

THE MIRROR



The Newsletter of 

The Dads OF DUP15q

BY NICOLE CLEARY
EDITOR

In honor of Father's Day, this issue of *The MIRROR* shines a light on the dads of dup15q. As Paul Rivard says in his article *The ACE in Her Life*, "We typically are not the half of the parental unit that stands up to speak. Traditionally, the guy is the one in the background." We are choosing to break with that tradition and bring the dads onto center stage.

In this issue you will hear the voices of fathers and grandfathers honestly sharing their experience, ranging from a dad acknowledging "I didn't know what to do to help. I felt completely lost.", to a father who shares "I found in my daughter a child who finds joy and life purpose in shared giggles and a hug.", to a grandfather who celebrates "we marvel at the progress he has made over the past 12 years". While there is no doubt that our dads experience the stress, challenge, and worry that comes with raising a child with dup15q, what shines through these articles is the resilience of dads who have found a way to balance those feelings with hope and happiness.

Keep talking, dads! It is your willingness to share your experience that makes it possible for dads of newly diagnosed children to find their way to the place of hope and joy in your child with dup15q that is so well articulated in this issue. These conversations are powerful. We hope that by highlighting your voices in this issue of *The MIRROR*, you will be inspired and feel supported in having more of these conversations with each other and with the world.

Dup15q Alliance sincerely wishes a Happy Father's Day to the dads of dup15q.

INSIDE THIS ISSUE

- 2 THE ACE IN HER LIFE
- 4 FATHER'S VOICES
- 6 CLINIC/REGISTRY UPDATE
- 7 NEW WEBSITE

In Every Issue

- FAMILY PORTRAIT 8
- VOLUNTEER OF THE QUARTER 9
- REFLECTIONS FROM SIBLINGS 10
- REFLECTIONS FROM A GRANDFATHER 11

Chromosome 15q duplication syndrome (dup15q) is a clinically identifiable syndrome which results from duplications of chromosome 15q11-13. 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.

The ACE in Her Life

BY PAUL RIVARD

June..... Summer begins, the weather gets warmer (unless you live in New England) and we have a day to recognize the male portion of the parental team that raises a child. It's a great month in my eyes. As a dad, I get that one special day that is always nice to look forward to. Father's Day is a day of sleeping late, going out on the pond to do some relaxing fishing, and then out for a meal with my family. It all just sounds so perfect.

However, that is only one day within the calendar year. The same is not exactly true for the other 364 days. The balance of those days are spent being a part of a family unit. That could translate into being the bread winner or maybe the care provider for the kids, or a combination of both. Either way, life happens for the rest of the year. This is true for all dads, regardless of any challenges your child might have.

We typically are not the half of the parental unit that stands up to speak. Traditionally, the guy is the one in the background. In this case, just to make things more interesting, some of us dads have had a curve ball thrown at us. It is one thing to be a dad and raise your children, but there are a set of different challenges that come with being a dad of a child with special needs like dup15q. Even with that statement, there are so many levels of care and effort that are associated with that world. If our life was a game of cards, we might feel that we have been dealt a bad hand. So, how does one respond?

As a dad of a child with dup15q, I feel the need to level the playing field for my daughter and be the **A.C.E.** in her life. The A.C.E. is simply this: Advocate, Communicate, and Educate for everything that involves my child.



ADVOCATE: You are the voice for you child, whether you are out in public and someone stares or questions your child and their behavior, or you are at an IEP meeting at the school. You know what is right for your child and should do everything in your power to gain that for them. They are completely dependent on you and need you to be there for them. Don't be afraid to speak up for your child. They may not be speaking it in words or letting you know, but they look to you and depend on you.

COMMUNICATE: One of the most important parts of the equation. Appropriately placed in the middle of this acronym it maintains the balance between advocating and educating. Like any other relationship, communication is key when it comes to the livelihood of your child. Dads need to be involved in communicating with their child's doctor, care providers, therapists, teachers, and all that are involved. Unfortunately, we are not able to be with our children 24/7, so as experts on our child we have a very important responsibility to communicate to help all others involved in their daily life.

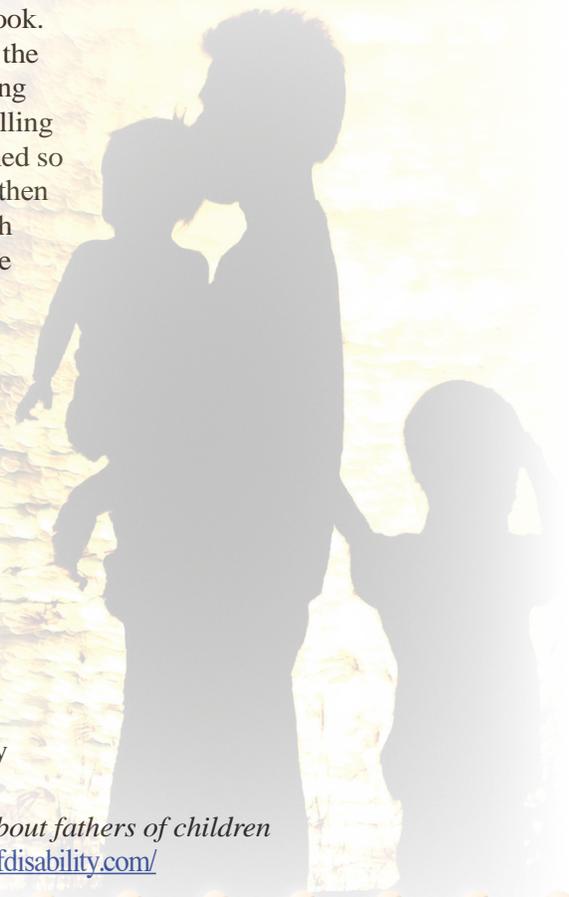
EDUCATE: As society will tell us, education is an important part of our development as a person. Same holds true when you have child with dup15q. Educating the public can go a long way. Remember you are the expert for your child. Sharing what you know with doctors will help them better understand and be able to help. Educating family members is also an element that can provide a smoother way of life for you and your child. Just because you are related by blood, doesn't mean they "get it". There have been many times when although family members mean well, they just don't understand. Continuing to educate these important people that are in your child's life will prove invaluable in the long term.

So, to the new dads or maybe some dads that have been around for a while but have not found peace with the situation at hand, have you really been dealt a "bad hand"? Maybe. Or maybe not. As the ACE in your child's life, you can definitely make this a winning hand. So much can be learned and so much personal growth can happen as a result of one child that enters your life in a not so typical fashion. I know this has been true for me.

Recently I was approached by a friend that we had met at a Family Conference for children with special needs. We met several years back when our children were young and we have touched base from time to time. A few months back, Gary approached me with a request. He was embarking on a mission to write a book. He felt like there was very little support and recognition for the male side of the equation when it came to raising a child with special needs. He was collecting essays/poems from dads that had a child with special needs. I am always willing to help, especially when something ties in directly with my daughter. I learned so much even during the writing process. I presented my first draft which was then followed by edits and request for additional information or elaboration. Each time it opened my eyes to more and more. It was a great experience, and one that would end up with a book titled "Dads of Disability". I was excited to contribute, but had no idea that the final result would be so powerful. The stories that were shared by dads throughout the book were truly inspiring. I am not a reader of books by any stretch, but I read this book of 200+ pages and enjoyed each page. So many emotions and memories were stirred as I read the book about dads that were truly the ACE in their child's hand of life. I was just proud to have my name within the same pages of that book.

In closing, it's very simple. Cherish the goodness of the situation. Your child needs you and loves you unconditionally. In Megan's case, she likes to give me kisses on the cheek and walk up to me and say "big hug" as she wraps one arm around my neck and smiles. It's the little things that you have to take in and absorb. They are all so innocent. They are jewels of goodness in our society. Be that ACE in their life, and Happy Father's Day to all.

You can learn more about the book Dads of Disability: Stories for, by, and about fathers of children who experience disability (and the women who love them) at <http://blog.dadsofdisability.com/>



SEATTLE RACE, MAY 4, 2014

On Sunday, May 4th the Lowell family hosted a successful fundraiser for Dup15q Alliance! Colleen Lowell reports, "We had over 200 people attend and a lot more just donate for a total that I believe is hovering around \$12,000. And it actually wasn't that hard to put on!" Thanks to the Pacific Northwest families and friends who braved the rainy day to support the Dup15q Alliance, and thank you Colleen and Jeff!



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Be prepared for everything to go slow...

As a dad of a child with dup15q, the best advice I can give you is have patience! Have patience with friends, family, other children, and your spouse. Until you live the life of a dup15q dad, you cannot comprehend it. Be prepared for everything to go slow, the treatments, your child reaching their milestones, etc. It's almost like living life in slow motion at times. So my best advice is be patient and just live day to day. Don't worry about tomorrow, next week or next year. Enjoy today then tackle tomorrow when it gets here. It's worked for me for 8 years now!!

RICHIE BOPP, PEMBROKE, MA



Father's Voices

In honor of Father's Day, we asked four fathers raising a child with dup15q to share their reflections on their journey of dup15q fatherhood.

Look deeply at how your child engages the world with their own unique approach.

In my opinion, the thing that a father should most want for their child is for them to be happy and at peace with the world. All the other things that we might aspire for our children: a good job, friends, a solid education, are a means to that end. Kids who have dup15q may not take the normal societally defined path to happiness, but that that doesn't mean they can't achieve this goal. I would encourage fathers raising a child with dup15q to let go of their own preconceptions of how happiness is achieved, and look deeply at how their child engages the world with their own unique approach. Once you see it, support what that approach requires to achieve happiness. I envisioned in my youth a child that would find joy in learning science and math, but I had to let that go. I found in my daughter a child who finds joy and life purpose in shared giggles and a hug. I think I can adapt to that.

TIM CLEARY, PORTLAND, OR

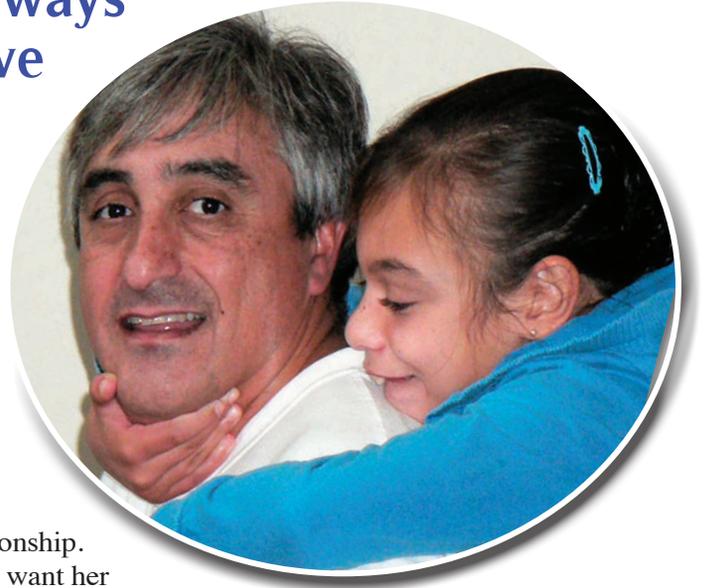


How do we keep looking for ways to enjoy the moments we have together?

How would I describe my relationship with my daughter Allison? She reminds me every day that we enjoy each other's company because we understand what each of us needs to find purpose and meaning. For example, as I am writing these lines, Allison keeps bringing me shoes from her bedroom because her idea of a perfect Sunday morning with Dad is to be riding her trike and not necessarily watching Dad getting caught up with work. Allison has a unique way of getting what she wants –like a ride around the block- by getting me what I really need – fresh air. She did not read Dale Carnegie's *How to Win Friends and Influence People*, but she gets it! Over the years, Allison has continuously challenged my previous ideals of a father-child relationship.

What started out as "how can I help this child become the person I want her to be", became a slow but steady transformation into "how do we keep looking out for ways to enjoy the moments that we have together". As Allison develops into a teenager with moody swings, we will surely skip the nights out with her boyfriend or the Senior trip to the Bahamas, or Freshman year in college. However we will find opportunities to enjoy each other's company doing things that we both like to do - swimming in the summer and biking in the spring and fall. Despite the formidable biological challenges she faces in life, Allison gets her way more often than the rest of us because she knows her way around our minds and hearts. Rain or shine.

FERNANDO GOMEZ, ROBBINSVILLE, NJ



It's okay to struggle sometimes...everybody will.

When we got Anna's diagnosis, our doctor told us that over seventy percent of marriages fail within the first year after finding out they have a child with special needs. I have thought about that statement a lot over the years, and I can remember the doctor standing in the hallway telling Heather and me this....and

I took it to heart. I'm sure that I'm not unlike most dads in that I'm not the primary caregiver at home, my wife is. When I get home, I try to help her out as much as I can. I help with dishes, give Anna a bath when needed, or it might be that I just come home and take everyone out to dinner if it has been a rough day at home for Heather. Raising a child with dup15q is challenging. The daily stresses of our lives can make it very difficult to stay connected as husband and wife.

It is also difficult to stay connected to your typical children. Knowing this, Heather and I try to recognize when the other is struggling, and give each other a break or support. We try to go out on a date night at least once a month. We also regularly make time for each of our typical kids individually. It's okay to struggle sometimes...everybody will. It's important, though, to be involved as a team raising your child with dup 15q.

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RON BRUCE, FAIRLAND, IN



DUP 15Q ALLIANCE CLINICS AND REGISTRY: TWO DATABASES, ONE GOAL

BY JANE KIM AND RYLIE MCHAM, DUP15Q ALLIANCE BOARD

Dup15q Clinics Database

We are currently in the process of developing a database so that our nine dup15q clinics can store and share information with each other. Our goal is to standardize care across the dup15q clinics and create a single database where information from each clinic could be uploaded and then aggregated.

Each time we have a child with dup15q come through one of our clinics, information will be gathered regarding development, seizures, behavior/autism, sleep, GI issues, etc. Standardized forms have been agreed upon so that all the clinics are gathering similar types of information. The data will then be de-identified and entered into our main database. The data management will be centered at the University of Tennessee Health Sciences Center. Dr. Larry Reiter, who is part of our Professional Advisory Board, is helping to drive the creation of this database.

We are working to finalize the format of the database, and we hope to go live with the database in the next few months. It is a 2 year project to get the database fully completed. The budget for creating this database is approximately \$40,000 per year for the next 2 years, with some additional funds needed to help with data entry.

The information we find from this project will help us better describe the effects of dup15q syndrome and determine which treatments are most effective. It is hoped that the data we collect will eventually be published in a medical journal so we can help spread awareness of dup15q syndrome in the medical community. Once the database is set up, we hope to continue to gain information from it for many years to come. Look for updates in *The MIRROR* later this year with our progress!

The Dup15q Alliance International Registry

is our patient driven registry, which allows for families to contribute important information about individuals affected by dup15q that can be made available to researchers and families. The information is de-identified so that every individual's privacy is protected. The dup15q clinic database (introduced above) is different from the current Dup15q Alliance international registry, and we want families to know that the current international registry will continue!

We feel that both the current international registry and the new clinic database are important tools for potentially improving the lives of those affected by dup15q syndrome.

The international registry contains a comprehensive questionnaire with about 100 questions covering topics such as development, seizures, behavior, sleep and general health of individuals with dup15q syndrome. The questionnaire was designed to provide meaningful clinical data to potential researchers. Our extensive registry provides researchers and scientists with accurate and firsthand information as they strive to develop a better understanding of this complex syndrome.

The international registry's website includes various features that participants have found to be a valuable resource. When individuals, family members or legal guardians complete the registry, they too can access information. Participants are able to view summary responses from all participants as well as see how their individual responses compare to others. The registry can be accessed at www.dup15qregistry.org

Our goal for the international registry is to increase our participant numbers and then to publish the data. Currently the Dup15q Alliance has about 900 members while the international registry has 393 total participants. Of the 393 total participants, 198 have completed their accounts. We can do better! Each addition of an individual's information makes the registry a more viable tool for understanding of dup15q syndrome. Please go to dup15qregistry.org. Create an account and/or complete your account. If you have a completed account, consider whether there are any important updates that need to be added. Play a part in helping scientists, doctors and families gain a better understanding of dup15q syndrome!

NEW WEBSITE

By KIM MARING,
 DUP15Q ALLIANCE

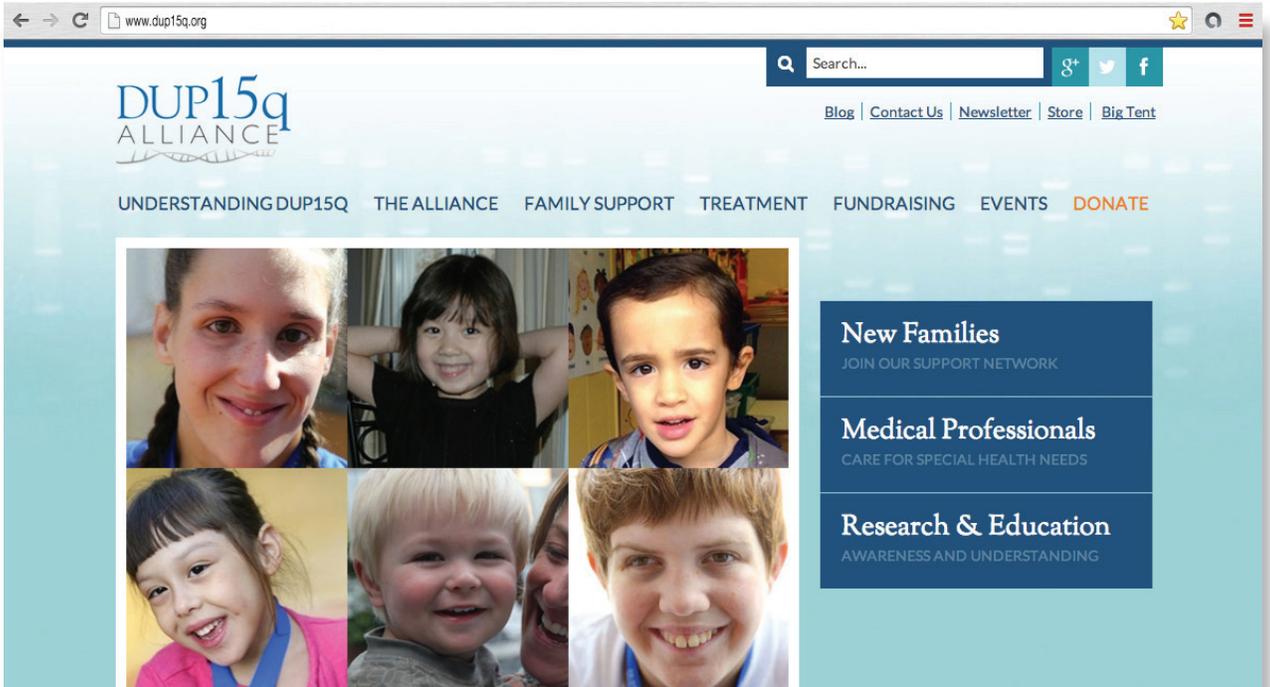
Our new website is here!

For several months we've been working behind the scenes to overhaul www.dup15q.org, and all the hard work has paid off. GlobalCloud, a web hosting and design company in Ohio, created a user-friendly, modern design for our new site. We have added many features, as well as edited and rearranged much of the content from the old site.

Our website is used by dup15q families, researchers, clinicians, educators, therapists, donors and the general public. Each of these groups looks at the site in a different way and needs to be able to find a wide array of information. That presented us with quite a challenge. The new site contains over 200 pages to meet the needs of our multiple audiences.

The best way for you to learn about the new site is to try it out. The first thing you will notice are all the pictures. Those are your beautiful children up there! It was important to us that we showcase the many faces of dup15q. We also now have the ability to imbed videos right in the site. This will make viewing presentations from conferences and science meetings easier for you and allow you to hear from other dup15q families.

There is a search feature which will help you to sort through all those pages much easier than before. We have even added tags to our past Mirrors, so historical information is at your fingertips. The calendar feature got a facelift, too. With the addition of super dropdown



menus, more information is viewable from the homepage and organized in a way that each group of users to the site can find relevant information quickly. We also hope that the genetics information does a better job of explaining the increasingly complicated world of chromosome 15q duplications.

We invite you to use the site and to check back often. We will continue to add content and features as we find a need. Part of keeping the new site up-to-date falls on your shoulders, too. If you know of an event or would like us to create a fundraising page for you, please let us know at info@dup15q.org. We can make a page just for your event or online fundraiser and take donations via credit card. It's never been easier to raise money for Dup15q Alliance. Tell your friends and family about the new website, too. The more people who visit, the more we increase awareness of dup15q syndrome.

Thank you to all of you who have shared your stories, your love of Dup15q Alliance, and the photos of your special kids. Our families are what make Dup15q Alliance thrive! As always, we'd love to hear from you. Let us know what you think about the new website at info@dup15q.org.

A DAD'S ENCOURAGEMENTS

Family Portrait

My name is Richie Baker. I live in Hamilton, Ohio with my wife, Jill, our 19-year-old son, Jared, and our 7-year-old daughter, Riley (dup15q). Jill and I met on a blind date when she was 17 and I was 19. We dated for 6 years before we got married. We got pregnant with our son on our honeymoon and started trying for a second child 4 years later. She was born 8 years after that. I remember finding out we were pregnant. We had literally given up and all of a sudden, she was there. Jill's pregnancy was amazingly easy and Riley was born in December, 2006. Because this pregnancy was so unexpected and so long awaited, we had a ton of people in the room waiting on us after she was born. It was a perfect day. Jared was the first to hold her and I'll never forget his smile. She was perfect and our family was finally complete.

Riley settled into a routine and life picked up right where it had left off. I didn't see anything different, but Jill did. I remember when she started becoming concerned about the things she didn't see Riley doing. I have to be honest; I thought she was overreacting and I didn't jump on the bandwagon. By the time Riley was 3 months old, she had been seen by a Pediatric Ophthalmologist and was wearing glasses.

She was signed up for early intervention and home visits started. She had her first seizure when she was 5 ½ months old and was diagnosed with Infantile Spasms. We spent a week in the hospital that time. The ACTH treatment and Keppra started. Life seemed to be speeding out of control. Riley received the diagnosis of idic(15) at 6-months -old. We found Dup15q Alliance within that same month.

I didn't know what to do to help. I felt completely lost. Jill wouldn't let me help much with the hospitalizations, therapy appointments, testing, etc. I didn't really understand then why, but I do now. Three long years later, Jill finally started sharing the

'guilt' she felt for everything Riley had had to go through in her life. Jill said that she felt like she was the one pushing to have another child, she was the one who had fertility issues, she was the one whose chromosome had duplicated, etc. You name it, Jill felt it, but didn't tell me. And, I didn't ask. I spent my time telling everyone who asked that Riley was doing well, bragging about what she was learning, and how beautiful she was. I hadn't fully accepted her diagnoses, the potential impacts on her, and therefore, I appeared to be ignoring them.

Jill and I struggled as a couple those three years. Looking back, it's a miracle that we stayed together. Jared and Dup15q Alliance kept us going. Jill and I finally realized that each of us had been grieving the loss of a 'typical' daughter in our own way. We had to learn to accept those differences and figure out a way to get on the same page for the future. During those three years, our son, family and friends had

also grieved. We had to accept that too. Riley, so small and innocent, had changed a lot of lives in those first three years. I am not telling this part of our story to scare anyone. It's actually meant to encourage you.

Today, we camp every weekend April through October. Riley absolutely loves the golf cart rides. She likes to ride horses and dance. She loves basketball and looking at her picture books. We love to wrestle. Barney is her best friend! She attends school full days in a classroom with 7 other students with needs similar to hers and she loves it. Over the summer, she brings you her backpack to see if you will take her to school. We

attend a monthly playgroup with children and families with rare diseases and have met some of the best people there. We continue to be involved with Dup15q Alliance activities and truly wouldn't be here today without all of the people we have met through our group.

Jared and his long time girlfriend, Taylor, love to fish and race cars. They are both working hard at their jobs. Our parents continue to spend every possible moment with Riley and they are all thriving because of it. Riley is a beautiful, healthy, little girl who loves life. She brings so many smiles to people every day. She has taught us the importance of talking, sharing and loving. I honestly can say that I wouldn't change one thing about the last 7 years and I am looking forward to being her daddy for the rest of my life!



Cheers to Our Volunteers!



Sarah and Chad Torrance

We BELIEVE in the efforts to find a cure, we BELIEVE in a cure, we BELIEVE in our children, we BELIEVE in ourselves, and we BELIEVE in each other.

Chad is my special reason to believe. Ever since the age of 18 months when we were told Chad had what is called dup15q, we wanted every bit of information our brains could take in so we can better understand and help our son to live the best he can until

there is a cure. We thank Dup15q Alliance for the abundance of information we get from their website, conferences, and sharing stories and friendships made on Facebook.

Through research, trial, and there's always room for error, we have learned and tried new experiences to help Chad's development at his own pace. We always search for hands on projects which seem to excite a desire to learn. Which brings us to how Chad and I started our home based business, Scentsational Soaps, and our BELIEVE soap bars. It began as a hands-on activity. He and I found something fun we did together, he was learning about measuring, mixing, cause and effect.

We now found a way to give back to Dup15q Alliance! For every BELIEVE soap bar sold, we donate \$1 to Dup15q Alliance. We have been doing this since 2009, and almost every month we are able to send donations we raised for selling our BELIEVE soap bars.

Besides making soap, we spend a lot of quality time together as a family. Our two older children and grandsons and my large family contribute to the happiness of my beautiful loving son Chad. He is now 20 years old. We never stop Believing. I am working with Chad's independent support coordinator to open more doors for him as a young adult. I believe he can and will succeed at his own pace. We believe in you and your children too!

Chad and I are honored to be Volunteers of the Quarter and will continue to support Dup15q Alliance. What a privilege to be part of a wonderful, caring, knowledgeable and loving group of people.

Stay Scentsational!

believe soap bars: [http://](http://scentsationalsoapsskincare.com/shop/believe-soap-bar)

scentsationalsoapsskincare.com/shop/believe-soap-bar

facebook: <https://www.facebook.com/pages/Scentsational-Soaps-LLC/124996700865383>



Dup15q Alliance

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Reflections *from Siblings* *A Huge Impact on My Life*

BY DYLAN RITTER

Isodicentric 15. Partial tetrasomy 15q. Inverted duplication 15. For pretty much everyone in the world, these words are just some fancy medical lingo. For my family and me, these words can change a life.

When I was three, my youngest brother, Travis, was born. He was soon diagnosed with isodicentric chromosome 15 and eventually autism. I then had no idea of the enormity of this situation. Over time, I grew more interested in the condition, attending various conferences. I learned that throughout their lives these individuals suffer from delayed development of motor and verbal skills, as well as possibly violent seizures. Realizing this would be part of my life forever, I wanted to learn as much as I could.

After fourteen years, one day our biggest fear became a reality. Prior to getting into the shower one cold January morning, I heard my mother frantically screaming for help downstairs. Travis was convulsing on the floor. Some head nodding over the prior weeks had developed into a full-blown seizure. I wanted to wake up and know that my brother wasn't actually having a seizure, that I just had a bad dream. In my half-asleep and panicked stupor, I called 9-1-1. I remember the scariest part about it. While I was on the phone, his lips slowly turned a purplish-blue hue. My mother rolled him over, hoping to open up the airway. It worked. Minutes later, the paramedics arrived to check him out, stating he would be okay. Since then, I always carry a picture of him in my wallet so no matter how much distance separates us, he will be beside me.

Along with my parents and other brother, Austin, I created a charity called Tend to a Friend. Its goal is to bridge the gap between children with special needs and children without special needs. Our motto is "Kids Helping Kids". Throughout the year, we hold monthly Kids' Night Out (KNO) events, partnering with the ARC of Somerset. We gather in a playroom in our high school, and play and have fun with these children with special needs and their siblings. Typical high school teenagers play with young children, developing a bond and a sense of admiration. The parents of these young children are able to have a night off. For many of these parents, one night per year is all they get. We offer them the chance to get a night out for a movie or nice dinner once every month.

This year as a freshman at the University of Mississippi, I have stayed connected to my roots. After meetings with the dean of the Honors College, we have both agreed that establishing a Tend to a Friend chapter in Oxford, MS, would be beneficial both to the university and its students, as well as the families in the local Oxford-Lafayette community. With some planning and organization over the summer, we should be operating by the fall of 2014.



Until then, I will be working in College Station, Texas, at Texas A&M University with Dr. Scott Dindot. He has received multiple grants for his research regarding the UBE3A gene and its correlation with Autism Spectrum Disorders (ASD). It appears that the maternal 15th chromosome is the one that expresses the UBE3A gene while the gene on the paternal chromosome remains inactive. If there is an overabundance of the UBE3A protein produced by the gene, there appears to be a larger presence of autistic behaviors. This appears at first glance to be more causation than correlation. Using mouse models to recreate dup15q syndrome, Dr. Dindot will continue research to test his hypothesis. In the future, these models could possibly provide therapies for those with ASD and dup15q syndrome.

My little brother has had a huge impact on my life. He has given me a new perspective from which to view the world. Not only has he taught me patience and self-control, but also compassion and empathy. He has had an influence on my morals for sure, but he has also intrigued me from a professional standpoint, possibly driving my passion in the field of chemistry and genetics. What is certain is that I have seen him get up in the morning, unsure of what the day may hold in store. Chances are high that he's going to need help getting dressed or showering, something rare for a fifteen year-old. Regardless, he always greets you with a smile, giggling as he goes about his daily routine. He takes nothing for granted, and takes every day one step at a time. I think whether or not you have a sibling, cousin, relative, neighbor, or friend with dup 15q syndrome, we can all learn a thing or two from the attitudes of these incredible individuals.

Reflections *from a Grandfather*

BY BOB PETERSON

William Edward Sales, IV, came into our lives in October, 2002, our third grandchild and our first grandson. Unfortunately, living almost a thousand miles away, we were not able to meet William at his birth. We were able, however, to spend his first Thanksgiving with him in Ankeny, IA. Since our second grandchild was born just six months prior, we could see William growing and gaining as she had. However, about William's first birthday, my wife, Barbara, who has a daughter born with cerebral palsy, noticed some similar traits with William, for example the way his legs spread when he sat, not progressing at crawling and sitting. Knowing it can affect relationships for a stepmother to voice concerns that may have a life changing effect, she decided she needed to speak to Karen about them. It didn't take Karen long to schedule consultations with doctors, including those at the University of Iowa's hospital where William's dup15q diagnosis was made.

We only see William three or four times a year, and we marvel at the progress he has made over the past 12 years. We have been able to run along with him on his Gator, looking back at us rather than where he's going; line all his cars up and parade them through the house; take him on his first venture into the Gulf of Mexico and the white sands of Destin, FL; and participate with him at the Indianapolis and Minneapolis conferences. The Indianapolis conference provided us a more in-depth look at what Karen had been relating to us over the years as she became deeply involved in the what, why, and how of William's condition.

Of course we wish William was closer to us here in Mississippi, but we are very glad he lives in a state that provides resources for children with special needs. The Ankeny, IA, school district has been superb in incorporating him into the regular class, providing helpers, and challenging him as a drummer in the fifth grade band this year. It's special for him to FaceTime a drum solo for us here! We've been happy to see on visits to Iowa the way his classmates interact with him and care for him. We were pleased to see Iowa finally get on the "cannabis bandwagon", and proud of Karen for being instrumental in that. Unfortunately, it will be hard for anyone in any of the states that don't have an in-state resource to take advantage of this attempt at seizure control.

Summers are busy here and that usually includes a visit by William, and a chance for him to see his cousins, all nine of them this year! As long as the weather is okay, William and I spend a lot of time in the pool. He wore arm floats the first few years and had no fear of the water. No floats now. Just bobbing and paddling, mostly in the deep end! And just like his cousins, both boys and girls, he's off behind the bush, the

We Marvel at the Progress

corner of the house, or the flowerbed (just not in the pool, please!) when "ya gotta go"! He also enjoys riding up and down the street with me on the lawn tractor, sitting on the motorcycles, or riding with me or a cousin in Uncle Jamie's ATV, especially in the mud! His visits give the other grandkids a chance to interact with a special needs child.

While it will be over before this is printed, we are looking forward to an Iowa trip over Memorial Day weekend to see William run in the Iowa Special Olympics, play baseball with his Miracle League team, and graduate with his fifth grade class. Just like things we go to see with the rest of the grandkids.

William is fortunate to have grandparents nearby that can give the support to both him and Karen that absentee grandparents aren't able to provide, and for that we are thankful. But through FaceTime and Skype, we are involved in William's life throughout the year. We have to laugh as Karen follows William around the house trying to keep him in the picture while he tells Nana and Papa story after story about school, about Maxie, and about life!!



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 chromosome 15q duplication.

UPCOMING MEETINGS AND ANNOUNCEMENTS

Many of our member families have agreed to organize regional gatherings or zoo outing in the next few months. We hope that you can find one near you! If you would like to help or host your own event, please contact us at info@dup15q.org.

June 7th - San Antonio, TX Zoo Outing

June 8th - Eastern Canada (Montreal) Regional Gathering

June 15th - Washington, DC Area Regional Gathering

July 12th - Southern California Zoo Outings

July 12th - New England Zoo Outing in Providence, RI

July 18th-20th - Northern Midwest Regional Gathering

August 2nd - Rockaway Township, NJ Regional Gathering

August 8th-10th - Northwest Family Gathering at Camp Prime Time in Yakima, WA

The 8th International Conference will be held in Orlando, Florida on July 30 - August 1, 2015.

<http://www.dup15q.org>

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