

Spotlight on A.J.



A.J., my son, is a living testimony. On August 1, 2004 at 11:39 a.m., this little miracle, Arthur D. Alexander III, was prematurely born at 28 weeks in North Kansas City Hospital. He was 13 1/4 inches in length and weighed 2 lbs and 1 oz. Because he was extremely premature, the Children's Mercy Trauma team was on site to stabilize him after delivery. The trauma doctor came to us with very disheartening news, "Your baby is in grave condition. He may not live for the next hour. He may not live through the night; but we will do everything in our power to keep him alive." An hour had passed and A.J. was still fighting to stay alive and we were only allowed see him for a few seconds. Thankfully, I was able to lightly touch and kiss his forehead before they closed the isolate and immediately transported him by ambulance to CMH-Neonatal Intensive Care Unit. A.J.'s dad and Grandpa Jones closely followed by car.

Early the next morning, I was discharged from the hospital and anxious to see my baby. In a few hours, we were at his bedside yet overwhelmed by the sight of all of the beeping and flashing monitors which filled up his room. There were so many tubes and wires attached to his small, delicate body. His team of doctors explained to me that A.J. was diagnosed with congenital heart condition, respiratory distress syndrome, chronic lung disease, premature grade 1 retinopathy, large supra-umbilical hernia, bilateral inguinal hernias, level 2 brain hemorrhage, anemia, hypothyroidism, jaundice and cerebral palsy. He would need surgery to repair the heart defect so they could thoroughly treat his undeveloped lungs.

Just two weeks after A.J. was born, we received some good news. We all, including the doctors, were amazed that his heart defect had completely disappeared. To confirm, they took several echoes of his heart and compared them to the original x-ray. They could not find the defect. They told us it was a "MIRACLE" because as they mentioned before, the condition would not correct itself without surgery.

A.J. remains in the NICU under bright lights to remove the jaundice from his body. For 45 days, he was on a breathing tube, 15 days on the C-Pap and received numerous blood transfusions. Finally, the bleed in his brain clotted. At that point, he was able to receive oxygen through a nasal canula.

On November 2, 2004, A.J. is 94 days old. Finally, they discharged

him from CMH with oxygen, a feeding tube, five different medications and a notebook full of instructions on how to care for him. We began our first year together. Grandma and Grandpa Jones took care of him during the day and A.J. began receiving in-home Physical and Occupational services through the Missouri First Steps program.

Two years had passed and A.J. routinely attended Children's TLC where he received PT, OT, speech and special instruction. At this time, he struggled to meet many of his Individualized Educational Program goals. Upon completing a series of developmental tests at CMH, the doctor informed us that his learning pace was consistent with severe mental retardation – another barrier. After digesting this news, we requested extensive blood testing for A.J. The results indicated A.J. had a very rare genetic disorder, Subtelomeric, caused by the deletion of the long arm of the 10th chromosome. These findings along with the bleed in his brain were big contributors to his developmental delays.

After A.J. turned three, he started his journey at Northland Early Education Center and Early Childhood Special Education. He had delays in fine motor/sensory, feeding, non-verbal communication, gross motor and social skills. He was at the beginning stages of crawling. Six months later, I took A.J. back to the CMH for another evaluation. The test confirmed our suspicions; A.J. received a diagnosis on the Autism Spectrum with Pervasive Development Disorder – Not Otherwise Specified or PDD-NOS.

After, A.J. turned four; he started meeting the majority of his 2009 IEP goals! A.J. moved from his "special" chair that kept him from leaning or falling forward to a regular chair. He is now able to cruise around in the Blue Room and he has learned sign language to communicate with his family, teachers and friends. His rocker bottom clubfeet are now strong enough to allow him to walk down the hallway with his "crocodile" walker and have fun on the playground with his friends. We appreciate the teachers and staff at NEEC for all that they do for A.J. Everyone is always so friendly, helpful, encouraging and supportive of our family and A.J.'s challenges. We are thankful to NEEC for teaching compassion for diversity to children. Thanks again for being a part of our journey of HOPE!

