2016 Vol 3

THE MIRROR

The Newsletter of DUP15q ALLIANCE

Growing A Strong Dup15q Alliance

JANE TRUE, *THE MIRROR* EDITOR

Though it is not possible for us all to get together in person and catch up on our lives, families, and Dup15q Alliance news, we invite you to a virtual coffee in this issue. Grab your favorite beverage, kick back, and read about the many ways in which your Alliance is growing stronger.

For this issue your guest editors are me, Jane True, and Alison Kalnicki. Though I edited *The Mirror* for seven years, I have been away from it for a few years. So for me the most immediate sign of growth is the membership. The Alliance currently has 1179 members who are "immediate family". This includes affected children and adults, their parents and siblings. There are 3700 people registered as subscribers to receive our news and fundraising information. On social media there are 658 Dup15q Alliance Parent Support Facebook group members and 2700 fans on the Dup15q Alliance general Facebook page.

To keep such a large group growing strongly, many elements must come together. Meet our newest staff member, our Executive Director Vanessa Vogel-Farley, in her introduction to all of you. Vanessa, together with the rest of our staff, handle many of the administrative, coordination and communication duties so necessary to keeping a group like ours organized. In addition to our staff, we also depend hugely on our volunteers to help us fulfill our mission. Our honored volunteer this quarter is Adrienne Felterman, our current treasurer. Get to know her in this issue as well.

A very key ingredient to growth in our Alliance is increasing awareness of our condition in the scientific field and promoting research. Inside you will find an update on the two research projects of the recipients of the fellowships which Dup15q Alliance is proud to be sponsoring.

Of course our bold mission requires funding to make it all possible. We have some phenomenal energetic and generous families whose dedication to fundraising is completely amazing. This past September, the Dup15q Alliance Believe Walk was held at eight locations across the country along with a Virtual Walk. Some of the organizers share their experiences inside this issue. Walk Day was tremendously successful and next year's date is already set for October 1, 2017. The Alliance is very grateful to all our fundraising families for enabling our support of science, our highly beneficial conferences, and so many other Alliance activities. Cheers to each and every one of you awesome fundraisers!

Another sign of strong growth is that meetings are now being held in other countries around the globe. Read about the latest European meeting held earlier this fall in Milan, Italy.

Our greatest source of strength in Dup15q Alliance is our wonderful families. There is power in sharing our stories and learning about one another's journeys. Don't miss the Family Portrait in this issue!

In the words of Tom Doyle, grandfather to Grace, and Board Chair, "We are grateful to all those engaged in research, those treating our children, those who participate so strongly in our Registry, and those who so generously donate to the Dup15q Alliance to help advance the cause of supporting our families and promoting the awareness and research that will one day lead to targeted treatments. Thank you for your support!"

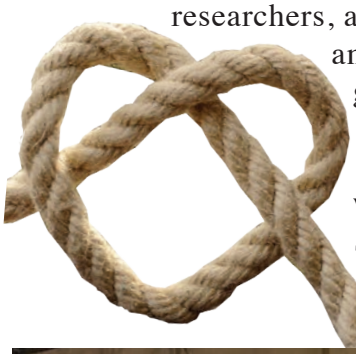
INSIDE THIS ISSUE

In Every Issue

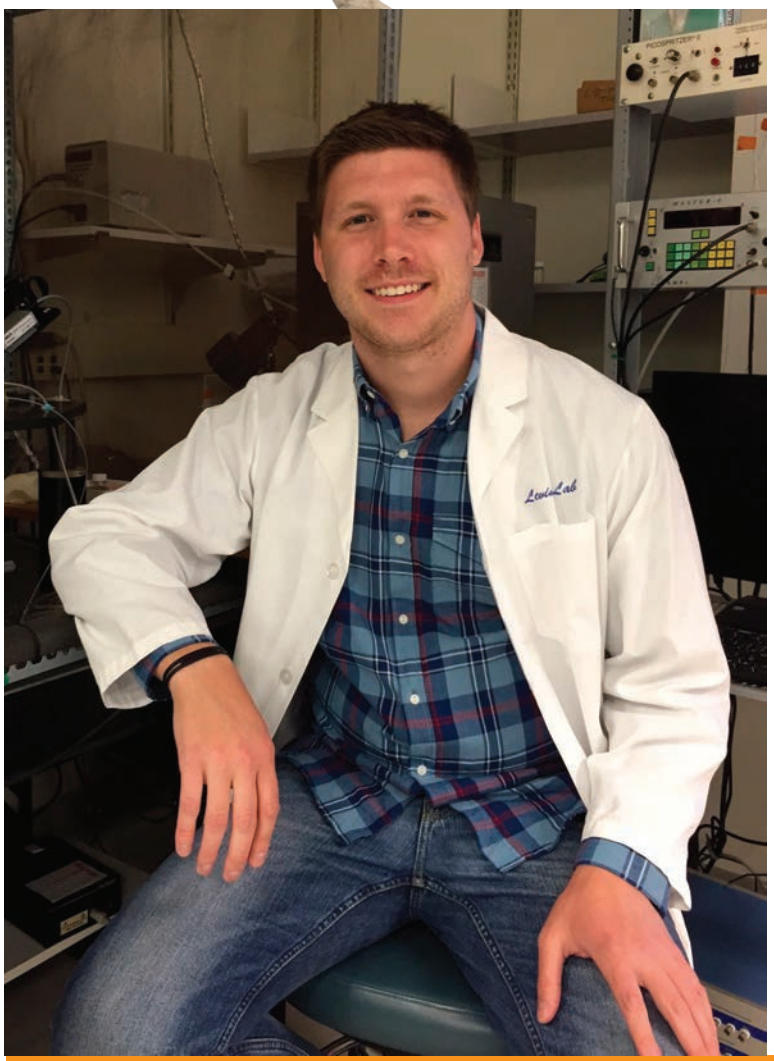
Chromosome 15q11.2-13.1 duplication (dup15q) syndrome is a clinically identifiable syndrome which results from duplications of chromosome 15q11.2-13.1. These duplications most commonly occur in one of two forms. These include an extra isodicentric 15 chromosome, abbreviated idic(15), which results in 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.

The Dup15q Alliance and Science

The mission of the Dup15q Alliance is to "provide family support and promote awareness, research and targeted treatments for chromosome 15q11.2-13.1 duplication syndrome." According to Tom Doyle, Board Chair, "We have made great strides over the last few years to consciously spread the word to geneticists, neurologists, and other medical personnel about the nature of dup15q syndrome so that families can be better served and get the needed treatments for their children. We have created a world-class science advisory group that guides us in approaching valuable research opportunities. We have dedicated funds to research grants, to the development of a mouse model, and to annually bringing together physicians, researchers, and scientists from around the world to discuss where we are with current research and to plan future initiatives. We have established a registry that provides us with great learning and sharing opportunities. We are on a journey into the science of dup15q, epilepsy, and other related issues. We have come a long way and have quite a distance to go yet. But we engage in the process, always looking to find ways to make the lives of our families better."



To that end, over a year ago the Dup15q Alliance received eleven proposals and awarded fellowships totaling $175,000 to two promising young scientists. James Fink received $25,000 for three years to study "Hyperexcitability In Human Stem Cell-Derived Neurons From 15q Duplication Syndrome Patients". Kevin Hope received $25,000 for four years for his project "Investigation of Synergistic Interactions Among Genes in the 15q Duplication Syndrome". Following are their lay statements of their progress to date.



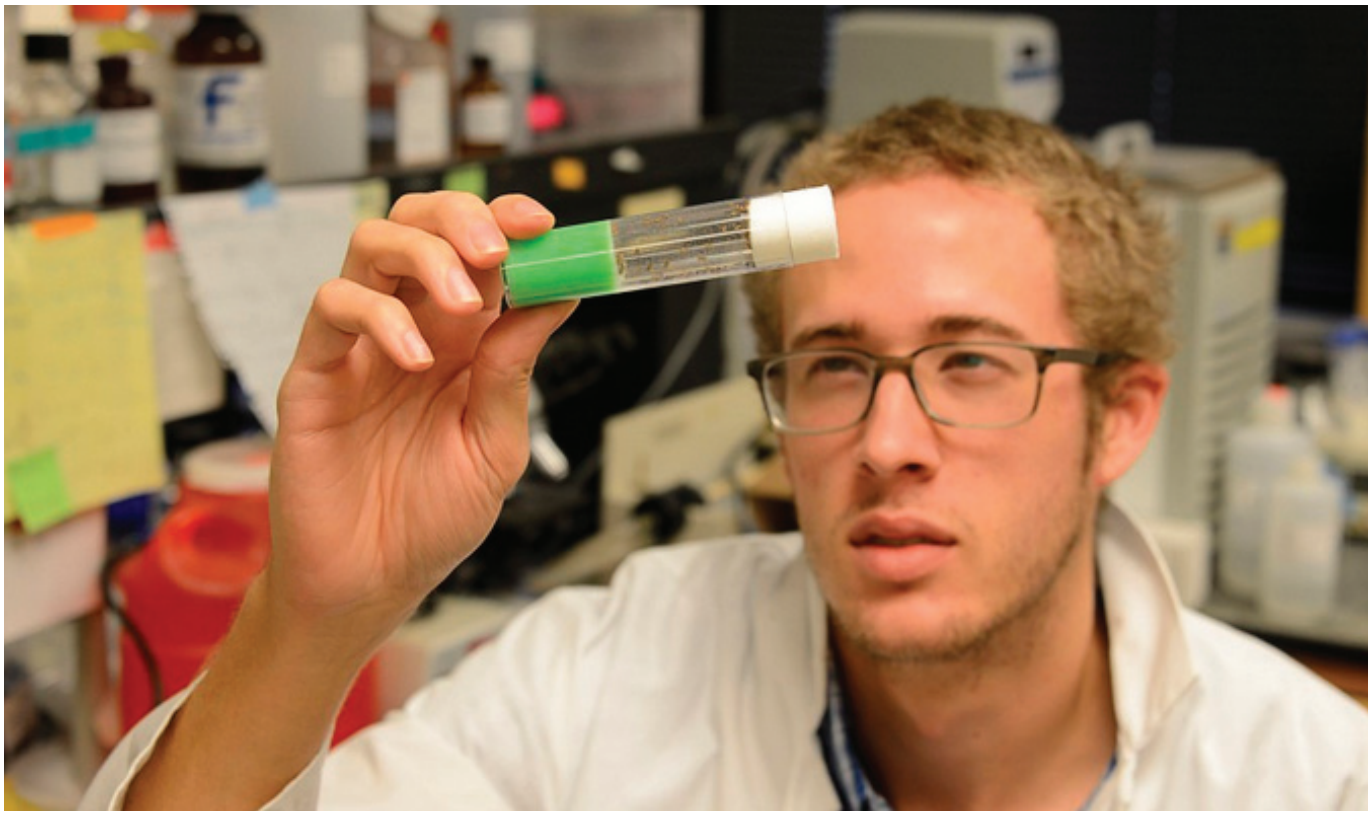
JAMES J. FINK

University of Connecticut Health Center

Seizures are commonly associated with dup15q syndrome and are particularly hard to manage as the mechanisms underlying these seizures are largely unknown. The goal of this fellowship is to use patient-specific brain cells generated using Nobel Prize-winning technology to study the causes of seizures in these human cells. This provides an attractive approach to study such processes in human brain cells as this has traditionally only been possible to study in animal models. Work supported by this fellowship over the past 12 months has helped us take significant steps towards understanding a specific culprit that contributes to excessive activity in brain cells from dup15q patients, a process that could contribute to the generation of seizures in dup15q individuals. Specifically, our experiments point to a molecule that, under normal circumstances, acts as a brake

for brain cell activity. We have found that this brake may be broken or weakened in brain cells of dup15q patients. Moreover, when we disrupt this brake in brain cells from control individuals, their activity becomes very much like dup15q brain cells. Together, this work identifies a particular target that leads to increased activity in brain cells from dup15q, which may act as a therapeutic target for seizures in dup15q. Work supported by this fellowship in the coming year will further investigate how this brake is disrupted in dup15q cells as well as examining other molecules that may contribute to increased activity.

KEVIN HOPE
University of Tennessee, Health Science Center



Over the past year we have been using Drosophila melanogaster (fruit flies) to investigate dup15q syndrome. The focus of our project is two-fold: how two different cell types in the brain, neurons and glia, are involved in dup15q syndrome, and how genes located within the 15q11.2-q13.1 duplication other than the UBE3A gene contribute to aspects of the disorder.

We have found that when we raise levels of UBE3A in glial cells, as we predict would happen in brains of people with dup15q, the flies have seizures. A majority of dup15q research has focused on the function of UBE3A protein in neurons. We show, however, that our new seizure model of dup15q using glia and not neurons may turn out to be more useful for understanding the seizure problems in kids with dup15q syndrome.

Additionally, we have been exploring how genes other than UBE3A located within the 15q11.2-q13.1 duplication may be involved in dup15q. Using flies, we are able to overexpress both UBE3A and HERC2 (another gene duplicated in most people with dup15q syndrome) at the same time. This type of double over-expression is very difficult to do effectively in mouse models. We have collected evidence indicating that HERC2 and UBE3A are interacting with each other to modify behaviors in our flies. We are currently working to understand both how overexpressing UBE3A in glia is causing seizures, and how UBE3A/HERC2 interactions cause dup15q phenotypes.

Your New Executive Director: Vanessa Vogel-Farley

Editor's note: Dup15q Alliance`s executive director for the last 10 years, Kadi Luschinger, stepped down to spend more time with her own family. We thank Kadi for her tireless and caring support, while at the same time we welcome Vanessa Vogel-Farley as Dup15q Alliance`s new executive director.

I am excited to get the chance to introduce myself as the new executive director of the Dup15q Alliance!

I come to the Alliance with a decade plus of experience in genetic disorders and child development research experience, as well as more than eight years of establishing and managing a non-profit organization.

Growing up on a dairy farm in rural Wisconsin, I learned the value of hard work and family immediate or extended, and the Dup15q Alliance is an amazing example of that. Every day I reflect on what your "family" (parents, families, caregivers and supporters of someone with dup15q syndrome) has created in the Alliance, and I am humbled to be able to serve you.

I have hit the ground running in my first couple of months, and while I was lucky enough to attend the 2015 conference as a researcher and met many of you and your children in person, I now have the opportunity to spend some time each day talking to dup15q families. I am learning their stories, their concerns, their triumphs, and what they want and need from the Dup15q Alliance as we grow this organization together. This has been a truly wonderful experience and I look forward to speaking with many more of you in this way. Please feel free to call (1-855-387-1572) or email me at vanessa.vogelfarley@dup15q.org .

You all have great ideas, comments and questions. The question that I have heard the most in these recent conversations is "do you have a child with dup15q syndrome?". The short answer is "no, I do not". The long answer is "no, I do not, but, I know that is an advantage to every family in the Dup15q Alliance. Since I don't have a child with dup15q syndrome, I am able to take all of the information that I get from every parent and every child I meet and combine it into goals/directions/research ideas/fundraisers that everyone in the Alliance can benefit from, with no concern about my own experiences and biases."

The Dup15q Alliance has brought together world-class physicians and researchers all who are dedicating their time and knowledge to helping characterize dup15q syndrome and exploring new treatments.The interest in dup15q syndrome is constantly growing!

I look forward to using all of my experience and knowledge that I have gained from every aspect of my career in order to grow and develop Dup15q Alliance and work with you to bring us all to the next level.

Clinical Takeaways from The Science Meeting

By: Vanessa Vogel-Farley

On July 28th, 2016 the Dup15q Alliance Clinics board met to discuss the current clinical care taking place at each of our Dup15q clinics around the United States.

The Dup15q Clinics are running well with each clinic seeing a new patient almost every month! The clinics discussion centered around ensuring that any family who travels to one of our Dup15q Clinics receives the same standard of care and has access to the same type of specialists at each site.

Based upon the current dup15q syndrome patients, the clinical group outlined what each site needed to provide in order to be listed as a Dup15q Clinic. These include neurology, genetics (referral ability), sleep (referral ability), gastrointestinal (referral ability), psychiatry (referral ability), and neuropsychological testing. This list, as well as other standard of care recommendations, will be added to the agreement that each site signs with Dup15q Alliance. With the new

agreements we will be designating any of the dup15q clinics as "centers of excellence" who meet these expectations successfully, and each center of excellence clinic will be given funds each year to support a clinic coordinator.

The clinic coordinator will help schedule appointments with the appropriate specialists, make sure proper testing is arranged, set up follow visits, help with arranging transportation and housing, as well as enrolling patients into various clinical research studies at each site. The clinic coordinator will also help input data into the centralized database and help answer any questions from patients about the database. These coordinators will be in contact with each other to enhance the standard of care across sites.

This new structure will help our clinics actively participate in the dup15q central database and the lead clinicians actively engage in dup15q research and collaboration. The dup15q clinicians are very motivated and passionate about learning more about dup15q syndrome and helping individuals with the condition. There continue to be conference calls roughly once a quarter and an in-person meeting once a year.

THE MIRROR

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More clinics:

Everyday we are adding families to Dup15q Alliance and getting them access to clinical care is one of our highest priorities. To that end, we are in discussions with two additional clinic sites in the United States as well as a couple internationally.

If you have met with a clinician who has expressed an interest in setting up a dup15q syndrome clinic, please have them contact Vanessa Vogel-Farley, the executive director, at vanessa.vogelfarley@dup15q.org

Please note that the Memphis clinic will not be seeing patients until further notice due to some personnel changes. They will continue to serve as the data core for the Dup15q Alliance.

Dup15q Alliance

CORPORATE OFFICERS & BOARD MEMBERS

Cheers to Our Volunteers!

Treasurer Adrienne Felterman

My name is Adrienne and my husband's name is Ben. We have four children: Cecilia, 7 years old, Charles, 4 years old, Charlotte, 2 years old, and a newborn called Caroline Grace. Our son, Charles, has dup15q syndrome. We live in Houston, Texas.

I have bachelor and masters degrees in accounting, am a CPA and currently have the privilege of staying home to take care of my family. My favorite activity is spending time with family and friends. My children will only be little for so long and I cherish the time I get to spend watching them grow up. I also enjoy exercising, cooking, reading and attending bible studies.

A few years ago, I started helping to send out birthday cards to children and adults who have dup15q syndrome for the Dup15q Alliance Sunshine Committee. In 2012 and 2013, I put on a couple of small fundraisers for Dup15q Alliance. This year I became the volunteer treasurer of Dup15q Alliance's Board of Directors. I also volunteer at church and my daughter's school.

I enjoy volunteering at the Dup15q Alliance because I want to improve the quality of life for those living with dup15q syndrome and their caregivers. My family and I learned so much about our son's prognosis from the Alliance website right after our son's diagnosis and from the medical support we received at the Dup15q Clinic in Boston. The Dup15q Alliance improves their quality of life by providing emotional support for families along with clinics, research and information that allows people with dup15q syndrome to receive appropriate treatments and therapies. I hope my assisting with the financial aspects of the Dup15q Alliance allows for others to focus on the research, outreach and clinical needs.

Reflections on The European Meeting 2016

By Lucy Parr, England

Editor's note: The European Meeting was held September 9 – 11, 2016, at Pax et Vita – Villa Sacro Cuore, a peaceful Catholic seminary in Triuggio in the beautiful Brianza area which is close to Milan, Italy. For more information or to contact Laura Piredda, Nonsolo15 President go to http://www.idic15.it.

In gorgeous Milano, we gathered together
With beautiful people and beautiful weather
To connect up the dots of our most awesome kids,
We came to learn more, and that's what we did.

The Italians had generously opened their meeting
To us fellow neighbours from Europe - their greeting
Was really impressive, quite second to none
Full of life, full of smiles, full of laughs, full of fun

The setting was special, the scenery quite stunning
Huge thanks go to Laura, who sorted the running.
Games for the children with bubbles and clowns,
A joining-in circus which brought the house down!

Meanwhile the adults sat in on the sessions
With doctors and others who taught many lessons
On what we could do with the info they'd gained
In how to support (without going insane!)

Eating together was a great friendship-maker
The chatting was just such a brilliant ice breaker.
To know you have family all over the place
Makes you feel much less lonely when running this race.

This race we call life, which is tricky it's true
But we keep marching forward, we keep pushing through
Our children are precious, quite special and rare
Better together carrying the load we all share.

So thank you Italia, you really were stunning.
You gave us all strength in this race to keep running'

Family Portrait

Believe in Butterflies

By: Heather and Tim Friesen, Winnipeg, Canada

On March 17th, 2007, after an uneventful pregnancy, we welcomed Ana Rylie Friesen to the world. We were thrilled and believed we were blessed with a beautiful, healthy daughter. I will never forget when the doctor examined her and confidently stated, "She is the picture of health." Ana was a sleepy baby, but gained weight well and seemed content. Her eyes tended to gaze up to the left, but I dismissed it as a variation of "cross-eyes" that newborns often have in the early weeks. At her two-month appointment her pediatrician noted her lower muscle tone and her eyes gazing upwards, and walked us over to the children's hospital next door to meet with neurology and opthalmology. Ana was admitted to the hospital for initial tests, and we were so relieved when her EEG and MRI showed no abnormalities. She was soon diagnosed with cortical vision impairment and CNIB (Canadian National Institute for the Blind) became involved. We were heartbroken that our daughter was not able to see the way other babies could but we were hopeful that with the right supports she would catch up to her peers. We all assumed her milestones were delayed due to her visual difficulties. Little did we know that this visual disability was only the beginning of the hardships she would endure.

Ana started occupational and physical therapy, and slowly reached some developmental milestones. We were so happy when she could finally sit by herself. When Ana was ten months old, I noticed some unusual eye movement and a quick startle-like reflex similar to that in newborn babies. The look on the neurologist's face when he saw the video clip had me immediately worried. After more tests and EEGs, it was determined that Ana had infantile spasms, a devastating form of seizures with a very bleak prognosis. Ana was admitted to the children's hospital for a week and put on ACTH (an injectable steroid) to help stop these seizures. These injections were continued daily at home in hopes that the spasms would stop.

Just after Ana had her first birthday, she began to deteriorate and was again admitted to the hospital. Health Canada no longer could supply the ACTH due to extreme high costs (had gone from $2,000 per vial to $23,000) so she was put on a synthetic form of the drug to continue the treatments. She had severe side effects to the steroids and was in a tremendous amount of pain. The infantile spasms had stopped but she was so swollen she was hardly recognizable and her blood pressure and electrolytes were very unstable. As the weeks went by, Ana lost many of the milestones she had previously reached and now could no longer eat, sit, hold her head up or even smile. She had always loved to be held and cuddled and now was in too

much pain for us to even hold her. Her pain was so intense the head of palliative care became involved to oversee her pain management. She continued to decline and a feeding tube was surgically placed, as well as a central line for her endless blood work. She had myriads of tests and procedures including a muscle biopsy, lumbar puncture, CAT scans, MRIs, Kidney Scans, x-rays, EEGs, and was on close to 30 doses of medications a day, all while trying to figure out what was causing her deterioration and why our little girl was in so much pain.

A day we will never forget was when eight doctors, all from different specialties, met with us for a consultation. They told us that Ana was a very complicated case, and everyone was deeply concerned. However, they believed they finally had an answer and explained that she had a rare neurodegenerative disorder called PEHO (Progressive encephalopathy with Edema, Hypsarrhythmia and Optic atrophy). They expected she would just continue to deteriorate, and would likely not live past age two.

A few weeks later, when more blood work and genetic testing came back, it was determined that she had a rare genetic abnormality, a duplication of part of the 15th chromosome rather than the PEHO syndrome. They referred to it as 15Q13 inverted duplication and admitted they didn't know much about it. Not much other information was given to us about this syndrome other than they believed the seizures were related to it. I think all the doctors were just relieved it was not the dreaded PEHO that had been first diagnosed.

After being weaned from the steroids, Ana slowly improved, and we were so happy when the day came when we could hold her again. Then finally, after 3 months in hospital, and with the support of homecare, we were able to take Ana home. She slowly began to tolerate oral feeding and after several months didn't require her feeding tube. She received much physiotherapy and occupational therapy, and we were thrilled when she learned to walk just before her third birthday.

For the first eight years of Ana's life, we had never been able to find out much about her condition. Doctors did not know much about it and every time we Googled, we could only find information related to either Prader-Willi or Angelman's syndrome. We were told that they knew of only two cases of this syndrome in North America, our little Ana and a girl located in Pennsylvania. Often on her medical forms the doctors would put the diagnosis of global developmental delay due to "extra genetic material".

In the fall of 2014, I decided to apply for a wish through Children's Wish Foundation. I attempted to explain how rare her syndrome was, and decided to Google one more time. This time when I searched, I used different criteria and was dumbfounded to stumble across Dup15q Alliance. I quickly called my husband over and exclaimed, "I think this is what Ana has!" I immediately joined the Parents' Facebook page. It was a whirlwind when Kim from the Alliance contacted us to ask if Ana was "interstitial" or "isodicentic" -- what? I had never heard these terms before so she graciously went over Ana's reports with us and informed us that Ana had the isodicentric version of dup15q syndrome. We started reading and absorbed as much information as we could. It seemed like we couldn't read enough, and my colleagues at work had to bear with my constant sharing of the revelations I was discovering. One of the first posts I read was of Heather Bruce's daughter dressed as the duplicated chromosome for Halloween. I showed the picture to every willing person I could find. Then when our area rep, Denis Myers, called us, we discovered we had a supportive community and we were not alone. We were surprised to discover there were three other children in our province with the same syndrome. What an incredible experience to meet them and finally be able to talk to someone who "got it."

Last year I had the wonderful privilege to go to the conference in Orlando and meet so many amazing families, and see so many children in their blue "Believe" t-shirts from all over the world. Almost all of these beautiful children had the same adorable button nose and pouty lips as our Ana. I remember updating my Facebook status in the airport on the way home: "My heart is full and my eyes are overflowing." It has also been sobering and heartbreaking to see the journeys our children and families have experienced or are currently going through. However, the support and love shown to one another has been so wonderful. We are so grateful to now have a community and a forum to ask questions, gather information to share with those who work with our children, and most importantly, a place to celebrate together, grieve together, and support each other.

Today, Ana is in fourth grade in a public school with the aid of a one-on-one educational assistant. She has blown away all the expectations of her doctors and keeps us running around each day. Her room is decorated in butterflies as a symbol of hope and a reminder for us to continue to believe. She enjoys music, dancing, water, and loves watching hockey. (I think she loves all the cheering.) She has only a few words; her older brother was overjoyed and burst into tears this summer when she finally said his name, "Noah". We know the experience is challenging, but we are so proud to be Ana's parents and are so grateful to have our dup15q family to share this journey with us.

Each child is like a butterfly in the wind. Some can fly higher than others but each one flies the best they can. Why compare one against the other? Each one is different. Each one is special. Each one is beautiful.

-Author unknown

$80,000.00! Fundraising Spectacular: Dup15q Alliance Believe Walk Day

On Sunday, September 18th, the 2016 Dup15q Alliance Believe Walk Day raised over $80,000. This incredible financial generating force took place in eight locations in the United States, and online in a Virtual Walk, where money could be donated from anywhere in the world.

Join with other fundraisers next year on Sunday, October 1st, 2017! Have a look at the Dup15q Alliance website for some ideas on what to do: http://www.dup15q.org/fundraising/host-an-event/ or contact info@dup15q.org for more information.

Thanks to each of our 2016 Believe Walk Day locations:

Atlanta, GA
Evensville, TN
Honolulu, HI
Indianapolis, IN
Medford, NJ
Miami, FL
Seattle, WA
Syracuse, NY

Here are some first hand accounts of how Believe Walk Day went:

Atlanta, Georgia: by Angelic Yao

Organizing the Dup15q Alliance Believe Walk Atlanta was an honor and informed Atlanta about the rare syndrome that affects our loved ones. I was greeted with support from organizations who provided sponsorships and donations. We walked around the beautiful Rhodes Jordan Park. The most humbling supporters were our family and friends who donated money and walked with our dup15q families. Being surrounded by their love was emotional! After the walk, we enjoyed snacks while the kids played with bubbles and got their face painted. Prize giveaways were offered to participants.

Evensville, Tennessee: by Tiffany Ciero

This was our first year hosting a Believe Walk. It rained the morning of our walk so we used our middle school gym and walked inside. We were overwhelmed by the love and support that our community showed for our son and all of his dup15q brothers and sisters! We were honored to be able to have another dup15q syndrome family in attendance. So many people came out and made our event a success. Our #1 goal was to bring more awareness to dup15q syndrome and we met that goal. We could never thank our family, friends, and community enough!

Honolulu, Hawaii: by Aiisha Ramiro

Believe Walk Day was a beautiful day: blue skies, sunshine and trade winds. We had a great turnout of about 150 participants and families, and over 30 volunteers who brought awareness to dup15q syndrome. We had raffle prizes and activities for the kids like face painting, balloon artists and shaved ice. We all enjoyed the day and the people. Most importantly, we shared about dup15q syndrome and Dup15q Alliance. We are so grateful for all those who made donations, volunteered time, or came out to show their support. You all helped make the pieces come together for an amazing day!

Medford, New Jersey: by Tina Delorenzo

At first the weather wasn't looking good, but the sun came out! Everyone was happy and we made new friends. We had about 230 participants - about 100 more people than last year. We added in a meet and greet, and a swap and shop with therapy items other families had used and were passing on to other families. We had the Medford police, fire, canine unit, and a race car! We also had a lemonade stand done by one of the siblings who wanted to do it for her sister. Next year, I would like to have something for the siblings and to make sure the dup15q kids stand out because it's their day to shine. Each year my goal is bigger and better!

Miami, Florida: by Christine Benitez

When I first ventured out into the community to share my daughter's story there was an immediate interest about dup15q syndrome. Ivonne, Lily, Coco and I grew closer as we worked to deliver the best for our dup15q family. Our story even caught the interest of a newspaper and radio show. Dup15q awareness was spreading rapidly and Miami was the sponge absorbing it all. Face painters, a craft table, and the Lions Club mascot provided entertainment. That bright sunny morning, I felt honored to be a part of something so meaningful.

Miami, Florida: by Ivonne Ruiz

What an amazing experience – from the planning to the actual day, our hearts have been filled with so much love, excitement, anxiety (me!) and generousity. Companies donated food and raffle items. It was a beautiful Miami day! At 8 a.m. on cue, everyone started to arrive, and by 9 a.m., 250 people were walking, including several dup15q families. That was the most amazing thing to me, to see so many of the families that share Devin's syndrome, and to feel so close to people you don't really know, but deep down you feel you do because you share the same type of worries, concerns and joys all at once.

Seattle, Washington: by Colleen Lowell

The Dup15q Alliance Believe Walk in Seattle was amazing! Happily, the sun shone on us despite terrible weather predictions. We had the biggest crowd ever walking the track — a sea of blue shirts in every direction. We love hosting the Believe Walk at a track as it becomes such a social event; every lap, you can talk with someone different! We felt so much love and support for dup15q families around the world, and especially for the 13 families represented at our walk. Hopefully we were able to educate everyone a little about dup15q syndrome, but at the very least, everyone had an enjoyable morning!

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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.

ANNOUNCEMENTS...

9TH INTERNATIONAL FAMILY CONFERENCE: NAVIGATING THE FUTURE 2017

MONDAY, JULY 24 TO WEDNESDAY, JULY 26, 2017

For the first time on the west coast of North America, join this year's conference in Los Angeles, California for a perfect combination of learning and fun.
Every two years, families, professionals and educators connected to children and adults with dup15q syndrome have gathered in one place to meet each other, share knowledge and make plans for the future.

LOCATION: CROWNE PLAZA REDONDO BEACH AND MARINA, CALIFORNIA, U.S.A.

THE CONFERENCE LINK: http://www.dup15q.org/events and click on family conference. This is your prime source for up-to-date information on registration, schedules and more.

COSTS TO BUDGET FOR:

REGISTRATION FEE: adults $150, children tba, includes 2 lunches, 1 dinner, all workshops, panel discussions, opening and closing ceremonies, and admittance to a water park event on Tuesday evening

ACCOMODATION: the conference rate is $199/night for 2 queen sized beds; some conference goers choose to use alternate accommodations

MEALS NOT INCLUDED IN REGISTRATION FEE

TRANSPORTATION

http://www.dup15q.org

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