, and an all-u-can eat catered meal of, fried chicken, sausage

sandwiches, three side dishes, cake and drinks. Nobody else in the area does this. Numerous local businesses believe in their cause and have donated many gifts to auction or raffle. Some of the donations have been: an 8 person hot tub, high scale jewelry, above ground pool, computers, big screen tv's, taxidermy mounts, local gift certificates etc..... The response by the local community has been fantastic. When people hear the name, Duboistown Dice Run, they say, that's the ride with the great food and big prizes! That's how they made their event the BEST!!

Since the first year was such a huge success, they started their own non profit organization named, **Andrew's Special Kids Foundation in honor of their son.** It is designed to help local children with disabilities. Amy & Dean wanted to continue to help more kids obtain much needed therapies, educational opportunities, adaptive equipment, & safety equipment. With their dedication and hard work, many children, for years, will come to benefit from Andrew's Special Kids Foundation.

**All money raised is for children in need. No child should do without therapy, adaptive equipment, doctor visits, etc... because their parents cannot afford it !!!!!!**

**To see what Andrew's Special Kids Foundation has done for others. View the "Services We've Provided" page.**