Luou US



Liam & Mark

PASSION

Our Blankets

Our Story

Meet Liam and Mark, identical twin sons of Brooke Poage and Teddy Enold, and siblings to big brother, Mack. At 34 weeks Mark started to get some fluid around his heart, so the doctors decided it was best to deliver them. Mark weighed in at 3 lbs 9 oz and Liam was 3 lbs 13 oz. They spent 24 days in the Neonatal Intensive Care Unit (NICU) learning how to eat. They have both overcome a lot since they were born, but their journey still continues.

When Mark and Liam turned one year old they were diagnosed with a genetic disorder called <u>SETD5</u>. "When they were diagnosed there was less than 50 people world-wide with the same condition. There was not a lot of information for the doctors to go by but we were told they possibly could never walk," said Brooke. "At two and a half years old they both finally took their first step, but Liam stopped walking until almost 3 years old."

Liam and Mark both needed help with their feeding. They would not eat food or use a baby spoon at all. "They never ate baby food. They will both eat some regular food now, but mostly love their snacks like veggie straws, gold fish and chips, and crackers," said Brooke. "They drink Pediasure

continued

The Busy Life with Boys













Peptide to make sure they are getting all the nutrients they need since they don't eat a whole lot of food."

They both spit up quite a bit and the doctors discovered they needed all their liquids thickened to a honey consistency to keep the fluid from going into their lungs.

They both have been in therapy since they came home from the NICU and are still receiving therapy today. They get physical, occupational and speech all through Akron Children's Hospital. "They couldn't sit up on their own until about 2 years old," said Brooke. "They are on a waiting list to get an augmentative and alternative communication (AAC) device the help them communicate. An AAC device is a tablet or laptop that helps someone with a speech or language impairment to communicate."

Both Mark and Liam started off with gait trainers to help them walk and now can both walk without it. They had ankle foot orthosis braces (AFOs) and Supramalleolar Orthosis braces (SMOs), and now just a baby's insert around the bottom of their foot to help them walk.

Meet Mark

"Mark seems to have more of a personality. He will throw himself on the floor when he gets mad or you tell him something he doesn't like. He loves to have all of everything, for example, cars. He thinks he needs them all and will carry them around in a bag or box without sharing with Liam."

Meet Liam

"Liam is pretty happy just playing with whatever he finds and can keep himself content until Mark comes along and destroys whatever he may be playing with. He loves to sit on the couch with his mom or dad or even big brother Mack while eating his snacks. Don't forget his blanket though because he can't be without it and he will let you know he needs that's blanket picked up onto the couch."











They love to get into everything they possibly they can. They always seem to find a way to get whatever they want by climbing on whatever they can find. They love getting into their big brothers things and making a mess out of it. They love playing with their cars, dinosaurs, and building things with their legos. They each have found a love for a special blanket that they drag all around with them.

Physical and occupational therapy was a challenge for them because they eventually just cried and cried and the therapist couldn't get anywhere with them. We had to stop going to therapy to give them a break and once we came back it was the same thing again... until they took their blankets. Now they absolutely love it and try to race to see who gets to go first.

Early Intervention: Getting help for children birth to age 3

Early intervention (EI) provides support and resources for family members and caregivers as they enhance children's development through everyday learning opportunities. The Stark County Board of Developmental Disabilities provides services to the young children in our county in partnership with Stark County Early Intervention (formerly Help Me Grow) and all 17 of our local school districts. Early Intervention Services are available to families whose children have been deemed eligible.

Stark DD Developmental Specialist Stacey Jenkins and Occupational Therapist Michelle McKenzie have been on the EI working with Mark and Liam. They have been in the Stark DD Early Intervention program since shortly after being discharged from the NICU.

"Mark and Liam Enold are always greeting others with a smile and a wave 'hi!' They are happy little twins who have proven to be determined and just downright amazing," said Stacey.

Early days in El focused on learning how to tolerate tummy time and how to lift their heads to look around. "The boys were very clear on what they liked and didn't like from the very beginning," said Stacey.

Together, the parents and Developmental Specialist worked as a team to make play time a bit easier, giving the boys the support they needed to learn to hold their heads up, roll, scoot on their bellies to get to what they wanted, which led to crawling, sitting up, walking with support, and then walking independently. "Now, they are all over, crawling on anything they can to get to what they want. They are able to play games together with parents and older brother Mack," said Stacey.

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(L to R) Mark, Michelle McKenzie, Stacey Jenkins, and Liam

When eating baby food came about, both boys showed their hesitance in trying new things. Occupational Therapy was added to the team as secondary support to help in advancing feeding. Now, both boys will use a spoon and fork to eat and they are working to drink their liquids from a cup.

Mark and Liam are very expressive in what they want, and will gesture to get their point across. Tools to assist in communication are being explored, such as the use of sign and picture cue cards, and their outpatient therapist is working on communication devices. Animated facial expressions let others know exactly what they want, as they are very social little fellows.

Since El services end at age three, Mark and Liam, who turn three on December 23, are transitioning to preschool services and supports. Louisville City Schools has stepped in to determine their eligibility for preschool services. A conference was held prior to their transition, led by the service coordinator so they could have a seamless transition as they enter preschool. "Mark, Liam and their family will be greatly missed as they exit from Early Intervention Services at Stark DD, but will continue to grow in their journey in preschool," said Stacey.

"Stark County Early Intervention has helped us as parents with guiding us through the medical process. We got Family Support Services (FFS) through the county board to help with their needs. They helped us with the process of applying them for preschool and getting everything ready. We will be sad to not be working with our Early Intervention team of Stacey and Michelle, but know they will be in good hands at the school," said Brooke.











