

ALL ABOUT ME

Claire Marie Reilly



INTRODUCING ME 😊



- ◉ My name is Claire Marie Reilly, and I am a happy 3-year-old. I was born on April 8th, 2010 at Hillcrest Hospital in Mayfield Heights, OH. I weighed 6 pounds 14 ounces and was a picture of perfect health.
- ◉ I currently live in Seven Hills, with my Mom (Colleen), Dad (Sean), 2 older brothers (Nolan and Brendan), our dog (Murphy) and Nolan's fish (Bob).
- ◉ I am very close with both sets of my grandparents, all of my aunts, uncles, cousins, and extended family (which is huge, on both sides!).
- ◉ My favorite color is blue. I love being around others. I smile when my others talk about how I'm going to school and will meet new friends.
- ◉ I love music. I love listening to all different types of music, but especially like classic rock (especially Queen), reggae (Bob Marley), country, and other popular tunes from Selena Gomez, Taylor Swift, Black Eyed Peas, etc. I only like upbeat, silly and fun music. Slow music makes me sad.
- ◉ My favorite TV shows are Mickey Mouse Clubhouse (Clarabell and Goofy are my favorite), Strawberry Shortcake, Princess Sophia and Dora. Sesame Street is okay... Cookie Monster is my favorite character.
- ◉ I like playing basketball, kickball, and baseball with my brothers. I also like watching their baseball and football games. Last year, their football teams gave me a trophy for being their #1 cheerleader.

INTRODUCING ME



- ◉ I am very funny, sassy and I like to joke around with others.
- ◉ My oldest brother Nolan, often times calls me “the Queen.”
- ◉ I think it’s funny when my brothers or dog get into trouble.
- ◉ I think it’s funny when my mom tells me “5 minutes to bedtime.” I respond with my Tobii talker “No, No, No. I want to do another activity. TV.” My mom says “yes, yes, yes, it’s time for bed. 5 minutes.” I respond “No, no, no” with a twinkle in my eye. And it’s fun going back and forth for a little.
- ◉ I thought it was funny when my speech therapist told me she didn’t like a song that I played on my Tobii music/ipod selection. I kept on playing it, while laughing, and looking at my mom before selecting that song again and again (another twinkle in my eye). I love how my speech therapist, and all other current therapists really “get me” and I really enjoy being with them, playing, learning, and teasing with them.
- ◉ I recently went to see the “Peter Pan” musical with my family. I loved Tinkerbell and Peter Pan. I also laughed every time Captain Hook came on stage and everyone “booed” him.
- ◉ I get upset when others are crying or sad. I don’t like to see others upset.
- ◉ I get lonely and sad if others don’t include me.
- ◉ I get upset when people think even though I can’t say anything, I don’t have anything to say and I am ignored or talked about, instead being talked to. I understand everything that’s going on around me, and everything that’s being said.
- ◉ Many nights, I don’t sleep. It’s not because I don’t want to; it’s because my body won’t let me. Often times, I can’t nap either. This makes the next day really hard.

MY FAMILY

The Reilly's...

Dad (Sean), Mom (Colleen),
Nolan (7), Brendan (5),
& me (3 years)



SO... WHAT IS RETT SYNDROME?

Imagine your baby growing, progressing, and becoming more independent. Then imagine her suddenly being robbed of her ability to talk, walk, or use her hands.

Imagine having to live your life as if your feet are tied together, your hands tied behind your back, and your mouth taped shut.

Imagine the symptoms of Autism, Cerebral Palsy, Parkinson's, Epilepsy, and a variety of anxiety disorders, all wrapped up in one little girl. This is Rett Syndrome.

Rett Syndrome is a rare and devastating neuro-developmental disorder that condemns 1 in every 20,000 little girls to an entire lifetime of challenges.

These girls are born just like most others and develop normally until 12-18 months of age when they suddenly begin to lose acquired skills. They are no longer able to speak, walk and use their arms and hands - requiring 24/7 care.

SO... WHAT IS RETT SYNDROME?

'Silent Angels', as they're often referred, continue to develop mentally only to be trapped by their inability to communicate along with their physical disabilities.

As they grow older, these girls struggle with disrupted sleep patterns, breathing disorders, scoliosis, fragile bones, seizures, digestive disorders, heart problems, and even sudden death.

Rett Syndrome currently has no cure and there are no treatments. Medicine can offer only supportive measures such as feeding tubes, orthopedic braces and surgeries, and trials of standard seizure medications which are often ineffective.

Scientists are working hard though, to reverse Rett symptoms in animal models. If a cure is found in Rett, it could lead to cures for Autism, Bipolar, Alzheimer's, Schizophrenia and more. This is hopeful! My parents have created a foundation to help the overall Rett cause, on both a large level as well as a smaller, more personalized local level. I am blessed to have a large network of supporters called "Claire's Crusaders" and so far, so good!

For more information visit: <http://clairescrusade.org>



CAN RETT GIRLS UNDERSTAND? YES!

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

Girls with Rett Syndrome are cognitively at the same level as their peers - often times above average... 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 and adaptations. They must be exposed to the same curriculum as everyone else and they must have high expectations and have those expectations communicated to them!

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

For more information, visit:

<http://www.rettsyndrome.org/understanding-rett-syndrome/living-with-rett-syndrome/school-and-day-programs/school-time>

CLAIRE AND RETT SYNDROME

To learn more about Claire's specific story of when/how she was diagnosed/ our story, please visit: <http://meetclaire.clairescrusade.org/story/>

Claire's Current Medical Issues Include:

Strabismus

muscle weakness/ tightness

gross motor impairment

lack of coordination

static encephalopathy

Rett Syndrome

Bruxism

Other symbolic dysfunction

Chronic constipation

Gastroesophageal reflux disease

Swallowing disorder

Feeding disorder

Eustachian tube dysfunction

Diastasis of muscle

Sleep disturbances/ irregularity

Epilepsy



COMMUNICATION: HOW CLAIRE COMMUNICATES (WHEN TOBII OR TALKER CARDS AREN'T IN FRONT OF HER)

Activity/Feeling

Method

Making Choices for Toys (if they are visually available)

Eye Gaze

Hunger

Low interaction, not smiling, no energy, whining

Thirsty

Smacks Lips

Toileting/Tummy Issues

Scratch Back, Appears Distracted

Enjoys an Activity

Smiling, Dancing

Doesn't Like an Activity

No Smiling, Rock Backwards, Sits still – looks bored

Boredom

No Smiling, Rock Backward, Sits still

Answering Yes/No Questions

Head nod yes, shake head no

*Sometimes based on positioning and due to apraxia, it's hard for Claire to answer yes/no this way. We are working on this and we all need to continue to do so. If not shaking head for no or nodding for yes, ask "Claire, if you want _____, you need to look at my eyes"

Tired

Pulls at Right Ear, Irritable

Scared/Uncomfortable

Facial Expression, Rocking, Crying

Indicating "more"

Touch Object (if in front of her)

Indicating "all done"

Sit, No Smiling, Body Rocking

Signs of affection

Smiles, tapping your face or head

OTHER COMMUNICATION TIPS

- ◉ Positioning of Tobii - best if slightly right of Claire. Technical training on Tobii will be provided. Mom will need ongoing list of vocabulary based off what's being done in classroom so she can program accordingly.
- ◉ Claire does best when any choice is in front of her (vertically positioned) vs laying flat in front of her. This is why the Tobii stander is important to use at all times if possible. If giving her cards to choose from, hold vertically in front of her.
- ◉ In addition to Tobii talker, we also use basic communication cards. These will be included in Claire's Communication binder.
- ◉ When in doubt, look at Claire's eyes and pay attention. They speak volumes.
- ◉ The Tobii device is used by many Rett girls within the classroom, nationwide, successfully.

*Jackie Babiarz - Wheaton, IL
Cameron AKA Cammy Can, age 4
Entering Preschool*

Cammy's school is made up of students who transition there directly through Early Intervention (EI) and tuition based students. She has a one-on-one aide with her at all times. Throughout her 2.5 hour day at school, she receives OT, PT and AT. Her staff uses her Tobii throughout the entire day incorporating it in everything they do and adapting it for every activity so that she can participate. She can access it sitting on the floor, in her wheelchair and in her stander or anywhere they go in school. She has been the Greeter for school events, using her Tobii to welcome people at the door. Cammy has done the introductions and closings for the Winter holiday program too. We also share daily back and forth with logs and a Set by Step button, which her OT loves as Cammy's timing hitting the button for each sentence is spot on now. Her school sends me photos and videos of Cammy during the day of her smiling playing with the other students and doing various adapted activities using switches and buttons.

For more information, visit:

<https://www.rettsyndrome.org/understanding-rett-syndrome/understanding-rett-syndrome---living-with-rett-syndrome---school-and-day-programs---school-time---advice#Babiarz>

CLAIRE'S SEIZURES

- ◉ Claire has regular seizures and will need Rx to be administered. See medical notes for what to look for, how to administer, and other medical release information, emergency contacts, etc.
- ◉ Triggers for seizures: stress, anxiety - change in routine, new situations, etc., being too hot/ too cold (Claire does NOT like being too warm), low sleep, dehydration (she needs constant clear liquids), low blood sugar or fast change in blood sugar. Diet is also a factor. Parents are looking into restricting gluten and dairy, MSG and sugar (to some degree) from diet. Seizures are increasing in regularity. Room for concern as this is still new territory for us.
- ◉ Claire has a few different types of seizures, described below. If either seizure lasts more than 3 minutes, diastat is to be given to Claire rectally, followed by immediate phonecall to Mother. Claire's has following 2 types of seizures, during the day:
 - 1) Absence (Petit Mal) Seizures. In this seizure, there are short periods of staring blankly (for up to a minute). During these periods, Claire is unaware of surroundings. When seizure is over, Claire comes back normal as if she's only "checked out" for a little bit of time.
 - 2) Temporal-lobe Seizures. This is where Claire shows "odd" behavior, such as strange opening of her mouth (freezes that way). These seizures are often times followed by drooling, irritability, and emotionally weepy and/or tired.
 - To watch a video of Claire having the Temporal-lobe seizure, please go to:
http://meetclaire.clairecrusade.org/?attachment_id=331

OTHER INFORMATION

- ◉ Mom to discuss sippy cup, bottle, how to eat. Importance of being hydrated - to help with constipation and to avoid seizures. Look for choking not even with eating but when drinking water or juice. Claire needs 100% hand over hand assistance with all feeding needs.
- ◉ Claire wears glasses, AFOs, and at times, hand splints. Mom will show aide how to put on/ use.
- ◉ Teaching vs. Testing - refer to “Catching a Glimpse and Fueling the Flames of the Hidden Torch Within” -- difference between teaching and testing. Motivation provides intent. Without motivation, intent is external and requires more cognitive and physical effort to perform.
- ◉ Motivation is key to truly understand and unlock what Claire knows. She’s very smart. What motivates her? Singing, music, sometimes eating crunchy snacks due to sensory system. If she’s not motivated, or if something is physically or emotionally bothering her especially, it will be hard for you to truly understand what she knows or is thinking. Ex: when walking, we sing “ants go walking 1 by 1, etc) Or when doing a craft, we make up and sing a song.
- ◉ Claire learns best/ performs better when sitting in an organized space.

OTHER INFORMATION

- ◉ **Sensory Needs:** Claire's sensory needs have a direct impact on her learning and communication ability. She continues to be very sensitive to light and heat, but she handles transitions much better. Her eyeglasses have the transitional lens which help when it's bright outside. She is uncomfortable when she gets hot, and often times, when indoors, her feet are always colder than the rest of her body. 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.
- ◉ **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, Claire holds her breath for 5-10 seconds on average. Holding her breath can often times make her feel faint, so she should never be left alone for safety reasons.

OTHER INFORMATION

- ◉ Safety Awareness: Due to Claire'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. Claire does not seem to scan her entire environment. We are really working on prompting her to scan her environment for objects, people, and dangers. 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!
- ◉ Apraxia: Due to apraxia, it takes Claire longer to respond to simple questions. Give Claire at least 30 seconds to answer a question. Sometimes Claire seems to need to move away before moving toward what she intends. If you don't wait for Claire to finish the intent, it may appear that she is rejecting or responding incorrectly, when in reality she hasn't finished her movement yet. Waiting for a response with patient anticipation is critical to success. Claire learns which people will likely take the time to wait for her, so she can decide if it is worth her effort or not. Sometimes talking Claire through the motor movements and /or modeling them can be helpful. Intrinsic motivation can help reduce the effects of apraxia. Peers can be powerful motivators for girls with Rett Syndrome.
- ◉ Gastrointestinal Concerns: All girls with Rett Syndrome struggle with GI issues. Most have problems with constipation. Claire is no exception. She is on medication to help with her GI troubles. It is imperative to have good communication between home and school about her bowel movements daily, along with noting how much liquids she's drinking. This determines her medications each night and if she does not have a bowel movement for 3 days, we must use a laxative suppository. Claire's constipation creates a lot of anxiety and discomfort and managing this via constant communication is important.

OTHER INFORMATION

- ◉ Neurological Stereotypies with Rett Syndrome Girls: Hand wringing, Pulling at her hair (right ear) Mouthing, etc. Neurologically caused - child does not intend to make these movements. Inconsistency is the norm - Varies day to day, and within a day. Varies with stress, anxiety, pain, fatigue and many other unexplained reasons. Masks intelligence. May be interpreted by others as severe cognitive disability - which is rarely the case. Music may reduce stereotypies for some girls. Splinting or gently holding her non-dominant arm may lesson and improve function of her other hand. Splinting one or both arms may work better for some girls. Even though using hands looks more “normal” and seems to work some of the time, the child may be able to move a different body part more reliably to indicate intent for communication purposes or switch activation - for example turning her head to activate switches or using an eye-gaze system. On some days and at certain times, being able to break out of the stereotypy to use hands may be very difficult and may be frustrating for the child and other options should be provided. Waiting for a response beyond the stereotypy with patient anticipation is critical to success. The child learns which people will likely take the time to wait for her, so she can decide if it is worth her effort to comply or initiate. Facilitate attention through movement, proximity, and/or moving your face into the child’s view. Claire sometimes uses arm braces, sometimes doesn’t. Depends on her positioning and level of fatigue, hunger, or what she is being asked to do.
- ◉ Fine Motor, Communication, Mobility, and Feeding Skills Notes- see IEP.

COMMUNICATION IS KEY

- ◉ Daily communication sheet to be filled out everyday, along with communication binder from each therapist. Home activity will be included in that binder, along with what's being worked on in private therapy. Binder is "home" for all Claire's activities, goals, progress, etc. and will travel with her everywhere she goes. We need your help in filling this out, reading what was written outside home, so you not only understand Claire better, but so we understand what's going on during school and what we can talk to Claire about when home, and relay therapy progress to private therapists.
- ◉ Meet with 1:1 teacher/ aide at least weekly (more if I have questions about information that wasn't in communication binder). Teacher/ aide to give me best day/time for a weekly 15 minute meeting regarding Claire.
- ◉ Mom would like to see what equipment Claire will be using - adaptive seating, etc. before Claire starts school, to ensure it's safe and a good fit for Claire based off activity.
- ◉ Mom would like teachers/ aides to join Rett Educator Network. It will only take a few minutes to sign up, but it will help you better understand Rett, and Claire, specific to your specialty. Click on following URL, and go ½ down page to where it says: Educators Network Invitation. Thank you in advance.

<http://www.rettsyndrome.org/understanding-rett-syndrome/living-with-rett-syndrome/school-and-day-programs/school-time>

CONTACT INFO

CAREGIVER TEAM

- Colleen Reilly (Mom) - xxx-xxx-xxxx (mobile) *best number to call
- Sean Reilly (Dad) - - xxx-xxx-xxxx (mobile)
- Colleen/Sean Reilly (home) - - xxx-xxx-xxxx
- (Emergency contacts and information were also included)



MEDICAL TEAM

- (We listed those doctors who care for Claire... Their names and the best way to contact them if an emergency or if for a general question. We included her Rett Specialist from NY, her Cleveland neurologist, pediatrician, dentist, etc.)