

## IN THIS ISSUE

1. Navigating the Future Conference Sessions
1. Promoting Conference presenters
2. Board/Advisor/Staff list & New Board Intros
2. Family Voices: Grandparents, Aunties, Siblings at Conference
3. Research Opportunities at Conference
4. Curbside Consults at Conference
5. Redondo Beach Fun/Love Notes
6. New Dup15q Research Publications
7. Alliance Cheers our Volunteers - AND 2017 Conference Thank You's
8. Family Story: I Happy
10. Remembrances

## Navigating the Future Conference Sessions



We are so excited by the expertise our presenters will be sharing at Navigating the Future. This conference is designed to meet the needs of all our families, from young, newly diagnosed children all the way up to families supporting their adult children with dup15q. We are providing a sneak peek of a few of the presentations in this issue of the MIRROR to whet your appetite for the engaging, helpful, inspiring sessions available at our 2017 conference. You can find a full list of conference sessions at [www.dup15q.org](http://www.dup15q.org).

## Sunday Session for New Families

On Sunday evening, July 23rd, conference organizers will host an information session for new families and first-time conference attendees. Helpful tips and the conference schedule will be shared to ensure that new families get the most out of their conference experience.

## Monday Sneak Peek

### Living with dup15q, Jeremy Sicile-Kira

Jeremy will kick off our conference by sharing his experience living with dup15q. Jeremy graduated with a full academic diploma from his local high school, and he is now creating the self-determined life he wants to have. Jeremy's first book, *A Full Life with Autism: From Learning to Forming Relationships to Achieving Independence*, co-authored with his mother was published by Macmillan in April, 2012.

### Mom's Group/Dad's Group/Extended Family Group

The Mom's and Dad's sessions at conference are a powerful opportunity to gather with other parents and share the challenges, fears, hopes and successes of raising a family when dup15q is in the mix. These honest exchanges bring both tears and laughter, and most of all the healing of knowing that you are not alone in your experience parenting a child with dup15q. We will also have an Extended Family session so that grandparents, aunts/uncles, and other family members can gather to share their experience supporting their family members.

To support these groups, Corporate Kids childcare will be onsite Monday 12pm-5pm, for a flat rate of \$50, paid in advance (in order to get count of children and their ages so we can make sure we have proper ratio of staff). This service is available for all children in attendance.

You can register to use child care on the conference registration form.

## Tuesday Sneak Peek

### IEPs, Catherine Whitcher, M.Ed

Catherine provided a great presentation at our 2015 conference, and is returning to our 2017 conference to help parents of school-age children navigate the IEP experience. Parents will learn:

- The Purpose of Your Child's IEP, It's Not What You Think! - When you understand this piece, your advocacy skills will drastically improve, FOREVER!
- How to Build a Long Term Vision for Your Child that Makes Sense to the School Team
- How to Decide Good IEP Goals vs Bad IEP Goals
- Know When to Give Up on a Goal and When to Stick it Out
- Get Teachers to Listen to What Your Child Needs
- Learn How to Push Your Child to Learn More WITHOUT causing MORE

## Siblings Session

Siblings will have an opportunity on Tuesday to gather together much as the Moms, Dads, and Extended Family did on Monday. These sessions are designed for siblings to share their experiences, and be recognized for their unique strength, compassion, and love as a sibling of a special needs child.

## Wednesday Sneak Peek

### Dup15q Funded Research, Panel

Our panel will help families understand the ongoing research funded by the Dup15q Alliance. This is a great chance for families to hear first hand about the ways that Dup15q Alliance investment in research is creating increased scientific understanding and hope for targeted treatments.

### Managing Self Stim Behaviors, Dr. Mauro Mario Coppa

Many intellectually impaired students present a wide range of behavioral problems. Stereotypical behaviors, like repetitive head or body movements, are common in this population. Dr. Coppa will share analysis of these behaviors, and educational strategies to manage and reduce maladaptive behaviours. Dr. Coppa inspired and motivated families at the European Dup15q Conference to recognize and effectively minimize the self-stimulatory behaviors in their children. Very few professionals have the ability to “put themselves in the shoes” of a family dealing with a challenging situation such as self-stim behaviors, and bring hope and motivation to succeed in reducing (and if at all possible eliminating) the behaviors. Dr. Coppa does so with humor and passion. Behind every behavior there is motivation!

### Transition Planning, Heather Stenberg and Jessica Leitner

Come learn about some of the current and available options for families planning or looking for long term housing and care for adults with intellectual and developmental disabilities. Presenters will share information about the Edwards Place project - family housing to support parents and their adult children with disabilities to age in place (located in Oregon), and Stephen's Place - a unique Assisted Living model for adults with disabilities located in Washington State. Benefits of the various types of housing offered will be discussed in addition to available options. Attendees will also come away with questions to ask when looking at options and resources for further information.

These are just a few of the sessions that will be offered at Navigating the Future. Families may find it helpful to preview the full list of sessions on [www.dup15q.org](http://www.dup15q.org) to identify the sessions that best meet your family's needs at this time. Rest assured, you will leave the conference with more information, more tools, and more ideas about how to Navigate the Future than you arrived with! 🐾🐾🐾



## Dup15q Conferences: A Family Affair

*Family conferences are a great opportunity for extended family members to learn about dup15q and to become connected to our dup15q family. In this article, a grandparent and an aunt share their conference experiences.*

**Fran Dunne, Grandparent** The 2017 Dup15q Alliance conference is fast approaching and I have been asked to write a few words about my experience as an attendee at the last five conferences. Of course, I must brag about my girl too. I am Riley Rozovics's grandma, Fran Dunne. Riley and I are very close. She is always excited to see me and greets me with a big hug and many times a smile. Mostly we sit and snuggle enjoying her books, talker, iPad, photos and songs together. Riley is nonverbal, but she says plenty to me. She is why my heart still beats.

Attending conferences is a very positive experience and so much fun. There is so much to learn and see. My favorite part of the conference is just seeing the parents and the kids. Everyone is so accepting and loving. It has been wonderful to watch the kids grow into adults both physically and mentally. It is amazing to hear about the research being done to help the kids reach their

full potential in adult life. If you have never attended, I urge you to give it a try. It will draw you closer to your dup15q child or adult and the journey they travel with their families. You will learn what real love is, and gain some knowledge regarding dup15q along the way. Support is so welcoming for these wonderful families. I see Riley's parents, Shannon and Jeff, share joys and frustrations with other families without judgement.

**Joan Ronan, Aunt** My sister and I attended our first dup 15q conference in 2005 in Chicago. My nephew, Jack, was 3 years old and had been recently diagnosed with Isodicentric 15 (idic 15). I offered to join Sarah (Jack's mother) at the conference. Jack's dad stayed home to hold down the fort with Jack and his older brother Kyle. Neither of us knew what to expect, but our goal was to find out as much as we could about idic 15.

My two lasting memories of my first conference was that this was the place to learn all that there was to know about idic 15 **and** that this organization was the “the lifeline” for my sister.

There was so much to be learned from every session including demystifying

idic 15 and its variable presentation and developmental paths, along with practical suggestions for dealing with common issues including seizures, mobility, language, feeding, toilet training, cognitive issues, IEPs and transitioning into adulthood. But more than the education was the immeasurable support we received from other family members who were either at the same stage as us in their journey or who had "been there, done that".

That was the first of many conferences for me. In Boston, Philadelphia, Indianapolis and Orlando we attended many sessions. My sister was in charge of figuring out what sessions each of us would attend the following day (assignments usually given over a glass of wine). Our goal was to ensure that we got all the information we thought was most

pertinent to Jack's developmental needs at that time.

We attended some sessions together, some alone. Some would get us excited about a new idea/ method that might be perfect for Jack. Other sessions made us think "been there, done that". Some got us thinking "we need to start thinking about that now!!!" and some made us cry, for we were reminded of the difficulties that Jack would face throughout his lifetime.

I like to think that my presence at the conference was a good thing for my sister. It certainly helped and supported me as Jack's aunt. We gained tons of new and relevant information at each conference that helped support Jack's journey. We were able to rehash the information with each other and start to strategize how to implement what we had heard that

day. Also there were now two of us to disseminate the information back home where all of our family members were waiting for the updates.

Along the way we have met so many moms, dad, aunts, uncles and grandparents. We came with similar and different needs and goals. Besides all the practical information, the conference provided us a place to express our concerns and fears as we helped our idic 15 kids, nephews, nieces and grandkids and each other navigate this world. We all understood where we were coming from and the support we gave each other was priceless.

If you can make it work in your schedule, I highly recommend you attend a dup 15q conference. I promise you won't be disappointed. 🐶🐶🐶

## Research Opportunities at Conference

Families raising kids with dup15q are keenly interested in the promise of targeted treatments that comes from research. Many families would be willing to participate if it were easy to do so, but sometimes the distance to a study site is a barrier. At the 2017 conference, the BBIGS study is coming and families will have the opportunity to participate in important research without ever leaving the hotel. Please read below and consider if this is something you and your child would be able to participate in.



Study Name: Brain and Behavior in Genetic Syndromes (B-BiGS)

Principal Investigator: Dr. Shafali Jeste, MD, UCLA Center for Autism Research and Treatment.

Summary: Our goals in this study are to measure cognitive and social-communication abilities in children with dup15q syndrome, and to find brain-based "biomarkers" using EEG recordings. EEGs record electrical activity in the brain, and they provide information about brain responses and processing. This information can help us understand development in children with dup15q syndrome, and it can help us in identifying targeted treatments.

Participation in this study involves three components: clinical assessments, EEG recording and parent surveys. Your child will participate in two play-based assessments, measuring cognitive development and social-communication skills. These assessments will take approximately two hours. Your child will also


complete an EEG recording. For the EEG recording, your child will wear an elastic "net", which fits like a swim cap. Your child will sit and watch images on a computer screen while they wear the net. The EEG recording session will take approximately 30 minutes. Finally, a parent will be asked to fill out several survey forms about the child's development and abilities.

There is also a component of this study investigating motor tasks. Dup15q syndrome can present with profound motor delays and hypotonia. It is often these early motor difficulties that are noted by caregivers and primary care doctors that lead to genetic testing and diagnosis. In a recent study, it was shown that children with dup15q syndrome meet criteria for autism spectrum disorder, but they show strength in social interest and responsiveness. It is likely that these motor delays relate to other areas of development (social communication) and adaptive skills. Measuring and accurately mapping the common motor difficulties in dup15q can be valuable to better understand what

targeted treatments might benefit these individuals.

We will have a fun, quick, group of motor activities to assess some of these motor strengths and difficulties in children who would like to participate. These include walking, running, balancing, reaching, and grasping. We will also have a gait mat that can just be walked on and sensors

within the mat can measure more subtle differences in gait and balance. The entire assessment will be 20-30 minutes.

Contact: If you would like to be involved in our study during the 2017 conference or have questions regarding our study, please contact Scott Huberty by phone at (310) 825-8738 or by email at [shuberty@mednet.ucla.edu](mailto:shuberty@mednet.ucla.edu) 



## Curbside Consults

*Would you like the opportunity to talk in depth with knowledgeable professionals regarding your child's education, genetics, or financial planning? Then plan to make some time for conference curbside consults.*

### Special Education/IEPs

Catherine Whitcher, M.Ed is passionate about advocating for special needs families. She has a brother with Down Syndrome, and has been in the special needs community professionally as an advocate, speaker and consultant for over 20 years. Catherine began advocating for better, more effective special education programs after experiencing the challenges of our school systems as a certified special education teacher. Catherine will be offering a limited number of 1:1 meetings with parents during the conference. There will be no fee for parents to meet with her during those times. Topics of meetings may include all areas of Special Education/IEP advocacy. Parents are encouraged to bring their IEPs to the conference for both the large presentation and the small meetings.

### Genetics Consults

Let's face it, genetics can be a confusing subject. Dup15q syndrome, in particular, involves a very complicated and confusing chromosomal region. Not only that, but this pesky region, known as


15q11.2-13.1, can duplicate itself in different ways; sometimes there's one extra copy, sometimes 2 extra copies, sometimes a mix of one extra copy and 2 extra copies in the same duplication. Sometimes the extra copies can all be right next to each other, and sometimes they can break off and create a whole new chromosome! Needless to say, it's not easy to read a lab report and know exactly what's going on with chromosome 15.

For those of you attending conference, genetics experts from Geisinger Health System will be offering "curbside consults" to answer some basic questions about families' lab reports. These consultations are not intended to replace genetic counseling. However, for most lab reports, we will be able to determine whether 1) the family's duplication involves dup15q chromosomal region, and 2) the duplication is interstitial or isodicentric.

In order to make this as efficient and useful as possible, we encourage you to check out the "Genetics 101" webinar on the Alliance website for a basic tutorial about chromosome 15q duplications. Additionally, be sure to check out Brenda Finucane's talk on the genetics at the conference. These resources will hopefully answer common questions about the dup15q region. If you are interested in discussing your lab report with a genetics specialist at

the conference, please upload a copy using the link on the conference page of the Alliance website as soon as possible. This will allow us to review the report in advance, so that we can address families' questions in a timely manner.

### Financial Consults

Jeff Rozovics, licensed CPA, Certified Financial Planner and Dad to Riley (dup15q) will be providing curbside consults for financial questions at our 2017 conference. Do you have questions about what kind of government benefits a disabled child might qualify for? SSI or SSDI? Medicaid? Do you have questions about potential tax deductions or other tax issues? Jeff can also help review the important financial planning documents and financial planning considerations families should be aware of. Bring your questions to Jeff, and he will help guide you toward answers. 



## Dup15q Alliance Corporate Officers & Board Members

**Tom Doyle** Board Chair

**Vanessa Vogel-Farley** Executive Director

**Elaine Lowell** Secretary

**Donna Bennett** Co-Founder & Board Member

**Anthony Marmo** Treasurer

**Guy Calvert** Board Member

**David Gifford** Board Member

**Fernando Gomez** Board Member

**Jane Kim** Board Member

**Mike Porath** Board Member

**Tessa Quinlan** Board Member

## Professional Advisory Board

**Dmitrios Arkilo, MD**

Minnesota Epilepsy Group

**Stormy Chamberlain, Ph.D.**

University of Connecticut Health Center,  
Farmington, CT

**Edwin H. Cook, Jr., MD**

Department of Psychiatry  
University of Illinois at Chicago, Chicago, IL

**Orrin Devinsky, MD**

NYU Comprehensive Epilepsy Center  
NYU Langone Medical Center, New York, NY

**Scott Dindot, PhD**

Department of Pathobiology and Department  
of Molecular and Cellular Medicine  
Texas A & M University, College Station, TX

**Brenda Finucane, MS, CGC**

Autism & Developmental Medicine Institute  
Geisinger Health System, Lewisburg, PA

**Shafali Jeste, MD**

Semel Institute for Neuroscience and Human  
Behavior  
UCLA Health Systems School of Medicine, Los  
Angeles, CA

**Janine M. LaSalle, PhD**

Medical Microbiology and Immunology  
UC Davis School of Medicine, Davis, CA

**Lawrence T. Reiter, PhD**

Department of Neurology  
University of Tennessee Health Science Center,  
Memphis, TN

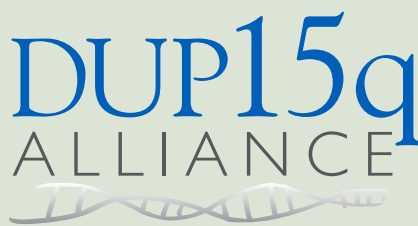
**N. Carolyn Schanen, MD, PhD**

**Sarah Spence, MD, PhD**

Department of Neurology  
Children's Hospital Boston

**Ron Thibert, DO, MsPH**

Pediatric Epilepsy Program  
Massachusetts General Hospital, Boston, MA



## Dup15q Alliance Staff

**Andrea Worthen** Administrative Assistant

**Alexandra Wendt** Development Consultant

**Stephanie DeLeon** Events and  
Administration Intern

**Adrienne Felterman** Accountant

## Introducing New Board Member: Tony Marmo

Tony Marmo joined the Dup15q Alliance board in July, 2016. Tony lives in Upper Saddle River, NJ with his wife, Nicole, and three children, son Tyler, and daughters Samantha and Madison. He has extensive experience in the healthcare market and in non-profits and brings a wealth of knowledge to the board.

Tony owns and operates Martab Medical, a business that provides innovative products and services to the healthcare market, and is the founding member and managing partner of the Marmo Group, LLC, a company that invests in start-up medical device companies. He has served as the President of the Board of Directors for the Independent Medical Distributors Association (IMDA), and worked on the Epilepsy Therapy Project as a reviewer of medical devices focused on epilepsy. Tony and his wife, Nicole, helped establish and served on the Board for the Garden Academy, a school that serves children with autism.

When Tony joined the board, he indicated that he'd "like to serve on the Board to help promote awareness as well as advance clinical research for people living with dup15q syndrome. Specifically, I'd like to leverage my 20 plus years of experience in the medical device and healthcare industry to help the Dup15q Alliance and its research partners discover targeted treatments that will help improve the lives of our children."

We are grateful to Tony for his willingness to share his expertise and his passion with our families and the Dup15q Alliance.



# Redondo Beach Fun!



*Besides being the site of our conference, there are many fun things to do in the Redondo Beach area and surrounds. Some families may want to make a family vacation out of this trip!*

**Beaches** – The beach at the Redondo Beach pier is quite touristy. If you are looking for something a little more laid back, Torrance Beach (RAT), 3 miles south of the hotel is more residential. North of Redondo beach, families will enjoy Hermosa Beach (2 miles) and Manhattan Beach (4 miles).

**Redondo Beach Pier** – The Pier is a South Bay landmark offering oceanfront dining, shopping and entertainment, including arcade, fishing off the pier, and people watching.

**Hermosa Beach Pier** – Hermosa Pier is very lively during the day as well as the night! Family oriented and great places for eating alone as well as with a crowd!

**Riviera Village** is a cozy neighborhood nestled in South Redondo Beach. The secluded, idyllic Riviera Village features over 300 unique restaurants, retail shops and services. Ride your bike or saunter along the streets lined with some of Redondo Beach's most distinctive boutiques, art galleries and craft studios.

**Bike Rental** – there is a little shop across from hotel with bikes to rent.

Ride all along the coast heading North towards Manhattan Beach -this will be a longer ride, highly recommended for biking enthusiasts. Or you could ride to Manhattan Beach and have lunch.

**Sea Lab** – this small aquarium/science center is convenient due to proximity – walking distance from hotel. If you love large aquariums, head to Long Beach Aquarium (30 minute drive).

**Stand Up Paddle Boarding** – Also within walking distance of hotel is TARSAN, a paddle surfing shop that offers lessons and rentals. TARSAN offers 60 minute lessons designed to introduce you to the stoke of stand-up paddle boarding while teaching you safety and technique with the intention of having fun at the same time. TARSAN offers private, semi-private, small and large group lessons. Lessons can be provided in the ocean or in the marina.

**Surfing** – RAT beach is a good spot for beginners. Boards can be rented at the beach. There's also a little café for food and drinks. Manhattan Beach near the pier is for more experienced surfers.

**Shopping** – There are wonderful shops in Redondo Beach, Hermosa Beach and Manhattan Beach. If you like mall shopping on vacation, the most convenient is Del Amo Shopping Mall. It's in Torrance, about a 15 minute drive from the hotel. They have everything including a brand new Nordstrom, an AMC theater,

and many restaurants. If you want to venture farther out, The Grove in west LA is pretty awesome. It's the old farmers market which is still there but it's a fancy outdoor mall with tons of really nice shops, restaurants and a movie theater.

## Love Notes

DUP15q  
ALLIANCE

*As part of our conference this year we are assembling a wall of encouraging and thoughtful words of hope from our generous supporters.*

### How can you help:

1. Go to [www.dup15q.org/lovenotes](http://www.dup15q.org/lovenotes)
2. Make a donation of \$15 to the Dup15q Alliance.
3. Fill out a virtual link with your name, the name of your favorite person or family with dup15q syndrome, or your well wishes.
4. Your Love Notes will be on display in Los Angeles during the conference, and we will post photos on our website.

# New Dup15q Research Published

by Nicole Cleary and Guy Calvert

Research into dup15q continues to be published at an exciting rate, expanding scientific understanding of dup15q syndrome. Because much of this research is highly technical bench science, it can be challenging for families to understand how these studies help move us toward the promise of targeted treatments. Here, we present three recently published studies and offer an overview of their significance.

## **A Quantitative Electrophysiological Biomarker of Duplication 15q11.2-q13.1 Syndrome**

Joel Frohlich, Damla Senturk, Vidya Saravanapandian, Peyman Golshani, Lawrence T. Reiter, Raman Sankar, Ronald L. Thibert, Charlotte DiStefano, Scott Huberty, Edwin H. Cook, Shafali S. Jeste

Many individuals with dup15q syndrome struggle with epilepsy at some point. Seizures can be crippling, and sometimes life threatening. The challenge for doctors is to figure out what kind(s) of seizure an individual is having, and how best to get them under control. An indispensable tool in this process is the EEG, a non-invasive test that scans and maps out electrical activity in the brain. Various kinds of seizures produce different patterns of electrical activity, which help point neurologists in the right direction for treatments.

This paper shares exciting news! This team of researchers have identified a specific EEG finding in dup15q syndrome that may help with treatment monitoring, and measurement of medication effectiveness for future clinical trials. By comparing the EEG of several groups of children (some with dup15q, some with “generic” autism, and some that were typically developing), researchers found that the children with dup15q had signature patterns of brain activity that were different from the other groups: spontaneous beta power were significantly higher in dup15q syndrome compared with both comparison groups, while delta was significantly lower than both comparison groups. The strength of one of the

characteristic EEG signals was linked to clinical aspects of the dup15q seizure disorder. Identifying this biomarker is exciting because it provides researchers an opportunity to evaluate changes from medication that may come before any clear behavioral change. Researchers may be able to see engagement of the biological target and, therefore, hope for clinical improvement.

The next two studies were made possible because of the donation of brain tissue to a brain bank at the time of death. These donations provide a critical resource in helping understand the effects of dup15q on the brain.

## **Genome-wide changes in lncRNA, splicing, and regional gene expression patterns in autism**

Neelroop N. Parikshak, Vivek Swarup, T. Grant Belgard, Manuel Irimia, Gokul Ramaswami, Michael J. Gandal, Christopher Hartl, Virpi Leppa, Luis de la Torre Ubieta, Jerry Huang, Jennifer K. Lowe, Benjamin J. Blencowe, Steve Horvath & Daniel H. Geschwind

This study reports on new understandings of gene expression patterns in autism, including dup15q. Brain samples were obtained from 49 neurotypical individuals, 39 individuals with idiopathic (no identified cause) autism, and 9 with confirmed duplications in the 15q region. Up to three brain regions from each individual were assessed in this study. The study demonstrated that chromosome 15q11.2-13.1 duplication syndrome (dup15q), shares the same errors in the molecules that convey genetic information (called messenger RNA molecules) that is observed in non-syndromic autism (autism not caused by a well known genetic variant).

## **Cumulative Impact of Polychlorinated Biphenyl and Large Chromosomal Duplications on DNA Methylation, Chromatin, and Expression of Autism Candidate Genes**

Authors Keith W. Dunaway, M. Saharul Islam, Rochelle L. Coulson, ..., Shin-ichi Horike, Ian Korf, Janine M. LaSalle

This study examined 41 postmortem human cortical samples, including some with dup15q, and cultured a human neuronal dup15q cell model. As a focused investigation on the brain, this study provides several important insights into genes, gene pathways, genome stability, and chromatin modulation in the complex causes of autism spectrum disorders, including dup15q. It also expands the scientific understanding necessary to start identifying existing drugs that could be utilized in therapies for treatment of autism spectrum disorders.

## **Coming Up: 2017 Conference Presentation on Brain Tissue Donations**

Alycia Halladay is the Chief Science Officer at the Autism Science Foundation. She oversees the science programs and portfolio. She previously served as Senior Director of Environmental and Clinical Sciences at Autism Speaks. She holds a PhD in psychology from Rutgers University and completed a postdoctoral fellowship in pharmacology and toxicology at Rutgers University.



# Volunteers

## Dup15q Alliance Cheers our Volunteers: Lauren and Marc Weissberg

In May, 2016, our son Holden was diagnosed with dup15q. After learning about Holden's diagnosis, we discovered that not much was known about it. We were given paperwork about the Alliance and very little else. Now, here we are, with our newfound family who offers support, hope, and explanations. In such a short time, the Alliance has made a profound impact on our family, and we want to give back. We know that doctors have a lot of knowledge, and we continue to pray that doctors and researchers will work to find treatments to help make the lives of everyone living with dup15q syndrome the best it can possibly be.

Our geneticist once said that he did not believe that gene therapy was out of the realm of possibility. For me, that meant that science just needed some time and resources to catch up. It was then that I decided I was going to do everything I could to raise money and awareness so that a treatment can be found, and our children can have better tomorrows. The idea for a fundraiser came to me one day during my kickboxing class. I thought it would be a lot of fun to offer a kickboxing class to raise money for the Alliance. I began to plan, but I wanted more. On a Friday night, I asked a bunch of local moms what they thought about adding a basket auction to my event and



the response was incredible. In less than 48 hours, I had 10 donations for my event. The very first "Hope for Holden to benefit the Dup15q Alliance" fundraising event, planned in just 2 months, raised just over \$10,000. I was amazed and determined to do more! I promised myself that in 2017, I would do my best to raise as much money and awareness as I possibly could. I have already secured a date (September 16, 2017) and a larger venue for the second annual "Hope for Holden to benefit the Dup15q Alliance" event, and our goal is to raise \$12,000 this year. In addition,

I have arranged for the school district I work for to participate in a district wide dress down day on February 28th for Rare Disease Awareness Day. The suggested donation is \$5/per person and we hope to raise at least \$1,000. I am also working with several of my friends who are LuLaRoe consultants to host an online sale on March 6th. 10% of the proceeds will be donated to the Alliance and LuLaRoe will match whatever amount is being donated. I am also going to do smaller raffles throughout the year to keep people interested in supporting us!

My hope for all of these events is to raise awareness of dup15q, and of course, money. I believe the money is necessary so that there is funding for research. My son is only 3 years old and I have every reason to hope, pray, and believe that a treatment will exist in his lifetime. I would also love to come up with something as brilliant as the ALS Ice Bucket Challenge for our organization because that was so incredibly successful! Volunteering with the Alliance could not be easier. The executive team will support you every step of the way, and offers so many wonderful suggestions. They are also so incredibly appreciative of our efforts, as are the families. Find something you enjoy doing and turn it into an event! 🙌🙌🙌

## 2017 Conference Thank You!!

Thank you to Michael Rozovics and Ruth Kross for helping make it possible for some families to attend conference.

**Riley's International Family Conference Award (RIFCA)** was created by Michael Rozovics, Riley's grandfather and founder of Roz Financial Services. RIFCA is designed to provide financial assistance to a registered Dup 15 Alliance family with limited financial resources so they can attend to the 2017 International Family Conference.

**Michael Kross Memorial Conference Award (MKMCA)** was created by Ruth Kross on behalf of her brother and uncle of Marlena (dup15q). Michael was extremely generous and opened his home to Ruth's family for several years. Some of his most favorite memories were from these years. He witnessed first hand Marlena's many early challenges including infantile spasms, dysphagia, endless doctor's appointments, nursing visits, therapies and was always there to lend a hand or give emotional support. Ruth shares, "My brother spent his life giving and helping other people. It is an honor to give back in his memory and provide financial assistance to a registered Dup 15 Alliance family with limited financial resources so they have the opportunity to attend to the 2017 International Family Conference."

## “I happy!”

Aiisha Ramiro and her husband David are raising Urijah and Bronson.

As I sit here struggling to find the right words to tell our family portrait story, my eyes are watery and tears begin to flow. The thoughts, the memories, the worries are all fresh and still make me very emotional. I'm sure many of you can relate and have felt this way at times through this journey of being a family with a child with dup15q. This is not my first attempt at completing this article; I've sat down many times over the past week trying to do just that.

I could start by listing all of Urijah's symptoms and disabilities, all his struggles. I could recall and list the day we got his diagnosis, his first seizure, the multiple hospital visits, the tests we ran, the specialist we've seen, the list would go on and on. But I won't, because you all have that same list- and that's what bonds us. We all know that there is another list that also bonds us and makes our “duper” that much more special: the cuddles and the smiles. The struggle and accomplishments are much more grand in our lives.

I feel like I cannot truly say how dup15q has affected our family or tell you how we've changed because Urijah is our first born, so our life doesn't know the difference. We don't know how it is to live a life without him and dup15q because it is a part of him and so we love every part. Do we wish he didn't have to go through everything associated with dup15q? ABSOLUTELY! And that's mostly because we hate seeing him in pain or struggling. As with any child we as parents want the best for them. We know we are who we are because of our experiences, and he has enriched our lives in so many ways we would've never thought possible. I know we can't change some things, we can only embrace it.



Urijah brings us so much joy - his love for his brother, his energy, his endurance and his cuddles are some of his best attributes. I am so proud of his accomplishments because I know how much harder it was for him to get where he is today. His smile and his laughter is infectious and even though his words are minimal, the best ones to me are when he tells me “I happy”, “Me fun” and “I love you”. All I want for him is to be happy, and seeing that light in his eyes is pure joy! He is a typical boy who currently loves Super Heroes, ninja turtles, Disneyland, playing water, playing ball, running and jumping! He is very affectionate to others and very friendly. He loves school and his classmates; he enjoys riding the bus and is well known on campus among students and staff.

I recently came across this saying - - “God only gives special needs children to special parents”

Not TRUE -----

“God gives special needs children to every day parents, who choose to step up and be strong for their child! That special child teaches life lessons that you never could have anticipated, and through your

journey together, you learn how to become the parent that your child needs!”

Our family lives our lives day by day, with a loving, caring and thoughtful 7 year old boy, a rambunctious and curious 2 year old boy, and two loving and strong parents who, like most, just do the best they can. We are truly Blessed! 🙏👨👩👧👦



# Remembrances

In this issue of the MIRROR, we want to celebrate three lives that touched so many.

## Sarah Kate Bernaldo

was born January 24, 1994. While we miss her every day, we are grateful that we got to spend as much time as we did with her, to learn from her, love her, be challenged by her, and laugh at her wicked sense of humour. Stealing biscuits from the kitchen cupboard, backing up and sitting on



your knee, dragging people to the door to be let out, singing and clapping, standing in front of the TV, dancing in circles, or shadow dancing outside in the sun; at these times she was pure joy. Her presence has left each of us with a personal legacy of growth and understanding. Honour her imprint by being open to the realisation that a broken body can house the most beautiful light. Fill your lives with laughter every day, with joy and the re-awakening of the child within who sees wonder everywhere they look. Sarah did, and that's her legacy.

## Layton Cade Roberson

was born on June 2, 2008. God allowed us to borrow one of his angels, named Layton, for eight short, yet beautiful years. Layton touched the hearts and lives of everyone he met, and he had a unique gift of speaking with his big beautiful eyes. His eyes spoke to us and taught us about joy, forgiveness, patience, unsurpassed peace, the absence of judgment, the absence of anger, and the complete absence of fear. His big, beautiful, innocent smile allowed him to make friends wherever he ventured, be it parks, trails, someone's backyard, the grocery store, church, restaurants, school, or daycare. Layton Cade Roberson, you are an extraordinary angel that has returned home after completing your assignment with honor and grace and perfection



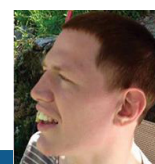
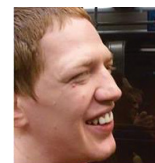
## Kyle Barrett

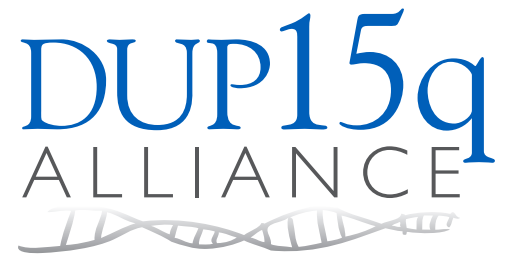
was a much loved son, brother and friend. His brother Mac and his sister Krystin were part of his direct care staff, and his sister Kati adored him. Kyle loved water, bacon, pizza, french fries, kale chips, music, going out with his siblings, rides in the car, giving hugs, barrettes for hair (he called them "clip-clips"), and chicken, which he would always celebrate with "you don't eat the bone, 'das right". Kyle and his Mom

### Kyle Palmer Barrett "WILD KYLE MAN" July 1, 1984 - January 29, 2017



lived in the same apartment complex. On his last day they went for a ride, had pizza, and played singing games. At Kyle's celebration of life, the podium was down among the congregation to show that all are included in God's family. The opening song was Leonard Cohen's "Hallelujah". It is a song Kyle loved (he laughed with delight when he heard it as a ringtone on his Mom's phone). Kyle only knew love in this life, and it is this love he leaves us with.





**Navigating the Future  
(2017)  
9th International  
Dup15q Alliance  
Family Conference:  
Navigating the Future  
(2017)**

**July 24 - 26, 2017  
Crowne Plaza Redondo  
Beach and Marina  
300 N. Harbor Drive,  
Redondo Beach, CA**

“We are looking forward to our International Family Conference this July in Redondo Beach California! Even if you are not planning on attending, one way you can help us make it another successful year is by donating to our raffle or sponsoring a part of the conference (there is a level for everyone)!

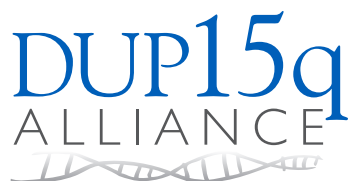
Hosting our family conference costs tens of thousands of dollars. Only a small percentage of that is covered by your registration costs. For the rest, we fundraise. View our sponsorship packet at <http://www.dup15q.org/events/family-conferences/navigating-the-future-2017/>.

Maybe you are willing to make a donation or maybe there is a business in your community that you'd be willing to ask? Every sponsorship makes a real difference. Together we can create a better tomorrow for all those affected by dup15q syndrome! Online sponsorships via credit card can be made here. We are asking for donations of state/country themed baskets, products, gift certificates, and asking friends and family who own businesses if they would like to donate. We had over 100 baskets for our last family conference! Help us make this conference raffle the best one yet.

Please contact [conference@dup15q.org](mailto:conference@dup15q.org) if you would like to sponsor or donate a raffle item and for shipping information if you are not attending the conference! Thank you all for your support of our Super Dupers!”

**<http://www.dup15q.org/events/family-conferences/navigating-the-future-2017/>**





Dup15q Alliance  
P.O. Box 1669  
Highland Park, IL 60035  
Phone: 855-Dup-15qa (855-387-1572)  
<http://www.dup15q.org>



Please help us to make it 10 sites this year!!!  
We would love to have at least ten walk locations this year, and to expand beyond the United States. If you are interested in organizing an event in your community or would like to help with one of the walks listed above, please email us at [info@dup15q.org](mailto:info@dup15q.org) to get started.

### BELIEVE WALKS: OCTOBER 1st 2017

**REGISTER:** [www.dup15q.org/events](http://www.dup15q.org/events)

**COST:**  
Non-Dup15q Alliance Member (ages 13 and older): \$200  
Adults (Dup15q Alliance member-13 and older): \$150  
Child (Under 13): \$100  
Dup15q individual (all ages): \$Free  
Under 2 years old: \$Free  
Includes 2 lunches (Monday and Tuesday), 1 dinner (Monday night),  
And Water park (Seaside Lagoon) admission (Tuesday night)

**CONFERENCE ROOM RATE:** \$197/night \*\*Book rooms through [www.dup15q.org](http://www.dup15q.org)  
**WHERE:** CROWNE PLAZA REDONDO BEACH AND MARINA, CALIFORNIA, U.S.A.  
**WHEN:** MONDAY, JULY 24 TO WEDNESDAY, JULY 26, 2017

### 9th INTERNATIONAL FAMILY CONFERENCE: NAVIGATING THE FUTURE 2017



# ANNOUNCEMENTS

Dup15q Alliance is a nonprofit organization that provides family support and promotes awareness, research and targeted treatments for chromosome 15q11.2-13.1 duplication syndrome (dup15q). Dup15q Alliance offers help and hope for families affected by dup15q syndrome.

