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Rett's Littlest Angel

By **Katie Miller**

(Created: Wednesday, October 22, 2008 12:05 PM CDT)

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GULF SHORES, Ala. — One in every 10,000 to 23,000 girls are affected by Rett Syndrome (RTT), a rare neurological disorder.

The developmental disorder is a mystery to most and little is known about the prevention and rehabilitation of RTT, a form of autism.

Nationally there is a lack of awareness but a Baldwin County girl, and her parents, are telling their story to shed light on the life altering issue.

Meet Avery

Blond-haired, blue-eyed Avery Akins was born in the Spring of 2006 with no indication of trouble. Happy and smiling, like Avery still is today, mom Carrie said she saw no red flags.

Carrie, who was already raising an autistic son, Cole, said that Avery was developing as expected.

But when Avery turned a year old and wasn't talking or walking, the family pediatrician started to keep a close eye on her. At 15 months, Carrie suspected Avery had autism.

"I've been there and done that, it's autism," Carrie said, speaking about her feelings of raising a second child with autism. "I can handle this."

A neurologist began genetic testing for autism, but all tests were negative. When Carrie stumbled across RTT symptoms online, she knew.

With the positive results of a new RTT screening test in April of this year, Carrie and her husband Thad were given verification of what they already knew — their daughter had RTT.

"All the dreams I had for her were crushed instantly. She will never get married, she will never have children — all of those things that you wish for your child. Just to hear your child say, 'Mom, I love you.'" Carrie said. "Those things will never happen."

Avery was almost 2-years-old before she was properly diagnosed.

What is Rett Syndrome?

There are 4400 girls living with RTT in the nation, and according to Carrie, Avery is the only child in Baldwin County she is aware of that has been diagnosed with RTT. Usually symptoms begin appearing within six to eight months of birth.

It has no prejudice in race or ethnicity, but is rare to occur in males — most males with RTT are stillborn, miscarried or succumb to early death due to fatal encephalopathy, according to the International Rett Syndrome Foundation.

The developmental disorder causes "problems in brain function that are responsible for cognitive, sensory, emotional, motor and autonomic function" the foundation Web site relays. Affected is the ability to learn, speak, control moods, as well as necessities to survive like breathing and swallowing. However, intelligence appears to not be affected.

The disorder spawns from a mutation on the X chromosome on the MECP2 gene. Girls who suffer from RTT can live into adulthood; RTT is not believed to be degenerative.

A simple blood test is all it takes to determine if a child is suffering from RTT. However, the disorder is commonly misdiagnosed as cerebral palsy, autism or delayed development. Early detection and proper diagnosis is critical for treatment.

Social withdrawal, regression of communication and the inability to keep balance and walk properly are all symptoms of RTT. A hallmark characteristic of the disorder is repetitive hand movements like squeezing fists or blowing bubbles into a balled fist. All of which are red flags to have a child tested.

A Day in the Life of a Rett Angel

Avery spends every day relying on the people around her. With the inability to use her hands she is drastically and dangerously limited to no self-sufficiency. She can't brush her teeth. She can't dress herself, feed herself, bathe herself or anything else that would require proper hand functioning.

"She is a constant infant; she will require my attention forever," Carrie said. "Every aspect of daily living requires somebody's attention. She can't do anything for herself."



One in every 10,000 to 23,000 girls are affected by Rett Syndrome. A Baldwin County family shares their story to shed light on the life altering issue

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Most of her days are spent at home watching The Wiggles, and at first sight Avery would appear to be like any other child — aside from the habitual hand-to-mouth motioning she has developed.

An unstable gait, which is as nerve-racking as a tight-rope walk, and her lack of speech is the realization that Avery is unique.

All of these problems restrict Avery to a life at home. Pillows cover sharp edges in the house, and furniture has been removed to create a safe haven for her.

Carrie said they have ventured out but problems always arise. Avery was faced with a patterned carpet while out one day and couldn't walk because it disoriented her already ill senses.

Heartbreaking is the evidence that Avery is alert and observes there is a problem. She surveys the people around her, and frustration crosses her face when she can't get words out like everyone else.

"She's in there," Carrie said, smiling at her giggling daughter. "Aren't you?"

Her inability to communicate is what makes Avery a puzzle. Carrie explained that everything they know about her — likes and dislikes, personality traits — have been on a trial and error basis.

Carrie said that during a rehabilitation session, the therapist blew bubbles to Avery, who would get up and run into the bathroom. Carrie said every time Avery saw bubbles she would head back into the bathroom and stand. Again she did it and Carrie followed her. Carrie realized that Avery was trying to get a bath toy that blew bubbles to play with too. It was that particular incident that verified she had memory.

Coping for a Cure

"There were lots of times where I thought, 'Why am I being punished?'" Carrie said at home with Avery one afternoon. "But now I realize that she was given to me. She is my gift not my punishment."

Carrie said that she had a hard time dealing with Cole's autism diagnosis and spent time in denial and embarrassed.

So when Avery was labeled with RTT, rather than spending more time in denial Carrie took an active role in the disorder and has become an activist as a way to cope.

She began spreading the word through a therapeutic blog: averycat.blogspot.com, where she would record the day's setbacks or successes.

Through the Internet she began connecting with other parents and has become a part of a coalition to bring RTT into the spotlight.

She is an advocate of Rett Syndrome Research Trust, a group focused on testing pre-existing medicines to see if they can treat RTT. Carrie said it costs \$168 per drug to test it for an off label use that could benefit those suffering with RTT.

Carrie is also part of a non-profit organization, Girl Power 2 Cure, which is a forum to collect money for research of gene therapy which may unlock the key to RTT.

Future Unknown

The future is unknown for Avery. Every day can bring either a revelation or a regression in her attempt for rehabilitation. Carrie said that Avery will enroll in school, but probably won't be mainstreamed.

As of now the Akins family continues on with a positive and hopeful attitude that their little girl will some day live a normal life.

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