

The Family and Professional Journal for the Special Needs Community
Infants • Children • Adolescents • Adults

EP

Exceptional
Parent

Vol. 11, Issue 4

Focus on Autism

Research
Studies

Helping a Child
with Rett
Syndrome
Thrive

Self-
Determination
Strategies

Connecting Via
Telehealth

...and more!

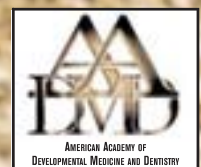
Genetics + Disability

Proprioception Tools

Spotlight: National
Meningitis Assoc.

UNITED STATES
MILITARY SECTION

www.eparent.com



A Full Plate

Helping a Child With Rett Syndrome Thrive and Grow

By Patricia Ladew and Christina Bock Giuliano, M.S., BCBA, May Institute

For 25-year-old Jessica Steventon, whose husband Alan is a sergeant in the Army, a good day is when their 4-year-old daughter Riley eats a good lunch or dinner. A great day is when she gains a little weight.

Like most moms, Jessica tries to provide her child with healthy, balanced meals so she will thrive and grow. Like most kids, Riley often refuses to eat the foods she is offered. But Riley isn't like most kids. Riley has Rett syndrome. She is unable to feed herself and has difficulty chewing and swallowing. Although her mother and therapists spend many hours every day trying to get her to eat, Riley weighs less than 30 pounds. Medical professionals have recommended a feeding tube.

Rett syndrome is a rare neurodevelopmental disability that is currently considered an autism spectrum disorder (ASD). Unlike autism, which affects more boys than girls, Rett syndrome almost exclusively affects girls. It occurs in one of every 10,000 to 23,000 female births. In addition to challenges with eating and digestion, girls with Rett syndrome also have problems with brain function that affect learning, speech, sensory sensations, mood, movement, breathing, and cardiac function.

A Difficult Diagnosis

"We knew from a very early age that there was something wrong with Riley,"

Jessica says. "She hadn't even begun to crawl when she was 12 months old. But she was a chubby baby and her doctors weren't worried about it. By her 15-month check-up, she had started to crawl, but she hadn't started to walk yet. Her doctors said it was just because she was fat and couldn't pull herself up."

It wasn't until Riley's 18-month check-up—after the Steventon family moved to Fort Campbell in Kentucky— that it was determined she had developmental delays. Jessica later learned that Rett syndrome is often misdiagnosed as autism, cerebral palsy, or non-specific developmental delay.

"The doctors here were very concerned about how she was progressing and they tested her for everything—everything except Rett syndrome because, at that point, she wasn't showing any of the signs," Jessica relates. However, before her second birthday Riley started wringing her hands, a hallmark sign of Rett syndrome. She was 26 months old when she was diagnosed.

"At first I thought, 'Well, thank goodness we finally know what it is,'"

remembers Jessica. "But my husband was deployed in Afghanistan and I didn't get to talk to him for a couple of days. I think the hardest part about being a military family is times like that—when we got the diagnosis and he wasn't there. It's difficult because you can't grieve together. You have to do it separately. You don't have your other half to be able to go through those emotions with."

Despite the difficulties involved in being a military family—Alan is currently back in Afghanistan on his third deployment—Jessica and Alan are grateful for the medical benefits the Army provides to the families of soldiers serving their country. "Alan would love to stay home with Riley," says Jessica,



“but he’s willing to sacrifice a year away from her—his life if he has to—so she can be provided with what she needs.”

Intensive Therapy Helps Maintain Skills

What Riley needs is intensive therapy to help her maintain the skills she has, and to perhaps develop new ones. On weekday mornings, she attends an integrated school on base that has both typically developing and special needs students. There, Riley participates in a program with other preschool children who have moderate to severe disabilities, and receives physical, occupational, and speech therapy. At other times during the week, she has physical and occupational therapy at Vanderbilt University, in Nashville, Tenn., and music therapy in Hopkinsville, Ky.

Three or four afternoons a week, Riley has in-home therapy with a board certified behavior analyst (one of the co-authors of this article) from May Institute’s Center for Autism Spectrum Disorders in Clarksville, Tenn. The Center, the newest of seven May Institute locations around the country that provide services to military families, serves families stationed at Fort Campbell as well as those who live in surrounding areas in Kentucky and Tennessee.

The therapist uses applied behavior analysis (ABA) techniques such as positive reinforcement, teaching in small steps, prompting, and repeated practice to help Riley increase her appropriate eating skills and functional communication skills and decrease her self-injurious behavior such as hand wringing.

[ABA has been endorsed by the National Institutes of Health and identified by the Surgeon General of the United States as the most effective way to treat ASD. According to the National Autism Center’s National Standards Report (2009), data collected through hundreds of studies indicate that ABA is a highly effective method to teach children and adolescents with ASD.

ABA is the only treatment reimbursed by TRICARE’s Extended Care Health Option (ECHO) and Enhanced Access to Autism Services Demonstration (“tutor”) programs for military families who have children with ASD.]

Mealtime Challenges

“Riley’s therapist and I are highly focused on nutrition right now,” says Jessica. “We work on feeding Riley and communicating with her. We talk about recipes and how to increase the calories in the foods we fix.”

During lunch, which usually consists of a high-calorie pasta dish such as macaroni and cheese or lasagna, Riley and her therapist sit together at the Steventon’s kitchen counter. Riley has a communication device in front of her that shows pictures of Riley eating and drinking; the therapist has the food and drink in front of her. By pressing the appropriate picture, Riley, who is non-verbal, will indicate if she wants more food or if she wants a drink. It was the therapist who recommended using the device at meal-times, a practice that has resulted in a significant increase in Riley’s requesting skills.

Riley actually loves to eat and will eat almost anything, according to Jessica. What she’s picky about is when she wants to eat. And it usually takes quite a while (at least 45 minutes) to complete a meal. Fortunately Riley gets along very well with her therapist. “They are really funny together,” Jessica says. “She and Riley are always giggling about something.”

Unfortunately, Riley doesn’t always like to eat at lunchtime. “It’s a pretty big hit or miss,” says Jessica. “If she doesn’t eat what we’re trying to offer her, our fallback is breakfast food. She loves breakfast. Her favorite foods are pancakes or waffles or eggs.

Dinner is normally another pasta or chicken. Riley loves chicken fingers and chicken potpie. We try to incorporate a protein at dinnertime. After dinner, we have a snack like ice cream. But dinner and snack times are also hit or miss.”

Jessica works with Riley’s therapist and her pediatrician to formulate meal routines that will increase her intake of calories. Based on preference assessment practices prescribed by applied behavior analysis, the therapist identifies which foods Riley would be most likely to accept with slight changes. For example, she advised adding minced chicken to macaroni and cheese to increase Riley’s protein intake. Riley has gained several pounds recently as a result of the increase of calories and protein, but based on the advice of med-



United States Military Section: ARMY

ical professionals, Jessica and Alan have recently agreed that Riley would benefit from a gastronomy feeding tube (g-tube) to get her to the weight she needs to be.

Seeking Outside Help

Riley is enrolled in the National Institutes of Health's Rare Disease Consortium Research Network (RDDRN) and is followed by the Rett Syndrome Clinic at the University of Alabama under the direction of Alan Percy, M.D., an international expert in neurodevelopmental and related disorders. Through the study, her medical and nutritional needs are evaluated every six months.

Suzanne P. Geerts, M.S., RD, is a Registered Dietitian who assists Dr. Percy. According to her, Riley will greatly benefit from a g-tube. "It would provide the nutrients she needs for energy and catch-up growth, increase her Body Mass Index (BMI), and promote bone growth and strength," she says.

Other benefits of g-tube placement include ensuring optimal hydration, providing immunity from infections and promoting overall health, and increasing strength and alertness which makes the patient more responsive to therapies.

Gains and Losses

Although helping Riley gain weight and improve her dangerously low BMI are top priorities for Jessica, she is also determined to help her daughter maintain the skills she has acquired. For children with Rett syndrome, regression, or losing previously mastered skills, is a very real concern. This is one of the areas where Riley's therapist from May Institute is most involved. She is encouraging Riley to practice her current food requesting skills and will soon be adding new goals as appropriate.

Before Riley was diagnosed with Rett syndrome, Jessica and Alan were unaware that she was losing skills. "We were focusing on things that she still

wasn't doing yet instead of the things that she was losing," says Jessica. Now, our goal for Riley is that she maintains the skills she has. If she can obtain new skills, that's wonderful, but we want to make sure that she doesn't regress any more and lose the skills she has gained."

Jessica knows that there will be losses as well as gains. For example, Riley had worked her way up to a more advanced level with her seven-level communication device, but then she experienced a minor regression and had to return to just two choices ("food" and "drink"). But Jessica reminds herself that Riley is a determined little girl who learned to walk at 22 months—after her first regression—and she will have other successes.

With help from her therapist, Riley has learned to spit less frequently during her meals, which enables her to eat more. The therapist has also been successful in helping Riley decrease her hand-wringing by having her wear gloves. When she wore the gloves, Riley did not experience the rewarding tactile sensation that reinforced the hand-wringing, so that behavior decreased. Consequently, the blisters on her hands diminished. Over the past few months, Riley has been wearing the gloves less and less, but the intense, blister-causing, hand-wringing behavior has not returned.

Moving forward, the therapist plans to address some of Riley's other self-injurious behaviors such as self-biting, introduce a toilet training program, and focus on increasing her play skills.

A Personal Mission

Although Jessica's days are filled with therapy appointments and feedings, she also finds time to help other parents whose children have been diagnosed with Rett syndrome as a co-representative for the International Rett Syndrome Foundation (IRSF) for Kentucky and Tennessee.

After Riley was diagnosed, Jessica's parents suggested she contact IRSF. "They were amazing," she says. "They were there for us, and we have stayed connected to them ever since. They have been our biggest lifelines. Now, when people get that diagnosis, they call me.

"I have a very big goal of letting the world know about Rett syndrome," she continues. "It's something nobody knows about before the diagnosis affects their family. Everybody knows what autism is nowadays. I want Rett syndrome to be like that too."

Having a child with Rett syndrome has been an empowering educational experience for Jessica. "I have learned that I am stronger than I thought I could be," she says.

"But I'm just a mom. I do what other parents would do if they were in my position. Alan and I just want to provide Riley with the best quality of life possible. For us right now that means maintaining her skills and doing fun things with her, surrounding her with life. When people ask us about having other children, we tell them that we don't think about having other children. We have never had 'baby fever.' We have 'Riley fever,' and every fiber of who we are is put into her. We just want her to be healthy and happy." •

To learn more about Rett syndrome, visit www.rettsyndrome.org

Christina Bock Giuliano, M.S., BCBA, is a board certified behavior analyst. Christina served as a Senior Behavior Analyst at May Institute's May Center for Autism Spectrum Disorders outside Fort Benning, Ga., before moving to Fort Campbell to open and serve as the Program Director for the Institute's seventh military Center last year. The May Center for Autism Spectrum Disorders in Clarksville, Tenn., serves military and civilian families in Kentucky and Tennessee.

Patricia Ladew is Senior Communications Writer for May Institute's Office of Communications. She has specialized in healthcare writing for more than 20 years.

Addressing the food issues of children with special needs

By Shannon Kay, Ph.D., BCBA

Many children can be described as “picky eaters,” but children with autism and other developmental disabilities are more likely to develop feeding disorders and food selectivity than typically developing children. Eating problems need to be addressed because they can affect the child’s ability to participate in family meals or go out to a restaurant, and more severe feeding disorders can have serious health consequences.

How should parents begin to address feeding issues? First, they should keep a food diary to track the types of foods that their child is eating. Some children may only eat certain types of food such as chicken and French fries, while others may only consume foods that have certain textures. Children with autism or obsessive-compulsive disorders may develop rituals around food. For example, they may only eat foods from certain containers or food that is a particular shape or color.

It is also important for parents to share this information with their child’s pediatrician and rule out possible medical reasons for their child’s eating problems.

Once medical issues are ruled out and parents are aware of their child’s eating patterns and preferences, there are several techniques they can use to expand the variety, type, and amount of food their child consumes. First, they can begin working on food selectivity by encouraging their child to eat a small amount of a less preferred food before eating preferred foods. There may be a

greater likelihood of success if parents change the type of food and amount very gradually. For example, if a child only eats a certain brand of cereal, the parent might ask the child to eat a teaspoon of a similar but less preferred cereal before rewarding him or her with a highly preferred meal. Other “reinforcers,” or rewards, such as toys or activities, may work better with certain children.

In some instances, children may have already developed problem behaviors such as aggression or throwing food when new or different foods are offered. In these cases, teaching the child to simply sit quietly while the food is present on the table for a few seconds before receiving a highly preferred food may be the best course of action. Over several weeks, the child may be taught to touch the food, bring it to his or her mouth, and then begin consuming small portions.

Another technique that may be helpful is called “fading.” Using this method, parents gradually mix a less preferred food into a more preferred food. For example, if a child likes plain yogurt but does not care for fruit, a very tiny piece of fruit might be blended with the yogurt. Once the child successfully consumes the initial amount of fruit and yogurt for several days, a little bit more fruit could be added. Eventually, the parent might fade out the yogurt entirely and present the fruit alone.

A third technique that parents may try involves presenting preferred and non-preferred foods simultaneously. For



example, a tiny bit of vegetable might be placed on a piece of pizza. For some children, it may be effective to present a preferred activity (such as watching a video or listening to music) with the non-preferred food.

Teaching children to expand their food repertoire may be a daunting task for parents, but with adequate help and support they can play a key role in improving their child’s health and ability to eat in home and community settings. •

Shannon Kay, Ph.D., BCBA, is Executive Director of the May Center for Child Development in West Springfield, Mass., one of May Institute’s four special education schools in the U.S. educating children and adolescents with ASD and other developmental disabilities.

Serving Military Families Across the Country

May Institute’s Centers for Autism Spectrum Disorders (ASD) in Georgia, North Carolina, Tennessee/Kentucky, Texas, Florida, and New England are dedicated to meeting the immediate and pressing need for services for children with ASD in all branches of the military—Army, Marines, Navy, Air Force, and Coast Guard. The Institute plans to continue expansion of its services for military families through new Centers in close proximity to key military installations.