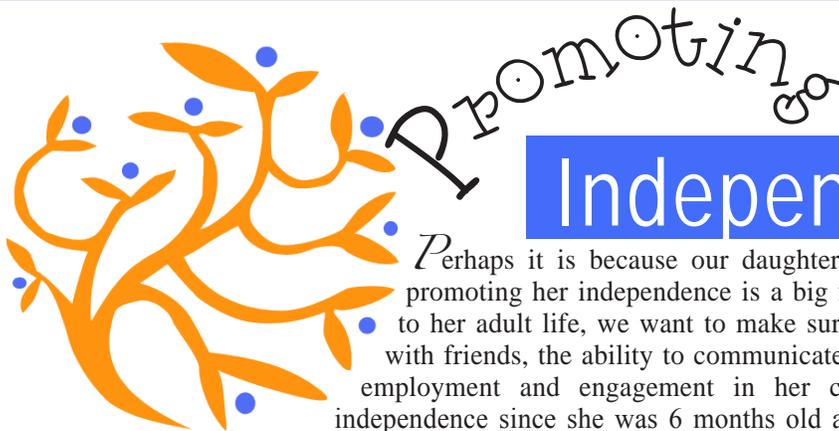


THE MIRROR

The Newsletter of

BY NICOLE CLEARY, PORTLAND, OREGON

Independence

Perhaps it is because our daughter, Corrina, is about to graduate from high school, but promoting her independence is a big focus in our house. As Corrina transitions from school to her adult life, we want to make sure she has some basic self-care skills, good connections with friends, the ability to communicate her wants and needs, and opportunities for meaningful employment and engagement in her community. We have been actively promoting her independence since she was 6 months old and could not flip from her tummy to her back. Hours of physical therapy and mom and dad support were required for her to start walking at 20 months. Years of practice and the help of teachers and therapists were required for her to feed herself, wash herself, and participate in dressing herself. Looking back, we've been actively promoting her independence since before we even had her dup15q syndrome diagnosis.

Being able to independently move around, express wants and needs, connect with others, and discover and pursue your own interests are key ingredients in a happy and full life. For kids with dup15q syndrome, these things may look quite different from what typical children do. It sometimes feels harder to support independence in these skills than it is to just directly "help" our kids. Certainly, I have found myself providing more support to Corrina than she needs at times, just because I want to get through an activity quickly. We know that when we consistently provide full supports in activities of daily living instead of encouraging our kids to do what they can for themselves, they learn to feel helpless or dependent, rather than self-reliant.

Promoting independence in children affected by dup15q syndrome requires patience, persistence, creativity, and above all a belief in our child's ability. In this issue of *the MIRROR* we hope to inspire and encourage families by exploring independence from both the family and professional perspectives. Families share their stories about supporting their child in sleeping, communicating, and finding meaningful work. A mother shares key lessons she's learned in promoting independence in her young son. A grandmother shares her involvement in her granddaughter's early therapies. One of our

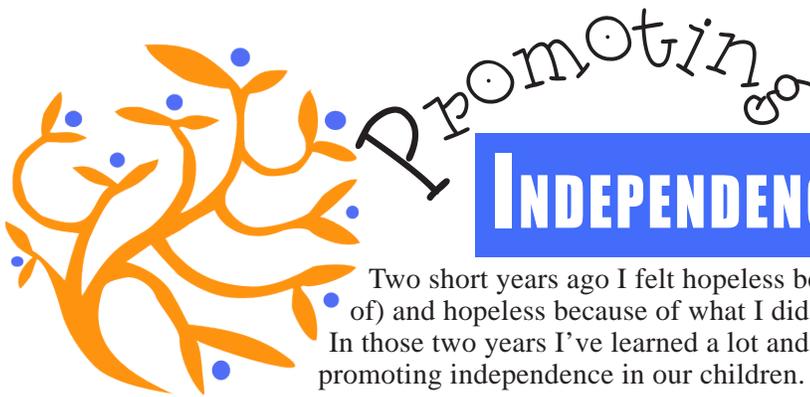
upcoming conference speakers provides her thoughts about how to support individuals who are impacted by dup15q syndrome with getting jobs.

On graduation day, it is my intent to give Corrina something new by her favorite author. Parents have been giving this to their graduates ever since it was written, but it has special meaning for the graduate with dup15q syndrome. *"You have brains in your head. You have feet in your shoes. You can steer yourself any direction you choose. You're on your own. And you know what you know. And YOU are the one who'll decide where to go..."*. ~ Dr. Seuss, *Oh, The Places You'll Go!* And just as we have for the past 18 years, we will continue to promote her independence so that she can have the happy and full life she deserves.

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Chromosome 15q11.2-13.1 duplication (dup15q) syndrome is a clinically identifiable syndrome which results from duplications of chromosome 15q11.2-13.1. These duplications most commonly occur in one of two forms. These include an extra isodicentric 15 chromosome, abbreviated idic(15), which results in an individual having 47 or more chromosomes instead of the typical 46. Individuals with an interstitial duplication 15 are born with the typical 46 chromosomes but have a segment of duplicated material within their 15th chromosome.



BY CYNTHIA MININNI, MONROE, MICHIGAN

INDEPENDENCE IN THE YOUNG CHILD

Two short years ago I felt hopeless because of what I didn't have (the child I dreamed of) and hopeless because of what I did have (a child with some serious health issues). In those two years I've learned a lot and I've come to believe that there are many keys to promoting independence in our children.



1. LOVE

Love yourself, love your life, love your child and love the moments you share with your child. I don't mean sit there and try to convince yourself how great it is to clean up your child's mess, I mean REALLY LOVE cleaning - because your child made that mess and s/he is sharing it with you because they love you!

2. ACCEPTANCE

Accept your child for who they are right now, this very moment, not for the end result of who you want them to be or what skill you want them to acquire. Yes, our children are an extension of us, but they are not us and we are not them. They deserve to be accepted for the little individuals that they are.

3. BELIEVE

Believe in the possibility that your child will be successful at reaching their highest potential - whatever that may be. Because when you believe in them, they build confidence and start believing in themselves.

4. PATIENCE

You MUST have patience in the process. Having special kids, you already know that some skills are acquired on their own, and others can take years to master. THAT'S OK!! The more patient you are, the more secure your child will be.

5. SUPPORT

A MUST!! This one was a hard one for me. I am Nicholas' only parent and my family is very small. You need to find someone, anyone, who can support YOU. Someone you can go to when you're down, stressed or just plain tuckered out! You should also go to that same person when your child reaches a milestone, acquires a new skill, or is just having a funny, happy day. Those who support you will do so longer and more willingly when you involve them in the good moments as well as the bad.

6. MAKE A PLAN AND MAKE IT FUN

When you're trying to get your child to acquire a new skill and actually use it, you want

to use things that motivate them. We are potty training Nicholas AND teaching him how to eat independently. While potty training, I give him his tablet loaded with his favorite apps while he's on the throne. It relaxes him and makes potty-time much more enjoyable. For eating independently, we're not so set on the "rules". Nicholas likes to pick out his dessert, and sometimes he even eats it first!

7. TEAM

You have to have a team of key players where everyone knows their role so your child knows who they are, what their purpose is and what s/he can expect from them. Your team can be just a few people, or the size of a small football team. As long as everyone knows their purpose, including your child.

8. ROUTINE, ROUTINE, ROUTINE

Having a routine is CRUCIAL!! You and your child will reap the benefits of it. This is the area where Nicholas' teacher and school staff have shared their time and expertise, and I've been able to bring it home (the best I'm able). All children thrive in familiarity; situations where they know what's ahead or what to expect. Sometimes, especially with our kids, it's necessary to do things over and over up to 100 times, maybe even more. But as long as you are consistent with your routine, your child will learn it and thrive.

BY THERESE FIMIAN, AUNT OF JOHN PAUL PETERS (DUP15Q) AND RESEARCH MANAGER AT THE INSTITUTE FOR ECONOMIC EMPOWERMENT

Promoting

INDEPENDENCE FOR THOSE IMPACTED BY DUP15Q

Throughout her 20 year career in the disability employment field, Ms. Fimian has established and managed a number of national programs and research projects that promote economic self-sufficiency for individuals with disabilities. She is currently managing the Pathways to Careers demonstration project, a project focused on an employment model which ensures that youth and adults with significant disabilities have an informed choice of available, competitive and integrated employment options. She will be a featured speaker at our 2015 conference.

Employment can be an important piece of promoting independence for individuals who are impacted by dup15q. However, for many families, solving the puzzle to obtain employment for their child with dup15q, while balancing the impact to disability benefits, transportation, residential and safety concerns – let alone finding a job that is meaningful, engaging and will increase the overall quality of life - can be so overwhelming that it may not seem worth the effort to put all the pieces together.

The good news is that there are many options for meeting these challenges to obtaining employment and funding for employment planning and job supports. The better news is that – when all the pieces can be pulled together and a job that matches with skills and interests is obtained -- it is absolutely worth it!

When considering a transition (from school to work) or vocational program to assist your child achieve their employment goals, it can be helpful to look for programs using the following strategies:



Flexible, person-centered, even person-driven approaches that seek to understand and achieve employment goals by considering the individual first –and from that identify what employment would be most meaningful for them.

Job assessment strategies that look for strengths, richness and patterns of each person’s life, instead of deficits and therefore uncover “what works” for a person, rather than what the individual cannot do.

Programs that do not over-rely on prevocational training or skills development, and start the process of identifying a good job fit that will work for the individual with their current skills and interest areas, beginning job development quickly.

Customized strategies that match the skills, interests and ideal work environments as identified through a person centered planning process to a job or even a series of tasks that can be made into a job description.

Opportunities to have work experiences (such as internships) that are matched to the skills and interests of your child and provide exposure to different types of work environments and create a pathway to achieving employment.

Programs that can effectively engage behavioral and mental health supports for those who may need the additional assistance in order to obtain and maintain employment goals. For lack of a better way to say it, “normalizing” vocational and employment approaches that can be generalized or would appeal to any person, with or without a disability (i.e, using an iPhone or iPad as a prompter).

Individuals seeking employment and their families will also want to meet with a professional benefits counselor prior to starting the employment seeking process and early into employment to consider how a particular job may impact their disability benefits (SSI, SSDI, Medicare and Medicaid), residential and other benefit programs that they may be entitled to in their state.

Through the experience of working with experts in the field, families, and the employment seekers themselves, I have had the privilege of witnessing individuals achieving job opportunities that allow them to maximize their skills and abilities, add clear value to their department or team, fit in with their peers in the work environment, and be a stepping stone to a meaningful career. I am increasingly optimistic that many more individuals who are seeking jobs that lead to meaningful careers will be able to achieve their goals.

Promoting

INDEPENDENCE: FAMILY STORIES

To sleep or not to sleep

By ANNE TIPLADY, VICTORIA, AUSTRALIA

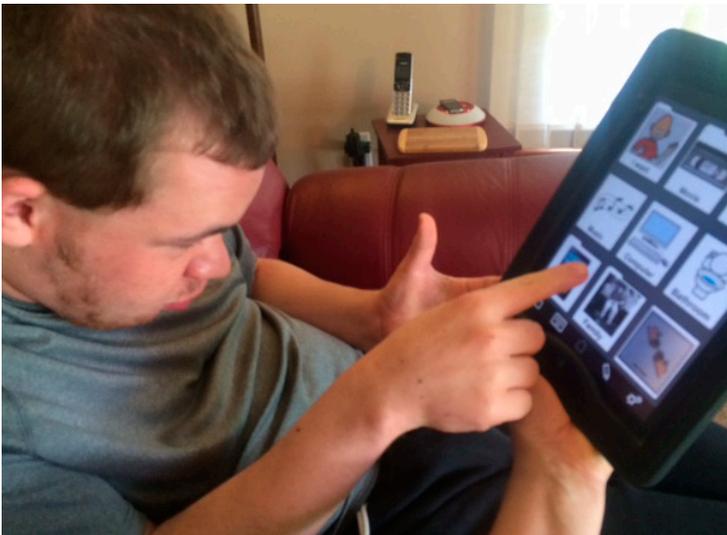
Evie was a dream baby. She slept all the time, so much so that we would have to wake her for feeds. Everything was fine with her sleep until she was 2 years old. Then, out of the blue, she stopped sleeping. She would stay awake for 20 hours at a time. We had no idea what to do. We tried lying in bed with her, changing her nappy, or giving her some warm milk. Nothing worked. She would go to sleep and then wake at midnight and be awake for the rest of the day. We took her to her doctor and he gave us a script for liquid melatonin. We started Evie out on a small dose. Evie would go to sleep but would still wake up very early in the morning. After a while it stopped working. Evie would sleep a few hours, wake at midnight, then go back to sleep at 5 am for a couple of hours. We

tried upping the dose but this made her more hyper and she wouldn't sleep. I started to research on the internet for different opinions. I found an article about a gluten-free diet working for autistic kids to calm them down. So we gave it a go. We took

Evie off the melatonin and started with the new diet. It worked like a dream. The first night she slept for 12 hours straight! We also removed sugar and preservatives from her diet. She was a new person, a lot calmer and sleeping through most nights. Now, 2 years down the track, Evie will sleep 12 hours a night 3 out of 7 nights. The other nights, if she wakes it will only be for 2 hours. Then she self-settles herself and goes back to sleep. We also found keeping her room very dark and not turning on any lights when she wakes helps, as well. Changing her diet was one of the best things we have done for Evie!

Talk to me

By ADELLE MADISON, CANFIELD, OHIO



Jesse will be 21 years old in August. He began speech therapy around age two. For years we tried to teach him to communicate using many types of communication - sign language, picture icons, battery operated switches and an \$8,000 communication output device; all without success.

Three years ago, we introduced Jesse to Proloquo2Go for the iPad. Within 8 hours, Jesse began making requests! At age 17, my son was finally "talking" to me!!! Having the ability to communicate wants and needs, and to engage in back-and-forth conversation has changed Jesse's life and the lives of those who love and care for him. Jesse is now able to independently request movies, music, food, beverage and activities. He is able to order his own food at restaurants for the first time in his life!!! He is able to tell us when he is

tired, and he is able to greet people and ask them how they are feeling. Jesse is able to give simple commands to his service dog. He is able to say, "I love you." I can't explain why, after all of the years of therapy, the breakthrough for Jesse happened.

I only know that it did. I encourage parents to keep trying to provide a mode of communication for their child. It is hard to imagine what life would be like without an ability to communicate. I am thankful that Jesse no longer has to live in silence.



I like getting paychecks

BY MICHELLE BERES, ROSENDALE, WISCONSIN

Jeremy Brenner, the owner of Generation's Lanes, has known Klara and our family for over 15 years. Our whole family participates in bowling leagues and enjoys watching Packer games at the local bowling alley. When Klara began to search for jobs in the community, it was more difficult than she had expected. Klara searched high and low for around three years. One day while we were at the bowling alley, I shared my frustration with Jeremy. He chuckled, and offered Klara a job on the spot. Jeremy said, "It didn't take three years to find a job. It took two minutes. All you had to do was ask!" Klara has been happily employed at the bowling alley since January, 2014. We have been blessed to find a business owner who supports self-determination. Jeremy believes that "every business has four hours of work a week that could benefit that business and the worker. It amazes me that more business owners aren't willing to go down that road." Jeremy appreciates what Klara has to offer the bowling alley. "We have a lot of jobs... and if she has the ambition to work, I'm going to let her work," he said. Klara's ambition to work makes her job fun and rewarding. Klara and her job coach usually go to work for a few hours a few days a week. Of all of Klara's job tasks, her favorites are organizing the bowling balls and portioning the onion petals, which is her favorite food at the bowling alley. "I like getting paychecks." Klara says. She continues to learn new things and enjoys her time on and off the clock at Generation's Lanes.

Dup15q Alliance

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Stronger Together: 2015 Conference Research Opportunities

The Alliance is busy getting ready for our 2015 conference. One of the things we are most excited about is the number of opportunities for families to get involved in dup15q syndrome research and to consult with genetic counselors. Some require pre-registration.

DUP15Q ALLIANCE INTERNATIONAL REGISTRY

We will be uploading current EEG, sleep study and genetic reports to the Registry. Please bring paper copies to the conference with you and we'll get them into your Registry account. To sign up for the Registry, visit www.dup15qregistry.org. (This is a separate registration from joining Dup15q Alliance.)

DUP15Q SYNDROME CELL LINES

Interested families can get blood draws at the conference hotel on Thursday, July 30th. Blood samples will be sent to the Genetic Cell Repository at the Coriell Institute for Medical Research. There is no cost to participate and there will be sign-ups for a time slot on the website closer to the conference.

EEG FOR UCLA STUDY ON AUTISM IN CHILDREN WITH DUP15Q SYNDROME

Dr. Jeste's lab at UCLA studies autism in children with dup15q syndrome. They are working to determine if the excessive beta activity that appears on many EEGs of people with dup15q syndrome is a clinical characteristic of this disorder. They seek to characterize cognition and behavior, measure resting state EEG, and correlate this to clinical variables in children with dup15q syndrome. Dr. Jeste hopes to increase the size of the study population by bringing their portable EEG system to the conference. Study participants will receive a cognitive assessment and EEG at the conference hotel. Participants will need to pre-register closer to the conference.

TOOTH COLLECTION KITS FOR DR. REITER'S STUDY ON DUP15Q

Tooth collection kits will be available for families who are interested in donating their child's newly lost teeth to Dr. Reiter's study. You must have the collection kit at the time the tooth falls out in order for it to reach the lab in time to harvest the cells, so bring your kit home and wait for those teeth to fall out! For more details on Dr. Reiter's study, view the study webpage.

GENETIC CONSULTATIONS

We will have genetic counselors on hand to answer specific questions about your child's diagnosis. Get accurate analysis of your child's genetic report.

FACEBASE

A group of doctors and scientists at University of California San Francisco is carrying out an international study to better characterize genetic syndromes that include craniofacial abnormalities. The aim is to develop a system to help physicians diagnose these disorders in the future. They are building a database of special three-dimensional facial photographs of people with different syndromes. The images taken at the conference will become part of the National Institute of Health's "FaceBase" database (www.facebase.org). Participation involves meeting with the study representative to discuss the study and sign consent forms. Then about 15 3-D photographs will be taken. The entire process will take about 20 minutes. Registration will be available on the website closer to the conference.

GEISINGER ADMI BALANCE AND EYE TRACKING STUDY

Researchers from ADMI will be conducting two studies. The first looks at balance and sway in individuals with dup15q syndrome. Participants will be asked to stand on a balance board for 30 seconds at a time. The second will look at eye tracking. Participants will be asked to look at pictures on a special computer that tracks where the participant is looking. More details, including registration will be posted on the Alliance website as they are available.



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Cheers to Our Volunteers!

Linda Meagher, Houston, Texas

The Dup15q Alliance is led by volunteer board of directors, made up of parents and family members of a child with dup15q syndrome. Some of our board members have served for many years and are moving on to different ventures. As a result, we will have new openings for our board in the fall. We want to acknowledge the generosity of time and energy of our board, and to invite families to take a look at what board service looks like.



Wow – I can't tell you how honored I am to be volunteer of the quarter!

WHAT INTERESTED YOU IN JOINING THE BOARD?

My interest in giving back to this organization started at the very first conference, before there even was a formal "Alliance" entity! We had just gotten Jessica's diagnosis and heard about the upcoming conference. Meeting other families, hearing their stories, seeing other children just like our daughter, and feeling like we finally belonged to a group that understood what we were going through - I knew then without a doubt that I would be involved in this organization in some way in the future. When our girls were older and life was not so hectic, I started volunteering on the conference committee. Working on a committee was a great stepping stone to board service as it gave me a glimpse of some of the details involved in running the organization.

WHAT PROJECTS DID YOU WORK ON?

While serving on the Board, I continue to help on the Conference Committee – one of my jobs is name tags and the secret behind that is it's a great way to learn the names of everyone's family members and where they are from! One of my other favorite things to do as a Conference Committee member is to greet everyone at conference – you will typically see me hanging out at registration as I find it so much fun to not only reunite with old friends but to also greet new families and make them feel welcome. I also serve on the governance committee, I assist on public relations and I helped out on the website committee. I have assisted with the Alliance's annual reports and probably my biggest accomplishment was putting the Alliance's First 100 Days manual together. I serve as the Texas contact for new families and last year I became Chair of the Sunshine Committee – which committee would not be possible without the help of 51 awesome volunteers (you all know who you are!) that help spread cheer to our families by sending birthday cards out to all our dup15q kids and adults.

HOW DID BOARD SERVICE IMPACT YOUR FAMILY?

My family is awesome – my hubby Mike, my super sweetie pie Jessica, almost 17, and our youngest, Madison, now 15 – they are my rock and I think without a doubt that they have all been very proud of me for helping out!

WHAT EXCITES YOU ABOUT THE DUP15Q ALLIANCE, NOW AND LOOKING INTO THE FUTURE?

Looking back to that first conference, I can't help but reflect how unbelievably far the Alliance has come! The area that I'm most excited about currently is the progress in the research and medical arenas. It is downright thrilling to see the growth in the number of professionals attending the annual scientific meetings – their collaborative efforts will benefit our children in the future. The number of new clinics that have opened and the database they are working on to share information is beyond amazing and so exciting to watch it all unfold. The Alliance's medical registry is critical to continue to foster interest in our kids by researchers.

Looking into the future, I think that as genetic testing becomes more advanced in other parts of the world, our membership will skyrocket and it will be important that our international groups continue to grow so that they can support the new families worldwide.

I feel so fortunate to have been a small cog in the bigger wheel of the Alliance over these past many years. Serving as a volunteer for this organization has truly been one of the best experiences I could ever have in my life, and certainly one that I will never forget! One of the most important life lessons I've learned through volunteering is that it truly "takes a village" to have a successful organization. The Alliance would not be what it is without the efforts of so many of you! Love and hugs, Linda

Reflections from Siblings

Katy has brought so much joy to my life

BY LAUREN AND GRETA JO BUSSIAN

Lauren:

As a senior in high school, I often reflect on the person I am today because of the blessing of my sister, Katy. Being so close in age (I am 18 years old and Katy is 17) has allowed us to form an incredible bond between us over the course of our lives. When I wrote for the “sibling corner” last, I was a solid 11 years old, and with my description I included a quirky song about her. While over the years I have matured and now laugh at the song that I was convinced would be the next great hit, the general idea and purpose remains the same. I love Katy with my whole heart. Every day she brings me so much joy, just by seeing her innocent smile. Having a sister like Katy has always played a huge role in my life and the direction I head. In choosing my career, I have the desire to help individuals with special needs, in order to make a positive difference - like so many nurses and doctors have for Katy. For as long as I can remember, I have had the desire to make a difference. It is like a burning fire that cannot be put out. I find it inspiring to think about my future. To think that it is indeed possible to feed this fire. I feel incredibly fortunate to have grown up with a sister like Katy, and through this experience to have my values and dreams. I am ready for the future and I am ready to make a difference. While there are ups and downs with having a sister with special needs, the ups definitely outweigh the downs. I believe that life is what you make of it. We all have our strengths and weaknesses. We all have our differences. These two facts are what make us human, and I am very grateful to have come to realize this through being a sister to the beautiful Katy Bussian.



Greta Jo:

Some call it a challenge, I call it an honor. Last time I wrote for the “Reflection from the Siblings” I was 6 years old. I am now 13. Since then, I have gained a greater understanding of my sister Katy Bussian’s challenges, as well as the delights. Katy is now 17 years old, and boy, have a lot of things happened in the last few months. For example, getting crowned honorary princess by her sophomore classmates for Snow Week. Her classmates, who have known her since she was a little girl, decided no matter who got crowned, Katy would be the honorary princess. The local TV station and newspapers shared the amazing experience. Everyone in our community celebrated with us! What her classmates shared with her brought joy to us as well as them.

Along with that amazing surprise, we hosted our first walk in honor of Katy to raise money for the Dup15q Alliance. We had a great turnout of 225 people and raised over \$8,200 at our Little Miss Sunshine Walk. We also had six other dup15q families at the walk.

Having a sister with special needs brings many challenges and also joys. Sometimes it’s hard, because we are not able to do certain things because Katy doesn’t have a Personal Care Assistant or we cannot go places because it is too difficult for Katy or she doesn’t travel well. Another big obstacle is the fact that she can’t communicate the way we would like her to. For example when she is angry, she can’t tell us what hurts or what we can do to help.

Yet, there are many positives too. You can see life through a different perspective. You are more accepting of those who are different. Katy has brought so much joy to my life. She can make something as simple as going to the grocery store seem like going on vacation. I will always cherish Katy and my moments of laughter, singing, and just being together! And I would never trade any of those moments for the world.

Reflections *from a Grandparent*

What got me was the first time she said Nana

BY SHERRILL BEAUDOIN, AURORA, COLORADO

I am Lilly Rash's grandmother, or as all my grandchildren call me, Nana. I am a grandmother to seven beautiful children with one more on the way in just a few weeks. They range in age from 16 years to 11 months. Five girls and two boys!! I have been active in the lives of all my grandchildren. I have been a Nana, caretaker, and friend to them all.

I remember the day Lilly was born. It was a crisp fall day with the sun shining. What a beautiful baby she was. After her mom went back to work when maternity leave was over, I took care of Lilly in my home. She was a joy. She did have what we called "Lilly-sodes" where she cried and cried and nothing could console her. After many months and lots and lots of testing she was finally diagnosed with dup15q.

Now it was time to find the right people to help Lilly. Since she spent most of the weekdays with me, much of her therapy was done at my house, including speech, physical and occupational therapy. All three therapists were such beautiful women and Lilly's wellbeing was their number one priority.



Lilly's progress seemed slow at first with bursts of improvement. I can remember thinking that she would never walk. Then, just after her second birthday, she surprised us and was walking!! I can just picture her mother crying with joy.

Lilly's occupational therapy was a bit challenging. She is what they call a stuffer at meal times. After learning how to feed her and also learning strategies to improve her independence we all got of the same page. Lilly seemed to be a much happier young toddler. She especially loved her older sisters who doted on her every move.

As with other children with dup15q, speech is a hard developmental area. Lilly knew how to sign a few words but that was the extent of her communication. She has expressed herself in so many other ways, it is incredible. She is now six and a half years old and is talking up a storm. What got me was the first time she said Nana. I melted.

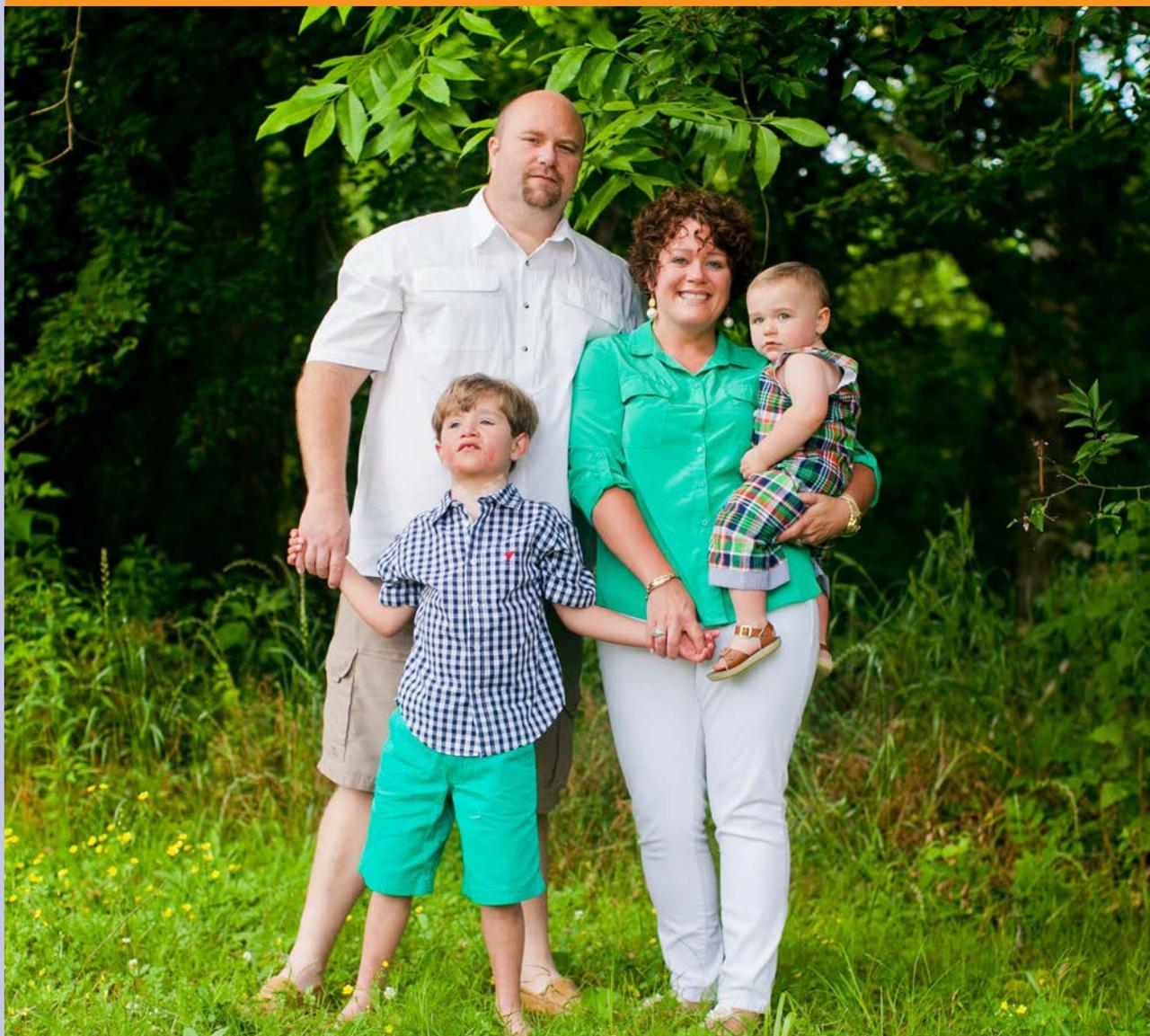
Lilly's older sisters are equestrians, horseback riders. Lexi is 16 and Emily is 8. They have always wanted to share their love of horses with Lilly. We own 3 horses and when Lilly was just under 3 years old her PT offered to meet us at the barn and put Lilly on a horse. It was a beautiful day. When Lilly got up on that horse her posture was remarkable. She sat up tall and smiled the biggest smile you could imagine. I felt too blessed that I could do something for Lilly that was going to help her. To this day Lilly loves those horses and rides with her sisters as much as possible. It is so good for her core, and she is always so happy in a saddle.

I don't take care of Lilly on a regular basis anymore because she is in school 5 days a week now. However, I still get to see her all the time. She is our "Little China Doll". Most importantly, we all try our best to treat her just like one of the grandkids. That makes her very happy. I hope to be a part of her life always and to help her in any way I can.

A Very Special Boy

BY ALICON K. JOHNSON, JACKSON, MISSISSIPPI

Family Portrait



Tanner was born July 13, 2006 after what was a wonderful pregnancy without any complications. Shortly after his birth, we were informed that Tanner was struggling with oxygenation while in the transition nursery. This led the team to perform an echocardiogram of his heart revealing Tricuspid Atresia, which is a significant cyanotic congenital heart defect (CHD). Ultimately, the right ventricle of his heart was underdeveloped, and he would have to undergo multiple operations to bypass this side of his heart. His heart would NEVER be normal. You can imagine the devastation! He was transferred immediately to our state's leading academic NICU where he would await the first of three heart surgeries. He underwent his first heart surgery at six days of life, his second at four months of age, and his third at 33 months of age. Given this timeline, we spent a majority of his first few months of life in a hospital. Fast forward to today, Tanner is now 8 ½ years old and doing exceptionally well from a heart health standpoint. What we know about children born with this type of CHD is that these children may not have a normal life expectancy, there may be future operations including pacemaker placement or even transplantation.

From the beginning, Tanner was always “behind” developmentally, but goodness, who wouldn’t be? We were told repeatedly by many physicians that this was to be expected given the length of his hospitalizations at such a young age. My husband and I expected primarily physical delays; however, Tanner actually progressed in this area. It was finally at his 2 year check-up that we insisted on “digging” further. Tanner wasn’t talking. There was no way that I could relate him being non-verbal with a heart condition requiring multiple surgeries. So, we were referred to genetics and labs were sent. As my husband and I sat in a waiting room while Tanner underwent his third heart operation, the geneticist called to give me the news of his Inverted Dup of Chromosome 15 diagnosis. Bad timing to say the least! He knew very little about this diagnosis but quickly began sending me articles to read. I, as well, did my own research.

Today Tanner is still non-verbal and is very dependent on us for most everything. He is on the autism spectrum, with social anxieties and sensory processing disorders. Tanner is very sweet and loving and can be affectionate with family and those he is comfortable with. Tanner’s world was turned upside down when we had another child, Sawyer, who is now 2 ½ years old and is healthy. With each day, the relationship is building, and I hope one day they become best buds. Tanner thrives in environments where there is routine that he is familiar with. Although he may not be able to communicate verbally with us, we truly know that Tanner understands a lot of what we tell him given his response or actions. We currently work with a communication board, although progress has been slow. Tanner mostly guides us by hand to show us his needs/wants. We are fortunate that Tanner has not experienced the seizures associated with this chromosome abnormality.

We recently spent a week at the LeBonheur Children’s Hospital Dup15q clinic in Memphis in hopes of gaining more knowledge about IDIC 15. It was a wonderful experience, to say the least. The physicians there spent a great deal of time gaining information from us as well as helping us better understand Tanner’s “uniqueness”. The team consisted of those specialized in neurology, genetics and neurodevelopment. Tanner underwent a sleep study, an EEG, and multiple evaluations. What we took away from this visit was that Tanner may actually also have another “mosaic” diagnosis that has yet to be identified. Given some of Tanner’s other congenital anomalies (cyanotic CHD, single kidney, skin hypopigmentation) that are not normally seen with dup15q, the team suggested we have further genetic testing done. We are in the process of completing this testing, and we hope that this will help to shed some light on how we can help Tanner reach his maximum potential.

Tanner was recently granted a wish through the Make-A-Wish foundation! We were so thrilled, humbled, and at a total loss on what to “wish” for Tanner. After much prayer and thought “outside the box”, we requested a trained service dog for him! We are excited to report that this process is ongoing, and we hope to unite Tanner with his new friend soon. Stay tuned.....



THE ALLIANCE INTRODUCES A FUN FUNDRAISER!!



In keeping with this year’s conference theme – Stronger Together – we are showing just how strong we are by assembling a chain with words of hope from all of our generous supporters. Our Links of Love chain will be on display in Orlando during the conference, and we will post photos on our website.

Make a donation to Dup15q Alliance before the conference begins and add a Link of Love to our chain. Return your paper link (coming to your mailbox soon) or fill out a virtual link (www.dup15q.org/links-of-love) with your name, the name of your favorite person with dup15q syndrome, or your well wishes.

Links of Love is a great local fundraiser. Contact us at info@dup15q.org and we will send you a supply of links. Collect donations in your school, workplace, civic group or neighborhood. Return the completed links and donations before the conference and we will add them to the chain. All donations - big and small - will be recognized!

Dup15q Alliance is a nonprofit organization that provides family support and promotes awareness, research and targeted treatments for chromosome15q11.2-13.1 duplication syndrome (dup15q).

Dup15q Alliance offers help and hope for those with dup15q syndrome.

UPCOMING MEETINGS AND ANNOUNCEMENTS



8th International Family Conference : STRONGER TOGETHER

July 30 - August 1, 2015

Hilton Orlando Lake Buena Vista, Orlando, FL

Everything you need to know about making reservations is available at <http://www.dup15q.org/events/family-conferences/stronger-together-2015/>

First Annual Dup15q Alliance Believe Walk

September 13, 2015

The Alliance currently has six confirmed sites around the country. We'd love to add a few more. Please contact info@dup15q.org if interested in helping. We will help with the planning. You supply the local knowledge. Be a part of the inaugural Dup15q Alliance walk. Together we can make a difference. www.dup15q.org/believe-walk

Regional Gatherings

Planning a regional gathering for some of your local dup15q families? Let us know so we can help spread the word!

<http://www.dup15q.org>

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