Catherine's Story and our Journey – Autism & Rett Syndrome

On August 8, 2001 Catherine, our 6th daughter was born. She developed normally but she lost her speech at 1 ½ years of age. She was diagnosed with **Autism** when she was 2 years old but we knew that it was more serious since she had lost her ability to speak. We did chromosomal and DNA tests to see what we were dealing with. At 4 ½ years old she was specifically diagnosed with **Rett Syndrome** which is on the severe end of the autism spectrum.

RETT SYNDROME- Mutation of the DNA ... Here is the list of what we were suppose to expect in our sweet Catherine.

Abnormal Head Size (Catherine- Normal)

SEIZURES (15-20 daily)- Catherine - has had 7 isolated cases of seizures and has not had on since 2007)

Low Muscle Tone (Catherine – excellent muscle tone)

Small Brain size (Catherine – perfect for her age

CONSTIPATION! 100% (Catherine – goes like clockwork)

Cold Hands and Feet (Catherine – warm hands and feet)

Deficits in lean body mass- muscle deterioration (none

Scoliosis (small start but maintaining same)

Lack of speech (Catherine – non-verbal but signs)

I cried for a few days! As her mom, I had a hard time accepting the above and thus began what has become a lifetime passion – to see what we can do to not allow her body to go down the road to becoming a vegetable! Mental handicap and delayed for non-verbal speech I cannot overcome, but physically – we can help nature along!

Getting informed: I joined Autism groups, went to Rett forums, and became an expert in the field of children's health. Then Dave and I and family traveled much throughout the years to find answers to the questions of how to make Catherine reach her full potential. She is in 3 national studies at John's Hopkins in Maryland, University of Alabama Birmingham, and Gillette in Minneapolis.

Many different intense treatments are recommended, but ALL children need the treatments of helping the body digest, assimilate and eliminate. Realizing that we are fighting a genetic disorder, and knowing that we only have a window of opportunity to help Catherine physically, we began an intense Shaklee supplement regimen when she was 2 ½. When she was diagnosed with Rett Syndrome, we were doing everything correctly, but had to increase some of the supplement intakes

due to the Rett Syndrome diagnosis, especially the Protein and later on the Vivix for the predicted loss of muscle tone.

From the Autism diagnosis, I continued to research every company that I heard about the distributors of the company and then would call the company to get answers to my questions. I was willing to try a product to help Catherine, if Shaklee did not have it, but I wanted to know the standards and research of the company before I would use the product. It opened an incredible world to me and I found the following:

SHAKLE IS UNIQUE! There is no other company with the solid, published research and philosophy of "*We will never make a product that will injury a single human cell"*! It came to a point that I honestly did not trust any other company besides Shaklee in the Nutritional Supplements, Personal Care, and Cleaners which were the main fields of my research.

Our journey with Catherine is a life-long blessing and learning process.

She had allergies to 72 different foods and was gluten intolerant when she was 6. We kept her off those foods for 2 years and became an expert in the allergy world. After a year, she was still allergic, and after two years we were tired of doing it. At the advice of Dr. Rodriquez, MD we added 2 Nutriferon, 1 Flavomax, and 1 Caratomax to her regimen. Nine months later, she tested allergic to nothing and to this day, she can tolerate any food. This was done by the body to help itself!

At one of the IEP meetings, they were complaining that Catherine was too active – she does not like to just SIT but loves to move and interact. This is so incredible since she is supposed to be non- mobile.

What should you do with parents of Special Needs – Autism, Rett Syndrome, etc?

1) Get informed

2) Eat the best you know how

3) Be consistent with supplements

CATHERINE'S Regimen - Shaklee only for the following:

ESSENTIAL: Yearly

Protein (3-6 TBLS) (muscles tone, energy) **Liver DTX Complex** (when liver is working, everything else works better.)

1 **Vitalizer with iron –** now that she is 13 years old (contains needed Optiflora, Vita-Lea, Vitamin E for her cold hands and feet, B-Complex, Vita-C for immune system, Omegaguard for brain, Caratomax – for immune and eyes)

Herb-Lax (for constipation)

B-Complex (Keeps her calm and focused)

Lecithin/ GLA/ 3 extra Omegaguard (Brain food)

OsteoMatrix (Calcium for muscles cramping during periods, anxiety, strong bones)

Nutriferon – (Immune system, especially in public school)

Vivix – (keeps up the mitochondrial activity in each cell – which translates to good muscle tone!)

IMPORTANT

Vita-C (immune system)

VitalMag (muscles)

Mental Acuity (Brain food)

Alfalfa (kidney, bowel, body cleanser)

CarotoMax, FlavoMax (immune system)

BENFICIAL

Stress Relief Complex (during stressful times)

Catherine's side-effects due to taking the above program: *Perfect height / Strong bone density/ / No Constipation/ perfect head, feet, brain size / NO Low Muscle Tone / No Cold Hands and Feet / No seizures*

OTHER BENEFITS OF HAVING A SPECIAL-NEEDS DAUGHTER:

Catherine helped us to get out of our comfort zone and to help make a difference in the lives of other families worldwide, both in health and financially. Personally, Catherine has also allowed us to appreciate the small accomplishments that most parents take for granted in their children! She can climb in and out of the car and van, she can go up the stairs, and she loves being around her family! Also, at school, those who work long with her, grow to love her. She definitely is our little Angel and feel very blessed to have such a wonderful sweet girl!

Heidi & Dave Carlstedt & family

What is Rett Syndrome?

Rett syndrome is a rare genetic postnatal neurological disorder that occurs almost exclusively in girls and leads to severe impairments, affecting nearly every aspect of the child's life: their ability to speak, walk, eat, and even breathe easily. The hallmark of Rett syndrome is near constant repetitive hand

movements while awake. Cognitive assessment in children with Rett syndrome is complicated, but we know that they understand far more than they can communicate to us, evidenced by their bright and attentive eyes, and their ability to express a wide spectrum of moods and emotions. It is a DNA mutation. Where Catherine's mutation is on the DNA strand makes it a very severe case.

Rett Syndrome Symptoms and how Catherine is an exception in so many cases!

Partial or complete loss of acquired purposeful hand skills – Catherine uses her hands meaningfully and can feed herself with assistance

Loss of acquired spoken language - she is still non-verbal but signs

Gait abnormalities She walks well and will climb stairs, also she ice skates, roller blades, and skis! This is unheard of for a Rett girl.

Stereotypic hand movement such as hand wringing – All Rett's girls have this trait

Breathing disturbances when awake – she rarely has breathing disturbances

Bruxism (teeth grinding) when awake – almost never- we increased her Alfalfa and this has stopped

Abnormal muscle tone – Catherine's muscle tone is fantastic we feel due to **Protein** & **Vivix**

Growth retardation – she is tall for her age and

Small cold hands and feet- not at all- the Vitamin E will eliminate this symptom

Inappropriate laughing and screaming spells – she laughs appropriately at funny scenes in a movie and sometimes has crying spells, but this is usually due to being hungry, thirsty, or may have a stomach ache

Scoliosis – She has a start but chiropractic care is keeping her from progressing which is amazing; her bone density is very good