

All About ME!! 2013-2014



Alyssa Grace Lee

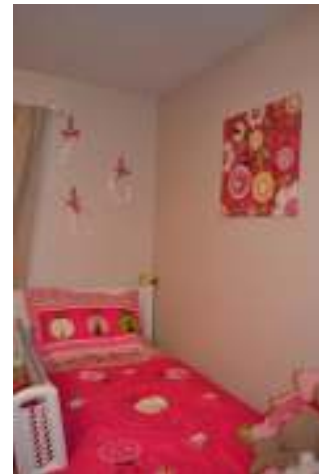
"They see a girl who cannot talk, I see a MIRACLE that doesn't need words!"
~~Unknown

Introducing ME

My name is Alyssa Grace Lee and I am a happy 5-year-old. I was born on January 14th, 2008 at 12:23 pm at Brookwood Hospital in Alabama. I weighed 7 pounds 0 ounces and was delivered by scheduled cesarean-section and was completely healthy.



I live at 6703 Winchester Lane, Pelham, Alabama 35124. I have lived here for about 3 years. My room is decorated in LADYBUGS with LOTS of pink!!



Pink is one of my favorite colors, as well as turquoise. Red is my least favorite color. I am usually very happy. I love school and I enjoy being with my friends.



My Family

I live at home with my Dad, Mom, 2 brothers, and my service dog. I am very close to both sets of grandparents, all my aunts and uncles, and my cousins!!

Dad- Walt- Manager at Tameron Honda

Mom- Susan- Special Education Teacher at Inverness Elementary

Brothers- Connor (11 years) and Austin (9 years)

Service Dog- Cassidy



Paternal Grandparents- Grandma and Grandpa



Maternal Grandparents- Nana and Papa



Cousins:



Jordan



Jonah



Bailey



Gage

Aunts and Uncles:



Uncle Emil and Aunt Tara



Uncle John and Aunt Brandy



Uncle Justin and Aunt Dana



Aunt Carol (Uncle Jason not pictured)

“Not being able to speak is NOT the same as not having anything to say!”

Me and My Family

I enjoy playing with my family. We like to travel, play games, be outside, and do everything together!!

I like to snuggle, give hugs and kisses, play with toys, and watch TV with my Dad!



I like to play with my toys, go for walks, read books, and ride my bike with my Mom!



"A mother understands what a child does not say!"

I like to play with toys, watch TV, read books, sing songs, play outside, swim, go boating, and play computer with my brothers!



I like to snuggle and kiss with Cassidy!



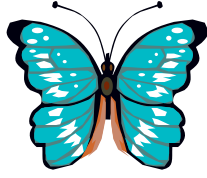
I like to use my gait trainer, communicate with my Tobii, and play with my switch toys by myself!



“Just because I can’t talk doesn’t mean I don’t understand!”

A Few of My Favorite Things

Favorite Colors- Pink and Turquoise



Favorite Toys: switch-activated toys that I can control by myself. I love anything with lights and music.



Favorite Music- I love ALL music, but not too loud.



Favorite Friends at School- Allie, Madison, Jack, and Estella



Favorite Activities at School- Water Days, Playground, Music, Gardening, and MISS BETH!!



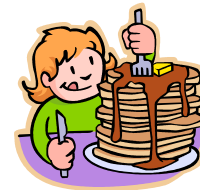
"What seems to us like bitter trials are often blessings in disguise."
~Oscar Wilde

Favorite Activities Outside of School- sleepovers with my Rett sisters, Horse Therapy, swimming, and boating.



"I believe in prayer. It is the best way we have to draw strength from heaven."
~Josephine Baker

Favorite Foods- I eat almost anything, but spaghetti is a favorite!



Favorite TV shows: Bubble Guppies, Team Umizoomi, Dora, and Little Bear



"Promise me you will always remember: You're braver than you believe, and stronger than you seem, and smarter than you think!"

~Christopher Robin to Winnie the Pooh



"Rivers know this: There is no hurry. We will get there someday"

~Winnie the Pooh



Alyssa's Story

Alyssa is an energetic, happy, and loving child. Our journey with Alyssa started in January of 2008, when she was born. She was a happy baby and loved to be held, cuddled, and played with. Alyssa's muscle difficulties became evident when she was about 6 months old. She was not trying to roll over, push up on her arms, or sit up. We began formal evaluations when she was 9 months old.

Over the next 2 years, we ruled out many things, but still had no definite answers. We received a global diagnosis of neuromyopathy based on a muscle biopsy, but we continued in our quest to find the specific diagnosis. We continued to see some areas improve and regress. When Alyssa was 12 months old, she had learned 8-10 approximated words, but by 18 months old, she had lost those words. She continued to make improvements in gross motor and fine motor skills. She was feeding herself with a spoon and taking independent steps.

We received Alyssa's service dog, Cassidy, in October of 2010. She has been so wonderful with Alyssa and a blessing to our entire family. Cassidy was trained to open doors for Alyssa, pick up dropped objects, give Alyssa physical support to walk, and as a general companion. She has reduced Alyssa's anxiety, especially in new situations. Cassidy previously attended school with Alyssa, however Alyssa's goals and abilities have changed since her regression and once we received her diagnosis, we had to change our focus.

Alyssa had a big set-back over a 6-8 week period from December 2010-March of 2011. During these few months, she went from walking 30 feet independently to requiring her gait trainer. She went from feeding herself with a spoon, picking up cheerios, playing with toys, and using a touch-screen, to no functional hand use. Her speech/communication had already regressed from her 10 approximated words to no words, but during the regression she even lost interest in social interactions. We literally lost Alyssa in a 4 month period! From January through April of 2011 we had another few rounds of testing: 2 more EEG's in January, an MRI in January, an eye appointment at Vanderbilt in February, a sleep study in March, and more bloodwork in March. It showed no seizures and no vision problems. Even her dental appointment went well; so what was going on with our daughter?

Our final test in our search for a diagnosis was done in April of 2011 and the results came back on May 3, 2011 at 9:30 am. The genetics testing came back positive for a MECP-2 mutation (basepair 35 deletion) which verifies her diagnosis as Rett Syndrome. Since that day, we have been on a quest to learn everything we can about Rett Syndrome and how to help Alyssa. We have been to the National and World Rett Syndrome Conferences the past 3 summers. We have learned SO much!! It is amazing how much your life can change with just a phone call from a doctor! Our dreams that we had when Alyssa was first born are now distant memories, however we have created new dreams and hold onto the hope of a cure! Feel free to read more about Alyssa's journey and follow her frequently with her updates on her website at: www.caringbridge.org/visit/alyssagracelee

"You may not hear my words, but look into my eyes and listen with your heart!"



What is Rett Syndrome?

Rett Syndrome is a neurodevelopmental disorder that affects, almost exclusively, girls. It is diagnosed by symptoms and confirmed by a genetic test. The diagnostic criteria include:

1. apparently normal prenatal and perinatal history
2. development largely normal through the first six months of life
3. normal head circumference at birth with postnatal deceleration of head growth in the majority of patients
4. loss of achieved purposeful hand skill between ages six months and 2.5 years
5. stereotypic hand movements such as hand wringing/squeezing, clapping/tapping, mouthing and washing/rubbing automatisms
6. emerging social withdrawal, communication dysfunction, loss of learned words, and cognitive impairment
7. impaired (dyspraxic) or failing locomotion (walking or movement)

Alyssa has all of the primary criteria. The secondary/supportive criteria include:

1. awake disturbances of breathing (Alyssa's presents as "panting"/ hyperventilation and breath-holding)
2. teeth grinding (bruxism)
3. impaired sleep pattern from early infancy- Alyssa's is fairly normal, but she occasionally wakes in the night giggling for no apparent reason
4. abnormal muscle tone successively associated with muscle wasting and dystonia
5. peripheral vasomotor disturbances (cold, blue hands and feet)- Alyssa has a difficult time regulating her body temperature. She becomes hot/cold very quickly and with little environmental cause.
6. scoliosis/kyphosis progressing through childhood- Alyssa's scoliosis has just been diagnosed and is very mild, at this time.
7. growth retardation- Alyssa's growth is close to average, at this time.
8. hypotrophic (small) feet; small, thin hands

So... what does that mean??? This is a life-long disorder, but it is not fatal. Life expectancy for girls with RS is not consistent. Approximately 50% of the girls live to reach 40-50 years old, while others pass away much younger. Unless a treatment or cure is found, Alyssa will never talk (girls with RS are often referred to as "Silent Angels") and many never walk, however most learn to communicate with their eyes at differing levels. Many will develop seizures, scoliosis, and need feeding tubes.

My Medical Needs

G-tube and fundoplication: I received a feeding tube on July 3, 2012. I was not gaining weight and was in a constant state of dehydration. After receiving my g-tube, I gained 15 pounds of the next year. I currently weigh 45 pounds and am very healthy. I eat by mouth during the day and receive calories and fluids by pump at night. I still have difficulty drinking effectively, so I receive a bolus of water daily at school. Since I had a fundoplication at the same time as my feeding tube, I am now unable to burp or vomit. Therefore, I require my tube to be vented several times a day, usually after eating. If I get a stomach virus, you will notice me “wretching” but not vomiting. At that time, my g-tube should be used to remove stomach contents.

Gastrointestinal Concerns: All girls with Rett Syndrome struggle with GI issues. Most have problems with constipation. Alyssa is no exception. She is on a mixture of Culturelle and Miralax to help with her GI troubles. It is imperative to have good communication between home and school about her bowel movements daily. This determines her medications each night and if she does not have a bowel movement for 3 days, we must use a laxative suppository.

Temperature Regulation: Girls with rett syndrome have the inability to regulate their temperature effectively. Alyssa become very hot or very cold quickly and with little change in the environment. When going outside on warm/hot days she requires the use of a cooling towel and needs to be kept in the shade when it is very hot. She is currently taking Robinul to reduce excessive drooling, but it also reduces her sweating. Alyssa requires liquids to be offered frequently when outside on hot days and upon returning to the classroom. When it is cold outside, she needs to be bundled well with an extra blanket around her legs.

Medical Trial: Alyssa is currently participating in a clinical trial through Boston Children’s Hospital and Harvard Medical School. This trial is looking for an effective treatment of some of the symptoms of Rett Syndrome. She receives injections twice daily of IGF-1 (a growth hormone). This study will continue through April of 2014. One side-effect of the IGF-1 is possible blood-sugar drops. She keeps a glucometer with her to check blood sugars if she becomes lethargic or teachers are concerned. I return to Boston for 11 day trips every 10 weeks. Dr. Kaufman is the primary investigator for the trial.





What is important to remember about girls with Rett Syndrome???

Many girls with Rett Syndrome have normal intelligence... they are simply trapped in a body that doesn't work! **Assume TOTAL COMPETENCE!!!** Many girls learn to read and function in a regular classroom with assistance, however, they must be exposed to the same curriculum as everyone else and they must have high expectations and have those expectations communicated to them!

They must be given the opportunity to communicate and have access to technology to assist in communication. People around her must respond to her communication efforts, both Tobii communication and nonverbal cues.

For more information on Rett Syndrome, visit: www.rettsyndrome.org

What Makes Me Special?

Mobility- Alyssa has lost her independent steps, however she walks independently with a gait trainer, walks holding someone's hands, and uses a wheelchair in public for long-distances. Alyssa can no longer walk in her Kaye walker due to her "rett episodes" which cause her to fall. Alyssa is not able to catch herself, so she will fall straight forward or straight backward. Alyssa is unable to stand up independently from a chair or the floor and is unable to sit down independently (safely). Once she is placed in her gait trainer, Alyssa is independent, although she has lost a lot of her ability to move freely. She occasionally needs a gentle prompt on her shoulder to go in the direction desired. Alyssa wears AFO's on her feet and they are needed anytime she is walking. If she does not have them on (swim days, etc...), she is MUCH less steady and needs to be carried or FULLY supported. Alyssa used to be able to scoot around on her bottom, however since she lost most functional hand use, she can no longer move herself around. She stays where you sit her. She is able to sit on the floor independently or in a child's chair at the table or at circle time. She will go through periods of time when she will "slouch-sit" and needs some dycem (spelling?) and she requires a seatbelt in her chair and toilet seat to keep her from falling in case of a rett episode.

Feeding Needs- Alyssa has a great appetite and she eats almost anything. She used to be able to self-feed with a spoon, however that skill was lost with her lost hand function. She drinks well from a cup with a straw and needs fluids offered regularly, especially when coming in from outside, due to medication she is taking. Alyssa's feeding requires full assistance. She does best when food is cut up into much smaller bites (that she can swallow whole, if needed). Many times, due to her hand-wringing or hand-clapping, her hands land in her plate, tipping the food off the plate and onto the floor. It is best to put her plate and drink at a distance and separated so she can eye-gaze or tap the table to direct you as to what she is wanting. She eats very well, but it takes her longer to eat due to reduced chewing ability. Alyssa may require additional time at meals and snacks to finish her food. She may also require an extra snack time occasionally for sensory purposes. Alyssa will eat breakfast and lunch in the lunchroom and parents will send her snacks.

"Courage is the discovery that you may not win, and trying when you can lose." ~Tom Krause

Fine Motor- Alyssa's fine motor skills declined significantly when she had her latest regression. A majority of her functional hand-use has been lost and has been replaced with hand-wringing and hand-clapping. Girls with Rett Syndrome have severe apraxia making all muscle movements difficult. She has trouble coordinating her muscle movements in every way. Even the smallest tasks, require a lot of effort and time to plan and fulfill. Her hand-wringing and hand-clapping gets in the way of her ability to use her hands. This is not a "self-stimulating" activity as originally thought. For girls with Rett Syndrome, it is an involuntary movement. We have begun focusing on her communication to allow her to participate with peers in play. Her primary focus in OT is working on eye coordination to help improve communication with her Tobii, as well as sensory activities. Hand-over-hand coloring, writing, etc... is not a useful activity or use of therapy time. It also can send her into sensory overload.

Communication- Until 1 year ago, Alyssa was unable to communicate effectively with us. Once we learned that she would not learn to talk, we began using new techniques to work on her communication and we saw amazing things. First, her receptive language is amazing! She understands A LOT!! Secondly, she WANTS to communicate! Girls with Rett Syndrome talk with their eyes most effectively because it is easiest to control their eyes rather than their hands or mouths. Alyssa will answer yes/no questions by looking at you/smiling for "yes" and looking away (usually to the right) for "no." She will also eye-gaze at a choice if 2 objects are held up for her to choose from. She occasionally gives "mixed-signals" and with a simple prompt ("I didn't understand that, you need to choose one by looking at it"/ "I didn't understand, remember to look at me for 'yes' or look away for 'no'") and then restating the options or the question, she does very well. ALWAYS PROVIDE WAIT TIME. Some girls require up to 30 seconds for processing the question, making the choice, and coordinating the muscles to answer. Alyssa generally answers in 5-10 seconds. Alyssa received her Tobii ("Talker") eye gaze communication device in December of 2011. She has shown us amazing communication ability with this device. Part of her success is the consistent use of the Tobii, both at home and at school. All children talk constantly throughout their day, and the only way Alyssa will become a functional communicator is by using her Tobii throughout her day. The main goal in the classroom is to expose her to the same vocabulary, verbalize your expectations for her, give her many choices, and use eye-gaze communication as often as possible, both high-tech and low-tech.

Sensory Needs- Alyssa's sensory needs have a direct impact on her learning and communication ability. She continues to be very sensitive to light and sound, but she handles transitions much better. She wears sunglasses when she is outside because the sun hurts her eyes. Sudden sounds still startle her, but she has learned to recover quickly. She does need sensory activities throughout her daily routine to stimulate her learning. Girls with Rett Syndrome have been shown to acquire new skills MUCH faster when they are stimulated daily through many sensory activities. Classroom staff should be very sensitive to her sensory regulation. If she becomes over-stimulated or under-stimulated, she will become fussy or will "check-out." At that time, her learning has stopped. She loves toys with lights and music, as they are very stimulating. Another key sensory activity for her is eating. Many times, a short, crunchy snack can help her to re-regulate herself. I have found that the toddler snacks (that melt quickly in her mouth) are crunchy, yet easy enough to eat. I will provide these for the school. She can even be given these "crunchy" sensory snacks AS SHE WORKS. You don't have to stop the learning.

Every night I turn my worries over to God. He's going to be up all night anyway!

~M. Crowley

Toileting- Alyssa is doing well with her toileting. We are taking her on a schedule every two hours. Prior to her g-tube surgery, she was maintaining a dry pull-up approximately 3/5 days and only had 1 wet pull-up on the other days. However, since her g-tube surgery, her schedule has been messed up. Her body is learning to process more fluids and nutrition on a different schedule. She continues to improve on her 2-hour schedule and has mastered bowel movements approximately 95% of the time. Alyssa sits well on the toilet with a ring-reducer and seat-belt for safety (she has fallen due to a Rett episode). She likes her privacy 😊! We usually allow her to sit for 3-5 minutes. Alyssa takes Miralax every other day (at home) to prevent constipation. 85% of girls with Rett Syndrome struggle with constipation and remain on a daily laxative throughout their lifetime. It is important to let us know the consistency of bowel movements if they get too hard or too runny so we can adjust her Miralax as needed. Alyssa has a “bathroom” button on her Tobii under “Something’s wrong.” She has used it occasionally; however I would like to see her begin using it more frequently to communicate her need to use the bathroom. One strategy is to prompt her to the bathroom button before she goes throughout the day. I also think a low-tech “bathroom” picture on her tray and desk would allow her to “tap” at the picture symbol if she needs to go to the bathroom. Aides/teachers could then prompt her using the picture symbol each time they head to the bathroom.

Behavior- It is important to realize the behaviors of girls with Rett Syndrome and knowing the difference between uncontrollable actions and true behaviors. Girls with Rett Syndrome often exhibit screaming/squealing/giggling spells. They also have irregular breathing patterns and breath-holding. At this time, Alyssa holds her breath for 5-10 seconds on average, but has held her breath until her lips began turning blue on several occasions. She also “pants”, especially when excited or happy. The only true “behavior” we have seen this year was going to the bathroom after her pull-up was pulled down and before sitting on the toilet. She would then laugh. She knew exactly what she was doing. Once we talked with her about it and told her teacher that she was to go to time out each time, she stopped immediately and has not done it since. Remember, she is VERY SMART and understands and manipulates like any other child.

Safety Awareness- Due to Alyssa’s lack of independent mobility, we are unclear of her safety awareness. We are not sure how much depth perception her brain perceives and if she understands that she can fall down stairs, curbs, and drop-offs. Alyssa does not seem to scan her entire environment. We are really working on prompting her to scan her environment for objects, people, and dangers. Now that she has lost her ability to walk independently and move her wheelchair through her environment, this is not as big of a problem. But, we do try to point out dangers in the environment to help make her aware. She has an extremely high pain tolerance, so she does not show pain due to AFO issues, clothing issues, or even ear infections/ sore throat. Watching her carefully and communicating with parents is imperative!

Medical/Therapy Team

Pediatrician- Dr. Glasgow/ Greenvale Pediatrics Brook Highland Office/ 995-1004

Neurologist- Dr. Percy/ Rett Clinic at UAB Civitan Research Center/ 934-1130

Pulmonologist- Dr. Makris/ Children's Hospital/ 212-7000

Nutritionist- Suzie Geertz- UAB Rett Clinic- 934-1130

GI Specialist- Dr. Jester- Children's Hospital

PT- Peggy Sedlacek/ Children's Hospital/ 939-6289

Hippotherapist- Special Equestrians/205-987-WHOA

Parent Contact Information:

Walt Lee- 444-4696 (home), 823-3333 (work), 965-7928 (cell), wlee4au@gmail.com

Susan Lee- 444-4696 (home), 682-5240 (work), 910-2353 (cell), slee@shelbyed.k12.al.us
Slee4al@hotmail.com

"It is good to have an end to journey towards, but in the end it is the journey that matters."

~Ursula LeGuin