



Newborn Screening  
Saves Babies  
One Foot  
at a Time

# Jonathan

THIS IS OUR STORY—SO FAR.....  
THIS IS A PERSONAL STORY SHARED BY A FAMILY WHOSE CHILD  
HAS ARGININOSUCCINIC ACIDURIA (ASA)

Jonathan Spencer Oliphint was born on August 17, 1994. He was our first child and he was two weeks late. The labor was induced and he had his umbilical cord wrapped around his neck twice. Despite this, he was a healthy, 8 lb 8 oz boy. He went home less than 16 hours after his birth and began developing normally, then he slowly started falling behind on his developmental milestones. His doctor wasn't concerned stating that "all children develop at different rates". By his first birthday he still couldn't go from laying to sitting. Still his doctor kept putting me off and even wrote in his notes "mother concerned" about Jon's delays. Jon began self-regulating his protein intake when he was very young. He stopped drinking milk, eating meat, and even stopped eating cheese (which he loved).



When Jon was 15 months, we moved to another town and I found a great pediatrician and the first time he saw Jon in the office, he immediately referred us for PT, OT and Speech therapy. Jon started therapy when he was 18 months old, and he finally began to walk at 21 months. When he was almost 3, we started noticing that he was having times when was just staring off into space, particularly at mealtime. We asked his therapist about this and she got us a referral to a pediatric neurologist in Fort Worth, Texas. We saw him in August of 1997 and Jon was diagnosed with absence seizures. He set up a "sleep deprived" EEG and we were told to keep Jon up most of the night and then an hour before the EEG we were to load him up with turkey meat (turkey has an enzyme in it that promotes sleep). All this was to assure that he went to sleep during the EEG. Of course, all this also caused his ammonia level to rise, I am sure. The EEG was done and the results showed abnormal activity all over the brain. He was started on Depakote (which is bad on the liver). It did little good and in October 1997 we were admitted to Cook's Children's Hospital in Fort Worth for a 24 hour video EEG. While we were there, they ran a battery of test, including a CAT scan and a metabolic panel. The doctor was shocked when the results of the metabolic screen showed ASA. He called me himself and did his best to explain what Jon had. We were set up with an appointment in Dallas at the metabolic clinic at Baylor. We saw them and got the official diagnosis on my husband's birthday, December 2, 1997. Jon was started on 9 grams of Arginine a day.

At that time it was recommended that the Depakote be discontinued and another anti-convulsant be given. This was done and Jon was started on Tegretol. He had a horrible reaction to it and basically lost control of his body

for 3 days. It was at that point we decided that we needed to be closer to family, since we knew this was not something that was going to go away. We moved to my parent's home on January 31, 1998 and transferred Jon's medical care to the metabolic Clinic at Baylor in Houston. As soon as the Arginine was started, Jon's seizures stopped (I believe that he was having the seizures when his ammonia went up). He has since been weaned off the Depakote and hasn't had a seizure since.

Jonathan started public school at age 3 and loves it. He is in a Life Skills class (special education) at this time. He is doing well but not ready for a regular classroom setting. Developmentally Jon is able to walk, run, jump, skip, hop, etc.. He speaks in complete sentences and speaks fairly clearly. His fine motor skills have improved and he can button and use scissors. His attention spans varies according to activity and what is going on around him. He does well if he knows what is expected of him, but I guess it is that way with all kids. Medically Jon is doing well. His liver is not enlarged and liver panel is normal. He takes his Arginine in an orange flavored syrup, which we have made by our pharmacist. He loves it and even looks forward to taking it. He has developed High Blood Pressure and takes medication for that.

Jon is a very happy child, which you hear often with ASA kids. He has a great imagination and good attention to details. We are very proud of him.

Written January 2004 by Jamie Oliphint  
Mother of Jonathan