



# Celebrating our Clinics !!



## Nicole Cleary, MIRROR Editor

As recently as five years ago, there were no specialty clinics for dup15q. Families and doctors had to glean what they could from research articles and, if they were lucky, a conversation at an Alliance conference with a doctor or researcher who had seen a few individuals impacted by dup15q. Families repeatedly heard some version of “we’ve never seen another patient with this disorder” and families found themselves educating their doctors about dup15q. This scenario changed for the better in 2011 when the first dup15q clinic was established at Massachusetts General Hospital.

The United States now has nine dup15q clinics, each using a multidisciplinary approach to provide comprehensive evaluation and treatment of the complex needs of individuals with dup15q. These clinics address medical needs ranging from sleep problems to seizure disorders to gastroenterologic problems to neuropsychological issues.

In addition to providing the most informed treatment available, the clinics are collecting information about dup15q syndrome and collaborating with Dup15q Alliance Professional Advisory Board members to publish articles in scientific journals. In May 2016 the Journal of Neurodevelopmental Disorders published the article on the “Identification of a distinct developmental and behavioral profile in children with Dup15q syndrome” (J Neurodev Disord. 2016; 8: 19) based on children recruited through the Alliance and the UCLA dup15q clinic.

All of this is a cause for celebration, and we are celebrating our clinics in this issue of *the Mirror*. Families who have visited a dup15q clinic share their experience in the Family Voices feature. You will learn about clinic coordinators, and recommendations for families visiting a dup15q clinic, and an interview with Jennifer Young, a clinic coordinator at the Minnesota Epilepsy Group, about recommendations for families visiting a dup15q clinic. Because of the committed fundraising of our families, the Alliance is able to invest in clinic coordinators in Boston and UCLA, two of the busiest clinics. We want to build on this great momentum! Summer is a great time for road trips, so we are planning a clinic celebration that takes the form of a fun virtual caravan to the clinics. Kim Maring, Alliance Operations Manager, outlines how we will celebrate the clinics and raise money to support the excellent work they do.

Through the evaluation and treatment of individuals with dup15q in the clinics, we are learning more about dup15q syndrome and promising treatment options every day. Our clinics improve the lives of individuals with dup15q by using the most effective diagnostic tools and treatments known today. They also provide the basis for hope that in a not so distant future, we will have specifically targeted treatments for dup15q syndrome.

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

# FAMILY VOICES

## Dup15q CLINIC EXPERIENCES



### *We found a collaborative network of clinics*

**Lisa Feehery**

When Gavin was first diagnosed with interstitial duplication 15q syndrome in 2011, there were no dup15q clinics. But we had the great fortune to meet with Dr. Carolyn Schanen, a dup15q specialist at Dupont Nemours Hospital for Children in Wilmington, DE. She answered all our questions about genetics, research, therapeutics, baseline testing, and expectations for the future. She gave us a positive vision for what Gavin would be able to do. It was invaluable.

Three years later, we also went to the Boston clinic at Mass General to see Dr. Thibert and his team. Dr. Thibert has personally seen about 100 people with dup15q and is a world expert in pediatric epilepsy. Our son does not have seizures, but we wanted to have a relationship with Dr. Thibert in case Gavin developed them in the future. Dr. Thibert had read Gavin's EEG sent to him by Dr. Reiter's interstitial study at Le Bonheur Children's Hospital in Memphis, so he knew our child's brain already!

It was very valuable to be able to talk about our son's challenges with experts who really know this rare syndrome, instead of being in our usual role educating doctors about it. After Carolyn Schanen and Brenda Finucane moved, there are no dup15q experts in the greater metropolitan area near our home. Our local developmental pediatrician is very reluctant, for example, to prescribe stimulant attention meds for a kiddo with a condition that often develops seizures; it is great to meet with a dup15q expert who has pattern recognition about what works and doesn't work with our kids.

Our visit to the Boston clinic helped us to screen for multiple medical conditions that might be present, so we did a blood test, an EKG, an EEG and eye exam. As Gavin had previously been diagnosed with autism at 19 months, he had already done a bunch of developmental testing and tracking over the years.

There is a lot of conflicting information out there about autism treatments--from supplements to diets to therapies--and again, it was very reassuring to get medical advice specific to our kid's real diagnosis (autism secondary to dup15q). It gave us confidence that our intensive ABA, OT, PT, social skills and speech therapy programming was the

way to proceed, and encouraged us to continue with academic skills instead of just adaptive skills.

We participated in dup15q studies in both Memphis (2013) and at UCLA (2015) and were able to talk with the researchers and doctors about our child and patterns they were seeing with the other children. We've also had stem cells extracted from teeth we sent in!

We technically only went to one clinic, but we found that everybody in this network collaborate together on understanding our kids better.

### *He references commonalities he's learned about kids with dup15q*

**Colleen Lowell**

Seattle's Dup15q Alliance Clinic is housed at Swedish Medical Center in their Neuroscience Institute. It is headed by Pediatric Neurologist Dr. Marcio Sotero de Menezes. Our daughter Grace has been seen there by Dr. Sotero for a number of years. Since becoming one of the official Dup15q Alliance clinics a few years ago, Dr. Sotero has seen a handful of dup15q patients in Washington. He also speaks regularly with other dup15q clinic doctors and attends conferences to share information and gain knowledge on the population as a whole. I love that whenever we see him, he references commonalities he's learned about kids with dup15q, such as medications that seem to work better than others with our specific population. Using information learned from the network of clinics has helped Dr. Sotero be more informed and knowledgeable about dup15q for our kids.

We typically see Dr. Sotero twice a year. In addition to that, we see the clinic's very well-informed nurse practitioner, who works closely with Dr. Sotero. It is easy to get ahold of them to schedule appointments and speak with nurses. I feel thankful to have a Dup15q Alliance Clinic with an exceptional neurologist nearby!

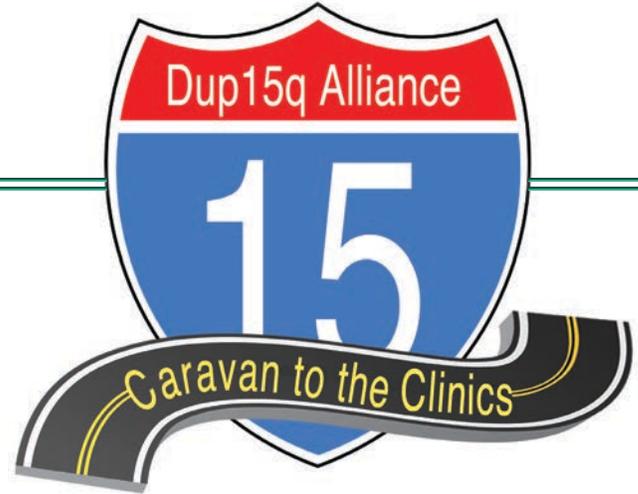


## *Kayden is doing better than he has in years*

**Teana Ebensperger**

My son, Kayden (dup15q), has suffered from seizures for 7 years now. In 2013, we were at a loss as to how to proceed because his neurologist at the time wanted to go a different direction for seizure control. We didn't have the means to travel all the way to the dup15q clinic in Memphis or Boston, the ones most near to us. I had heard about a neurology clinic called Minnesota Epilepsy Group in St. Paul, MN and took a chance on a new neurologist, Dr. Dimitrios Arkilo. I invited him to our Dup15q Alliance Conference that summer in Bloomington, MN. It was there that I asked him if he would be interested in starting the first clinic in the Midwest for dup15q families. He graciously agreed, and the clinic opened in October of that year with Kayden being the first patient. Our experience at the dup15q clinic in St. Paul has been nothing short of exceptional. Dr. Arkilo is truly family to us, and is one of the most compassionate, kind, and genuinely caring individuals you'll ever meet. His nurse, Jennifer Young, is also amazing and has been wonderful to work with. Going from not having anywhere to turn to and now having this valuable resource so close to home has been very comforting and life changing for Kayden and our family. We have been to the clinic a few times now and although we may never have complete seizure control, Kayden is doing better than he has in years and we owe it all to Dr. Arkilo and the St. Paul Dup15q Clinic. It's also been very rewarding being able to help so many other Midwest families have access to a regional location. We feel extremely grateful and blessed to have the opportunity to be a part of a dup15q clinic.

# Meet a Dup15q Clinic Coordinator



In the last issue of *the MIRROR*, the Alliance announced its \$10,000/year investment in clinic coordinators for Boston and UCLA. We want to help families understand how this investment benefits families visiting a dup15q clinic. Jennifer Young, a clinic coordinator for the dup15q clinic at the Minnesota Epilepsy Group was happy to share information about what clinic coordinators do and how they support families visiting their clinic.

## *What do clinic coordinators do in a dup15q clinic?*

Clinic coordinators wear many hats. It starts with the initial intake, understanding the unique needs of each family, and ensuring the clinic day runs smoothly. There is plenty of behind the scenes work as well, such as gathering records and coordinating with multiple providers. We strive to guide families step-by-step through the process leading up to the appointment(s) and help with what to expect when they arrive. After the patient is established in the clinic we continue to build on the relationship and the patient will guide us from there.

## *What do you like best about being a dup15q clinic coordinator?*

The most rewarding part about being a dup15q clinic coordinator is interacting with the patients and their families. Getting to know the patients and watching them grow and transition between stages of life is incredibly satisfying. Developing relationships over time with these remarkable patients and their dedicated parents is truly gratifying. This group of parents is noteworthy and admirable, and it is a pleasure to be on their side working to achieve whatever goals we have set in place for their child.

## *What are some of the common challenges families should prepare for when visiting a dup15q clinic?*

Be prepared for a big day! There will likely be an overload of information and it can make for a long day, sometimes multiple days. My advice, which is easier said than done, is to try not to get overwhelmed with the information and remember we are here for you. It is very normal to leave with no questions and then before you get home, sometimes before you even get to the car, a list a mile long starts forming in your head. This is no problem; just make a list and give us a call and we can run through it together. Remember, we are here for you for the long run.

## *Do you have any other suggestions for families considering a visit to a dup15q clinic?*

My suggestion for families would be to set this appointment up during a time when the patient is not in crisis, a.k.a sooner rather than later. Although we can definitely help and will work to get families in sooner if needed, it is best to establish care with a new provider when the patient is stable. Even if families don't have many concerns currently, getting to know the family and patient when things are stable gives us a better understanding of their baseline. Then, if anything changes or concerns arise down the road we know where we were coming from and where we need to go. There is also the benefit that if we have time we can better coordinate any needed appointments and make the trip more worthwhile. This is most important for families who may be traveling from farther away.

Another good thing to consider when visiting a dup15q clinic is the Dup15q Alliance Multidisciplinary Clinic Database. We are working to create a searchable collection of information for medical professionals about patients with dup15q. The purpose is to collect information about duplication15q syndrome over a long period and work to improve care, treatment, and provide a happier life for these individuals. This is not something families have to participate in but it is available to them.



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# Caravan to the Clinics

Kim Maring, Dup15q Alliance Operations Manager



What was once a dream to have specialty clinics for dup15q is now a reality! Dup15q Alliance has facilitated the creation of nine dup15q clinics in major medical centers around the United States. These clinics see patients with dup15q syndrome, share information with each other in regular clinic meetings, and a multidisciplinary clinic database was successfully launched at the Memphis site in 2014.

This summer we are going on a virtual road trip to celebrate the clinics, and we invite you to join our Caravan to the Clinics! Along our 6,337 mile journey we are raising money to improve and expand the clinics. Each \$10 donated sponsors one mile of the trip. To follow our adventure or make a donation, [visit www.dup15q.org/caravan-to-the-clinics](http://www.dup15q.org/caravan-to-the-clinics).

We start our road trip in Boston, where it all began. We owe a huge *thank you* to Dr. Thibert who took a giant leap and founded the first dup15q clinic at Massachusetts General Hospital in 2011. Over the last five years, families have come from near and far for the specialized care that their children need. Along the way, our caravan will also visit New York, Lewisburg, Miami, Memphis, St. Paul, Seattle, San Francisco and Los Angeles. We will update our website at each stop. Check back often to see how far we've gotten.

Our clinics are not only centers of excellence in medical care, but they are hubs of research, continually expanding our knowledge of dup15q syndrome and working to find the best possible treatments. As always, our goal is to give each person with dup15q syndrome the best quality of life now, while striving for future treatments targeted specifically to the genes affected in dup15q syndrome. The clinics provide the winning combination of knowledge, compassion and research to help us reach our goals.

Families who have visited a clinic give them rave reviews. We have heard:

*“The doctors, clinic coordinators and staff were nothing but helpful, kind and welcoming to our family! It was so nice to talk to people that truly understood our situation and could give us information and answers about our son’s condition.”*

*“We love having doctors who know about the syndrome and can talk to us on an educated level. The care we have received at the dup15q clinic doesn’t compare.”*

*“Visiting the clinic was better than visiting our local doctor because they understand our kids and their unique ways without having to tell them!”*



But our clinics would not exist without our caring supporters. Dup15q Alliance is a small nonprofit and our programs rely upon the generosity of our friends and families. So whatever adventures await you this summer, please make sure to join us in our Caravan to the Clinics!

## Let's Get Together

Regional gatherings are a terrific way to meet other Dup15q Alliance families. We've been told over and over again how valuable it is to hear the stories of families who really understand what living with dup15q syndrome is like. Share your tips, tricks and best ideas for conquering life's challenges and chat with other families like yours in a comfortable, friendly setting.

No experience is necessary to host a gathering and it can be as simple or as fancy as you'd like. Sometimes gatherings have just a couple families; bigger ones can have 10-15 families. Size depends on a variety of factors, including how many other Alliance families live close to you. Our membership list is constantly growing and we are happy to give you an idea of how many families are nearby.

Typically the host family picks a date, location and what the event will be. Meeting at a playground, park, zoo, or your backyard works well. Often families will choose to include a pot-luck or picnic meal. We find that family-friendly ideas that are good for a variety of ages work best. If there is an activity that your child loves, chances are others will, too. We have also had regional gatherings that include educational speakers, such as therapists or clinicians, or parent-only get-togethers which give the adults a chance to talk without distraction. Most of our fundraising events, such as the Believe Walk, have regional gatherings held in conjunction with them, too. Really it's all up to the hosts and is limited only by your creativity.

Dup15q Alliance has \$200 grants that are available to host families to help cover the costs, such as space rental or food. We will also help by sending out invitations to Dup15q Alliance families in your area. Contact Kim at [kim.maring@dup15q.org](mailto:kim.maring@dup15q.org) if you have questions or are interested in hosting a regional gathering.



**Spring, 2016 Northern California Dup15q Gathering, from left to right:** Simon Segars and Rachel with their son Luke (hosts and gathering organizers). In the middle back you can see the Evaristos: Norma and Adam with their lovely daughter Lauren, Next to the Segars you can see Wendy Yang with her daughter JJ, Monica Reina is behind her son Dylan's stroller, and finally you can see Jane Kim carrying her son Zach with his older sister Abby standing next to them.

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## Cheers to Our Volunteers!



*The Dup15q Alliance cheers Tiffany and Justin Ciero. They are hosting a Believe Walk in Evensville, Tennessee. We send a special THANK YOU to all families hosting Believe Walks in 2016. Your efforts strengthen the Dup15q Alliance and support our mission.*

We found the Alliance around September, 2013, shortly after our son's diagnosis. He had just turned 2. The Alliance has been an invaluable resource for our family. The website offers a wealth of knowledge and guidance for new families as well as those of us who have been members for a while. I find myself referring back often.

The parent support group has been our lifeline. It's truly amazing to be able to connect with so many other families who truly "get it"....whether it's a problem, or rejoicing together over a victory, or laughing so we don't cry, or being a shoulder to cry on, we've experienced it all with this amazing group. Because of the Alliance, we've been able to visit a dup15q clinic and participate in a research study which we were so grateful to be a part of. The list could go on...

We decided to host a Believe Walk in 2016 at our local high school because we want to be advocates for our son. We want people to know about dup15q syndrome to help raise awareness and funds for research for this disorder. We know that the more people who know about it, the more likely they are to donate or help raise awareness as well! Our goal is to get the people of our small home town of Evensville, TN involved in raising awareness. We want everyone around us to know what dup15q syndrome is! The other reason we are hosting this walk is to bring other dup15q families together. We would love to have as many dup15q brothers and sisters as possible at our walk! We're all in this together!

The most exciting part of preparing for the walk is getting out in our communities and being able to say "Hey have you heard of dup15q syndrome?" and proceeding to talk to them about it and make others knowledgeable about this disorder. We are also very excited at the thought of having several dup15q families together in the same place and being celebrated.

## Did you know?

Did you know that only 13% of our member families fundraised for or donated to Dup15q Alliance last year? But far more than half have participated in our programs!

Dup15q Alliance is the only U.S. nonprofit whose sole mission is improving the lives of those affected by dup15q syndrome. While we can dream many different ways to assist our families, our ideas are limited by the funds we have available. Every dollar donated to the Alliance makes a real difference. We work hard to keep expenses low, but we need your gifts to continue to make strides for better tomorrows!

There are many ways you can help. You can make a donation to our Caravan to the Clinics fundraiser and encourage your friends and family to do the same. Or how about hosting a Believe walk on September 18th? We are still accepting new locations until June 30th and will provide you with all the instructions. If you aren't available on September 18th, plan your own event. We can provide you with your own web page and online donation form. We are here to support you in all your fundraising endeavors. The first step is contacting us at [info@dup15q.org](mailto:info@dup15q.org). We hope to hear from you soon!

## He surprises us every day with something new he has learned

# Family Portrait



ROBERT AND ADRIENNE PARADIS,  
ROXBOROUGH, COLORADO

Our son Aidan was born in 2006, and like many dup15q parents we knew something was different early on. But being new to the parenting world, we didn't want to overreact to every missed milestone. When he never cried (not even when he was soaking wet), never looked at us when we entered the room, never tried to roll over or crawl, and never made any sounds by 9 months old, we definitely knew something was wrong. The developmental pediatrician at Children's Hospital suspected Fragile X and ordered genetic testing. When the results came back with isodicentric 15q tetrasomy 11.2 – 13.2 along with a microduplication at Xp11.22, she didn't have a lot of information.

Since Aidan was mostly displaying autism characteristics, we focused more on therapies for that without having a full understanding of how dup15q was impacting his life. Once we overcame the shock of having a special needs child, we decided that even though his life would be consumed by therapies, we wouldn't treat him any different than if he was a typical child. We didn't view him as being broken

and needing fixing, we viewed him as a child that needed help and guidance to overcome some obstacles. All of his therapies are woven into everyday life and are based around play. From his point of view, he isn't overcoming a sensory issue, he is playing with play-doh or silly putty. He isn't learning how to shape his mouth to form words, he is blowing a whistle. He isn't building up muscle tone and working on balance or coordination, he is jumping on a trampoline.

After several years of therapy we were seeing progress but not as quickly as we had hoped. We began doing more research into dup15q and came across the IDEAS website and realized that the autism was secondary to the dup15q diagnosis. We attended our first conference in 2013 in Minnesota and were blown away at the diversity of those affected with dup15q. We met some amazing parents who were living the same lives we were living and fully "got it." We were also amazed at how incredible all the kids, and a few adults, that have dup15q were. Given all that they have to deal with, they would still greet you with a smile. We were also really grateful to hear about all the current and ongoing research into the disorder. Once we returned home, we had a new understanding and respect of how Aidan was interacting with the world. We began learning all that we could about dup15q and couldn't wait for the next conference.

The more we learned about dup15q the more we understood how Aidan's body functioned and we were better able to focus therapies to specific areas. We finally understood why he didn't fit into the typical autism profile. We were able to educate his teachers, therapists, and even his doctors regarding the specific challenges that face those affected by dup15q. We now just laugh when they all say "it is unusual, rare, or never seen that before!" After seeing numerous different specialists over the next few years, Aidan received multiple secondary diagnoses including: hypotonia, sensory processing disorder, apraxia, cognitive impairment, global developmental delay, moderate/severe autism, bilateral strabismus, GERD, femoral anteversion, cortical visual impairment, second degree heart block Type I and Kohler disease.

Despite these challenges, he has the most amazing smile and infectious laugh. He also likes exploring his surroundings - although sometimes not in the most appropriate ways. While we try and be vigilant and prevent him from licking things, he is very sly and fast. He likes to lick whatever he can, including door knobs, windows, the glass at the aquarium, escalator handrails, toilet seat (just once or twice), etc.

Luckily, we have been able to integrate him into our neighborhood school with a 1:1 para. He spends 40% of the time with his peers and 60% in a significant support needs classroom. We found that Aidan's progress is slow and steady, and he has his own timetable. He has taught us patience, unconditional love and what is important in life. Our beautiful boy is happy, loving, courageous, tenacious and he surprises us every day with something new he has learned. We love him so much, and wouldn't trade him for the world!



## If I could write a letter to myself on the day I received Erin's diagnosis

Eileen Flood O'Connor, Rye, New York

*\*This article was originally published in TheMighty.com, an online community where people share stories about disability and disease.*

**Our daughter, Erin, 14, was diagnosed with dup15q at 22 months. We had recently moved back to New York from London, where she and her younger brother were born. Our son was four months old at the time.**

Okay, breathe.

Yes, you heard right. Erin was diagnosed with something called isodicentric 15. I know. *What the hell?* That wasn't in the realm of things we worried about. She has ten fingers and ten toes. But she also has an extra part of chromosome 15. Yes, you heard right. Developmental delays. Speech, language, motor impairments. No, this is not good. But it confirms what you've been thinking for the past 22 months. Something was not right. So in a way that's a positive. Your instincts were right.

But I know you're not feeling very positive right now. And that's ok. It's ok to take some time to be sad – and to process what the very unfeeling geneticist outlined. But don't ignore it because you're mad at him. Don't space out and slip into denial. You heard him mention PT, OT, Speech Therapy. Early Intervention. Get on that.

And do not dismiss that scary sounding therapy, Applied Behavior Analysis, just because the slide show and presentation at the seminar made it look cruel and unusual. And do not ignore the urging of the woman from the agency who suggests a home-based 40-hour a week ABA program just because you don't like the way she sits on your sofa and sizes up your mess. Do not dismiss her because you suspect she really just wants to get Erin out of the classroom. It's okay. Let your guard down and realize that oddly enough there are people out there who want to help Erin – and know how. Curt manner aside, this woman actually knows what she's talking about. ABA will help. It's not going to isolate her. Erin needs it more than she needs to sit alone in the corner of a classroom spinning the wheels of a matchbox car. It will help her. It will draw her out of herself. She will learn to sit and to listen and to respond. She will learn to communicate.

Steel yourself. It will not be easy. It will be gut-wrenching to hear your three-year-old daughter crying because she doesn't have the words to say that she just wants to sit on the floor and admire the ceiling fan. You don't want her to go through life comfortable and happy only when she gets what she wants.

ABA will take her a long way.

But when you feel she has plateaued and you learn of new therapies, don't torture yourself about leaving her team of teachers. They know how you feel. You can never thank them enough. But it's time. It will be okay. Be confident. You are the mom. And you're a good mom.

Give yourself a break. Don't feel guilty. Don't blame yourself and don't blame your husband. Don't blame the move to London or that you sometimes drank unfiltered tap water or a glass of wine. Don't blame the cups of coffee. Don't blame EU emissions standards. Do not blame Tony Blair.

Bad things happen for no reason all the time. You know this. Don't feel guilty. You did what you were supposed to. You took the vitamins. You avoided soft cheese. No, you didn't deserve this, but people don't get what they deserve. They get what they get.

You get what you get and you don't get upset. In a few years your son will skip home from pre-school reciting this mantra. He will still get upset when he doesn't get what he wants. And you can too – for a short time. Then get on with it and realize that while this diagnosis is bad, it is not the end of the world. In fact, if you're up for hearing it now, it will bring many positives.

This diagnosis will bruise but not break your heart, your family, your marriage. It will strengthen and enrich every relationship in your life. It will stretch your soul. But before you can begin to understand this you have a lot of work to do, and so many exceptionally kind people to help along the way. Some you have known all along, some you will know for only moments. But with a smile or a word they will remind you that you can do this. You can't see them from here, from this awful chair, in this awful office, on this awful day. But they are out there waiting for you.

So get going and enjoy your daughter. Don't focus on what she can't do or is not doing by the time she is "supposed" to be doing it. Celebrate what she manages to do on her very own timetable.

Know that she will learn to walk and talk. In fact one day she will walk miles beside you and talk and sing about the sun and the trees and how they dance in the wind.

She will learn to hug and to love.

Hug and love her back and go home and hold your son. Hug him as much as you can and celebrate his milestones too. Don't be sad when he surpasses Erin. Incredibly enough you will have two more boys who will do the same. This is okay. You will be blessed with four very different children with unique personalities, interests and strengths. Don't compare and contrast. Celebrate them. Listen to them. Learn from them.

This will not be an easy road. Your sadness will be cyclical. But on the darkest days know that it will always abate and the good and beautiful moments and people will far outnumber the bad. Have faith in this and that Erin will one day teach you and all who cross her path what matters most: love and hugs – and dancing trees.





COMPILED BY ALISON KALNICKI

Nonsolo15, the Italian dup15q syndrome advocacy group, is hosting a European Meeting in Italy, from September 9th to 11th, 2016. They invite you to come and connect with others in the dup15q community!

Nonsolo15 was founded in 2008, when Italian families, friends, and professionals involved in the lives of those affected by dup15q syndrome joined forces to improve the quality of life for all who have dup15q. Nonsolo15 has become a force of action and positive energy, working to break down isolation of families and professionals by sharing information about daily life and scientific advances from around the world. Nonsolo15 has also spearheaded scientific research to shed light on some of the mysteries of this rare genetic syndrome. Their website is <http://www.idic15.it/>

## LOCATION

The European Meeting will be held at Pax et Vita – Villa Sacro Cuore, a peaceful Catholic seminary in Triuggio, in the beautiful Brianza area, which is close to Milan, Italy. Go online to <http://www.villasacrocuore.it/> to learn more about the villa.

## ATTENDEES

Mainly European families are expected to participate, but all international families are welcome! Also, Nonsolo15 reminds everyone to invite care providers, therapists, educators and medical professionals who work with children and adults who have dup15q syndrome.

## LANGUAGE TRANSLATION

Professional translation between Italian and English will be available on Saturday. The discussions for men's and women's groups on Friday will likely be divided into mini-groups by language, so participants are able to communicate with others who speak the same language.

## SCHEDULE

The details of the schedule will continue to get fine tuned as the European Meeting approaches. Currently, two Dup15q Alliance Professional Advisory Board members are planning to present at this meeting, in addition to many Italian professionals. At press time, here's what is on the agenda.

*Friday, September 9th* has been set aside for specialists to meet. Please contact Laura or Lorenzo for more information about the schedule for scientists and therapists. Friday also will see an Opening Ceremony and presentations by Nonsolo15 and Dup15q Alliance. Friday will wrap up with separate sessions for men and women to discuss how dup15q syndrome has impacted their lives.

*Saturday, September 10th* will be a day full of informative sessions such as:

- "Family and Disability" presented by Dr. Andrea Dondi
- "Towards Autonomy" by Dr. Maria Mastino
- "Sensory processing disorders: how to manage self-stimulatory behaviours" by Dr. Mauro Mario Coppa

# EUROPEAN MEETING

## September 9th to 11th, 2016

*"We love sharing info, meeting other families, and sharing about research and therapies. We love having fun together!"*  
 – Laura Piredda, Nonsolo15 President

Also planned for Saturday are updates on research projects and studies:

- "Study protocol: validation study of the diagnosis of Dup15q Syndrome, objectives and experimental plan" by Dr. Ettore Beghi
- "Which therapy for chromosome disorders associated with mental disability?" by Dr. Orsetta Zuffardi
- "Epilepsy in Dup15 Syndrome" by Dr. Giovanna Randazzo
- "Dup15q and Angelman Syndrome stem cells / Research Update" by Dr. Stormy Chamberlain

*Sunday, September 11th's* schedule currently has a discussion facilitated by Dr. Andrea Dondi about "How Dup15q Syndrome changes the lives of relatives, friends and volunteers" followed by a meeting of Nonsolo15 Shareholders.

## CHILDREN'S ACTIVITIES

In addition to a break room and an outdoor area for children, activities are being planned. Examples include:

- *Saturday morning* a local circus comes to the villa. Children will see jugglers, acrobats and more: <http://www.spaziobizarro.com/>
- *Saturday afternoon* children do a dance laboratory with dance therapist, Dr. Serena Fantini, then do a giant bubbles activity.

## COSTS

The registration or participation fee is €150 (euros) for each family (not per person) or €100 (euros) for a single individual. This fee includes Friday and Saturday nights' accommodation (single beds/private bathrooms) and seven meals for all members of the family. Participants are responsible for transportation costs to and from the meeting, and all other costs. To calculate euros into another currency, such as American dollars, use an online currency converter like this one: <http://www.xe.com/currencyconverter/>

You may be able to lengthen your stay at Villa Sacro Cuore for additional costs. Prices vary depending on menu selections, age and number of occupants.

## VOLUNTEERS

Nonsolo15 is looking for qualified volunteers to look after children with dup15q syndrome (1:1 assistance) and their siblings. Interested? Please contact Laura or Lorenzo (see below).

## TO REGISTER CONTACT:

**Laura Piredda** [piredda.laura@gmail.com](mailto:piredda.laura@gmail.com)  
 tel 0039 347 0467585

OR

**Lorenzo Cerutti** [lorenzocerutti@yahoo.it](mailto:lorenzocerutti@yahoo.it)  
 tel 0039 335 7206636

*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...

### **EUROPEAN CONFERENCE -- YOU'RE INVITED! SEPTEMBER 9 – 11, 2016**

Italy's Nonsolo15 group is sponsoring a dup15q syndrome meeting near Milan, Italy from September 9-11, 2016. Join some of our European families as they gather at a lovely Catholic seminary to learn and share about dup15q.

### **BELIEVE WALKS, SEPTEMBER 18, 2016**

We're walking for our kids on Sunday, September 18th. We currently have confirmed walk sites near  
Atlanta (GA),  
Boston (MA),  
Evensville (TN),  
Honolulu (HI),  
Indianapolis (IN),  
Medford (NJ),  
Miami (FL),  
Seattle (WA)  
Syracuse (NY)

Are you interested in hosting a Believe walk on September 18th? We are still accepting new locations until June 30th and will provide you with all the instructions. Contact us at [info@dup15q.org](mailto:info@dup15q.org).

<http://www.dup15q.org>

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