The Seventh International Conference on Isodicentric 15q and Related Disorders is just around the corner! The Conference Committee has been working hard to bring you the Reach for the Stars Conference, which will take place in Minnesota this summer. In this issue of The Mirror, learn about the inspiring and knowledgeable speakers who will present sessions, the activities planned especially for our families, and everything else you can expect at the conference. Read on for more information from Conference Committee Chair Karen Sales.

—Jean House, Editor

Jean lives in Wilmington, N.C., with her husband, Chris, and son Jonah, 6 (dup15q). E-mails are welcome at jean@editorhouse.com.

Reach for the Stars

dup15q conference 2013

By Karen Sales, Conference Chair

Come to the 2013 Dup15q Alliance conference Thursday, July 25, to Saturday, July 27, 2013, at the Mall of America’s Radisson Blu Hotel in Bloomington, Minn., USA.

This conference is designed for both new and returning families. There will be learning sessions with researchers and physicians, and practical workshops on potty training, planning for life after high school, and more. You also will have many opportunities to network with families and conference attendees. You can be a part of fun activities including the opening parade of individuals affected by dup15q, and a dinner with raffle, silent auction, and music! There will be a special opportunity for families to connect with each other at the Nickelodeon Universe Amusement Park at the Mall of America when it opens exclusively for Dup15q Alliance families and conference attendees on Thursday from 8–10 am.

Your registration fee covers all conference sessions and workshops, four meals (Thursday dinner, Friday breakfast, Friday lunch, and Saturday breakfast), and the helpful conference binder, which is full of presentation slides from the sessions.

Anyone who has an interest in dup15q syndrome can attend the conference. At past conferences we’ve enjoyed a wonderful mix of both children and adults with dup15q, parents, siblings, grandparents, aunts, uncles, and friends. Also, health and education professionals such as doctors, teachers, physical therapists, occupational therapists, speech and language therapists, behavioral therapists, and care providers have attended our past conferences.

The link to frequently asked questions on the Dup15q Alliance website provides additional information about the conference. The conference registration materials will be posted to the website, www.dup15q.org, in January 2013.

See you there!

http://www.dup15q.org
Our family has been very fortunate to have attended all of the international conferences, and we can hardly wait for the next one! Every two years, we look forward to the opportunities this brings us. The conferences allow us to attend seminars on a wide variety of topics and equip us with practical information to carry home and use in the complex world of our very special kids. They give us the latest research directly involved with dup15q syndrome that is so important to each and every one of us.

The conferences also give us so much more. For example, one of our favorite parts is the opening parade. This introduction to the conference, when our beautiful kids walk together to start the event, is always very emotional for us. There is a feeling of sadness for their struggles that quickly turns to tears of joy as we witness their positive energy and hope for the future.

Chad, our son with dup15q, is now 37 years old. He enjoys the conferences, too, because he is greeted like a rock star by the many people he has come to know over the years. These are true friends who engage him in conversations about his interests, including James Bond, state capitols, presidents, and Star Trek. They don’t mind answering many personal questions repeatedly and sometimes bring him postcards of his favorite historical sites. He has had the good fortune to meet people like himself and their families from all over the world.

The best part of the conferences for us is meeting the other families. This has been a real gift to us. We love catching up with returning friends and also getting to know those who have just joined Dup15q Alliance. We immediately know we belong together because we have so much in common. We find there is a unique connection between our families that we have not found anywhere else in our lives, and many of these associations have continued for years. These are nurturing relationships with true understanding and acceptance, and support is just a call or e-mail away in times of need.

We are looking forward to seeing everyone in July 2013!

*The Lindgren family lives in Minnesota.*
Your 2013 conference committee has been hard at work lining up some fantastic speakers for the Reach for the Stars Conference. Here is a preview of some of the outstanding clinicians, professionals, and parents who will be speaking at this year’s conference.

Chantal Sicile-Kira
Chantal Sicile-Kira’s passion for empowering others, her love of writing, and her personal interest in autism has led her to become an award-winning author, speaker, and leader in the field of adolescence and transition to adulthood. She has been involved with autism spectrum disorders for more than 20 years as both a parent of a son with dup15q and a professional. Chantal will be presenting several sessions on Thursday, including “Why Me? Things I Wish I’d Known Sooner,” “More Than Just Coping: Empowerment Strategies for Parents,” and “10 Essential Abilities Every Child Needs and Deserves to Learn.”

Sheila Merzer, MA,LP
Sheila Merzer is a licensed psychologist who has been working in the field of autism since 1972. She co-directed a day treatment and consultation training program at Minneapolis Children’s Medical Center and has established a private practice. In her private practice, Sheila and her colleagues specialize in providing assessments, consultations, and training services for educational and therapeutic interventions supporting students with autism spectrum disorders. She has worked with six individuals with dup15q syndrome and will be presenting dup15q-specific information on Friday during three afternoon sessions. These sessions include “Translating Observations into Interventions to Support Development and Behavior: Our Interpretations of Behaviors Guide What We Do.” We are especially excited because this session will include videos of children and adults with dup15q to illustrate the content of the presentation. She will also be presenting “Beyond Behavioral Basics: Practical Strategies for improving Behavior and Coping Skills in Autism Spectrum and Other Challenging Disorders.”

Lori Guzmán
Lori L. Guzmán is the founder of Guzmán Law Firm, P.A. She focuses her practice primarily in the areas of disability and elder law, guardianship and conservatorship law, estate planning, probate and trust litigation and administration, supplemental and special needs trusts, tax planning, and tax-exempt organizations. She will be presenting information on Saturday about special needs trusts.

David S. Geslak, BS, CSCS, ACSM-HFS
David is an autism fitness specialist and has been developing exercise programs for youth and adults with autism spectrum disorders since 2004. He serves as the director and founder of the Exercise Connection, an internationally renowned autism fitness program. David has authored the Autism Fitness Handbook 1 & 2 and produced the EC DVD. He serves on the board of directors for the Autism Society of Illinois. He is the fitness liaison for Autism One as well as the program director for Dad’s Track and Dad’s Night Out. David is also the co-host of “Outspoken with Karen Gibson,” a television show in the Chicagoland area that promotes health and wellness. David’s mission is to educate and empower parents, educators, and physicians to become leaders in health and fitness for individuals with autism and developmental disorders. He will be presenting a fun and interactive workshop on Saturday.

These are just a few of the presenters you can look forward to hearing at Reach for the Stars. You will also have the opportunity to attend these sessions:

- Breakout sessions for women, men, extended families, and parenting siblings
- Research and clinic update from Dup15q Alliance professional advisors
- Genetics overview
- Assistive technology and apps for the child with dup15q
- Managing anxiety in individuals with dup15q
- Managing epilepsy in individuals with dup15q
- Music therapy
- Potty training

We are thrilled to have such an excellent lineup of speakers for our families. Our conference binder will include handouts from many of the sessions and limited copies will be for sale following the conference for families who may not be able to attend.
**Dup15q Clinic Opens Second Site in Florida**

**BY KADI LUCHINGER EXECUTIVE DIRECTOR**

Dup15q Alliance is excited to announce the second Dup15q Clinic, which is headed by Roberto Tuchman, director of the Autism and Neurodevelopment Program at Miami Children’s Hospital Dan Marino Center. The Miami clinic joins the Dup15q Center of Excellence at Massachusetts General Hospital as a multidisciplinary clinic specifically for children and adults with duplications of chromosome 15q.

Dr. Tuchman is a leader in the field of autism and epilepsy. I attended a meeting at the NIH (National Institutes of Health) in the spring of 2012, where I was formally introduced to him. He was an instrumental organizer of this meeting, which was for experts from around the world to discuss autism and epilepsy. Dup15q Alliance was one of three parent groups present at this meeting of 50 invitees. During our discussions, it became clear to me that Dr. Tuchman would be a great leader for a dup15q clinic. He obviously had the knowledge and expertise, but his passion to help families made him a perfect fit. We had several follow-up conversations after the meeting to iron out the details, and the second dup15q clinic soon became a reality.

I have been asked how we decide where a clinic is developed, and there are many factors. First is location, second is strong neurology expertise, third is obviously an interest in starting a clinic, and last (but not least) is the passion. We want people who are passionate about helping our children and who will work well with our families. They must be willing to be team players and work toward collaboration to share their knowledge and findings with our other clinic partners.

The first Dup15q Alliance family to visit this clinic was Ivonne Ruiz-Feteman and her son Devin. Altogether, the Miami Dup15q Clinic has seen five children with dup15q with a wide range of abilities and challenges as of mid-December. If you are interested in visiting the Miami clinic, please contact Johanna Guerra at (954) 385-6202 or by e-mail at jguerra@nnpmd.com to schedule an appointment. Please mention that you are looking for the Dup15q Clinic.

We are continuing to search for other locations in the United States and internationally for our dup15q families. In addition to improving the quality of care for our families by developing a network of providers familiar with dup15q, we plan to have quarterly meetings with the clinics. The directors of each clinic will discuss what they have seen at their clinics, share insights, and help to develop standards of care. We should all be proud of the direction we are moving in—together we can make a difference!

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**Board of Directors Update**

**BY TOM DOYLE INTERIM BOARD CHAIR**

As we have announced through BigTent, Len Poore is no longer on the Dup15q Alliance Board of Directors. Len served for many years as a dedicated board member and as a wonderful leader of the organization. He led with patience, understanding, humor, and class. He will truly be missed.

The board has asked me to temporarily sit in the chair’s position while it determines who will follow Len in that critical role. As I am introduced to the workings of the board from the perspective of the board chair, I am struck by the generosity and commitment of all of our families. As I often say to people, as a grandfather, I am one step removed from what parents experience on a daily basis with children with dup15q. You really are the heroes who face your daily joys and struggles with such grace. Thank you for your support of your organization, of the board, and of each other.

We have had quite a year. We have raised more money than ever through your generosity and family fundraising efforts. We held our scientific research meeting in Boston in August and loaded most of those presentations onto our website. We began preparations for the 2013 Conference in Minneapolis next July under the able leadership of Karen Sales. We completed work on getting the registry published and ready for input from our families. Our sister organization in Spain translated the registry into Spanish so our Spanish-speaking families can complete the questions as well. We contributed to the creation of the mouse model and have seen an expansion of interest and research as a result. Under the direction of Linda Meagher, we published the First Hundred Days Manual. And so much more . . .

I would like to offer a special thanks to our board members who so graciously volunteer their time to Dup15q Alliance and to Executive Director Kadi Luchinger, who lives and breathes dup15q business every day. They willingly accept the responsibility and the hassles that come with leading such an organization. Our conference calls are often interrupted with the same bedtime issues many of you deal with daily, yet the board members find a way to work through those times. Membership on the board comes with a lot of extra work, some extra anxiety and grief, and a load of responsibility. But my experience of the board members is that they do it joyfully and professionally. Thank you.

Thanks, most importantly, to you for your support of the organization and of each other. I spoke with a family in England recently who told me how important their contacts with other families on Facebook were. You provide support, comfort, love, and wisdom for each other. You provide hope through your financial support of Dup15q Alliance. You promote education and research through your participation in the registry and the conference. Thank you from all of us on your board for all you do to make the lives of others living with dup15q just a little better. We look forward to 2013 with excitement! We hope that you will be able to join us at the conference in Minneapolis as we continue to try to find ways to fulfill our Dup15q Alliance mission to “provide family support and promote awareness, research and targeted treatments for chromosome 15q duplication syndrome.” Have a wonderful new year in 2013!
Financial Report

By Tom Doyle
Financial Officer

The nature of print media is that the articles are written some time before you read them. So you will be reading this as the new year (2013) begins and I will be providing a report that goes through only 11 months of 2012.

As of the end of November, your Dup15q Alliance financial status is healthy. We have over $51,000 in our checking account and $257,000-plus in our savings accounts. As of the end of November, we have raised just over $150,000 through donations and family fundraising events with several events still to come in December and the bulk of the Direct Ask taking place in December as well. We have exceeded our budgeted income by about $25,000 this year! This can only be attributed to your commitment, support, and energy, along with the dedication and leadership of Mike Porath and the fundraising committee. Thanks to all who have contributed in so many ways.

Our expenses will exceed budget this year by about $15,000, but we expected that when we made the decision to fund the mouse model ($40,000) in the spring. We have been careful to save in other areas to offset a large portion of that new expense.

The board is currently working on the 2013 budget and will formally adopt that at its December meeting. We will share that with you when it is completed. We anticipate expenses to be up dramatically because it is a conference year. The corresponding income from registration fees and conference-related fundraising help us to balance the budget, however. We hope to build on this year’s successes in fundraising and surpass that next year. On the expense side, the conference accounts for the largest part of the increase, but we have built in some increases to help us with the cost of supporting the registry and building a more complete website.

We will once again be going through our annual audit in the spring to get an independent look at how we keep our books and protect your organization’s resources. I am always available to answer any specific questions you might have about the budget. Feel free to e-mail me at tom.doyle@dup15q.org with any questions.

Scientific Conference Videos Online

We are pleased to announce that we have completed editing and uploading to our website all videos of speaker presentations from our Dup15q Scientific Conference in Boston last August (with the exception of a few where the recording failed or was of poor quality or where the speaker withheld permission to protect still unpublished data). The videos are posted at www.dup15q.org/scientificvideo.html.

Also, we were able to obtain slides for some of the presentations, even if video was unavailable (e.g., for the talk on the Dup15q Registry). These slides are available as PDF files on the same page as the videos or for download from the “files” tab on BigTent.

To read a round-up of the scientific meeting, please see Guy Calvert’s article in the Fall 2012 edition of The Mirror.

We hope the material contained in the slides and videos is helpful and informative. If you have any questions about the talks, please e-mail info@dup15q.org

Two New Members of Professional Advisory Board

We are very pleased to announce that Stormy Chamberlain, Ph.D., and Orrin Devinsky, M.D., have agreed to join our Professional Advisory Board.

Dr. Chamberlain is the Raymond and Beverly Sackler assistant professor of Genetics and Developmental Biology at the University of Connecticut Health Center and a member of the University of Connecticut Stem Cell Institute. Her lab studies chromosome 15q11-q13 imprinting disorders and has been focusing on induced pluripotent stem cell models of dup15q and Angelman syndromes. Stormy received a B.A. degree in molecular biology from Princeton University and a Ph.D. in medical sciences-genetics from the University of Florida, where she studied mouse models of Prader-Willi syndrome. Stormy and her husband, Scott Oloff, have two children, Jacey and Marshall, and live in Oxford, Conn.

Dr. Devinsky is professor of neurology, neurosurgery, and psychiatry at New York University Langone School of Medicine. He directs the NYU Epilepsy Center and Saint Barnabas Institute of Neurology. His epilepsy research includes phenomic-genomic relations, sudden unexpected death, surgical therapies, tuberous sclerosis, new medicines and devices, collaborative translational research, quality of life, cognition and behavior, and neuro-inflammation. Behavioral neurology research includes hyperlamamity, Klein-Levin syndrome, delusions, autonomic nervous function, and anterior cingulate gyrus functions. Orrin has authored more than 300 peer-reviewed papers and written or edited more than 20 books. He founded Finding A Cure for Epilepsy and Seizures and co-founded www.epilepsy.com and the Epilepsy Therapy Project. He serves on the boards of these organizations and has served on the board of the American Epilepsy Society and Epilepsy Foundation. Some of Orrin’s other interests include the history of neuropsychiatry, evolution, anthropology, and animal intelligence.

Save Those Teeth!

Help dup15q research by donating newly lost teeth. Request your collection tube today, so you are ready the next time a baby tooth falls out. See www.dup15q.org for more information.

Dup15q Alliance is looking for volunteers for our committees. Do you have a special talent to share? Are you interested in holding a fundraiser? To learn more about opportunities to volunteer, contact info@dup15q.org.
Cheers to Our Volunteers!

Our volunteer of the quarter is Len Poore. Len was initially elected to the board of directors in June 2008, then elected board chair in June 2010, serving in that role until his departure in October 2012. Len has also served on the fundraising committee since 2007 and initiated publishing a formal annual report to the entire organization, beginning for the year 2010.

Len and his wife, Joanne, who reside in Massachusetts, received their daughter’s diagnosis at Boston’s Children’s Hospital back in 1992 when Lisa was 18 months old. Len remembers the journey began with a routine amniocentesis, a resulting visit to Dr. Aubrey Milunsky at the Boston University School of Medicine, a possible diagnosis of either Angelman syndrome or Prader-Willi syndrome, and a final diagnosis of something called inverted duplication 15.

“It was my daughter’s diagnosis that pushed me to join the board so I could give back to an organization that provides a valuable resource to new families being diagnosed and also to existing families,” Len said. He went on to say that those resources are knowledge, experience, and hope for the future. Len did not volunteer for any personal recognition for himself; rather, he looked for the organization to be recognized. He takes satisfaction in knowing that the Dup15q Alliance website is now the first stop for many families as well as physicians, providing a wealth of information that will answer many initial questions, including letting parents know they are not alone in this journey.

During his tenure on the board, Len often wondered about decisions made and the direction for the organization. But when he left the board, he received many e-mails thanking him for his leadership. One particular e-mail from a board member answered those questions he had: “You led us through some of the most difficult times in our history and did it with calm and class . . . There obviously can be lots of stress in our families and board members which sometimes leads to reactive behaviors, and you had the strength and wisdom to deal with those and keep us pointed in the right direction . . . So I just want you to know that I always appreciated your leadership and your courage to deal with the good and the bad.”

Dup15q Alliance is grateful for Len’s service on the board of directors and his dedication to both the organization and our families. We pay tribute by cheering him: Thank you, Len, for your years of service!

Please Provide Samples and Consent for Research

Over the past 14 years, many of you have generously contributed blood samples from your family as part of our study on chromosome 15 duplications. We currently have approximately 350 samples. For most individuals, we used the blood samples to make cell lines, long-lived cultures of cells that can be used for years and shared among laboratories. Many of these lines have been submitted to the Coriell repository so that other labs studying dup15q can access them. However, most samples have not been submitted because this process requires a separate consent form to allow us to transfer the samples to Coriell. Having the samples saved at more than one site increases their availability to other researchers interested in studying duplications of chromosome 15q and provides a backup resource in the event of a problem with the samples in the laboratory.

We would like to submit as many of the existing samples in our study as possible to the NIGMS Human Genetic Cell Repository at the Coriell Institute and must enlist your help. If you have already participated in our study by giving blood samples, then we can work to set up transfer.

To Allow Us to Transfer Samples:

1. A signed transferred consent form is required for each individual.
2. Please sign the transferred consent form and return it to the Schanen laboratory by mail or fax. We will send the consent form with your cells to Coriell.
3. For questions regarding the consent form or any questions about the Coriell Repository, or to request a blood collection kit, please contact:

   Tara J. Schmidlen, MS, CGC
   Certified Genetic Counselor
   NIGMS Human Genetic Cell Repository
   Coriell Institute for Medical Research
   403 Haddon Ave.
   Camden, NJ 08103
   tschmidlen@coriell.org
   (856) 359-4122 (phone), (856) 964-0254 (fax)

Please note that a separate consent form is needed for each individual. Often this is not just the individual with dup15q but also parents who have submitted samples. One form for each person must be sent to Dr. Schanen before the samples can be sent to Coriell.

To Participate in the Study

If you have not already participated in our study, but would be interested in submitting a blood sample directly to the Coriell repository, please contact Tara Schmidlen (see left). A blood sample collection kit containing blood collection tubes, a consent form, and a submission form will be sent to you. Coriell pays for the shipping of this kit both ways and can reimburse you up to $40 if you are charged for a blood draw. Once again, thank you for participating in the study.

Dr. Schanen is head of Human Genetics Research Laboratory, Nemours Biomedical Research and a member of the Dup15q Alliance Professional Advisory Board. You can reach her at (302) 651-6702 (phone), (302) 651-6767 (fax), or schanen@medsci.udel.edu.
Fun and Fundraising at the Second Annual KayJay

By Teana Ebensperger

On September 22, the Ebensperger family held our second annual KayJay 5K & 1-mile walk in the little village of Wheeler, Wis., on a chilly Saturday morning. This year we were given the use of a building that was large enough to accommodate our event thanks to Wisconsin Industrial Sand Co., which was once again our biggest sponsor.

Around 90 participants turned out for the event, including some Dup15q Alliance families from the Midwest; there were eight Dup15q Alliance families including our own. The other families that came were the Supinas, Lindgrens, Matuzas, Rissians, Morans, the Salesees, and the Krosses. Some of the families stayed at a hotel not far from the event, and we all met up the night before and had dinner together. We also had the wonderful opportunity to meet the Raschka family that night for the first time. Some of us went swimming after dinner and had a great time.

The event included kids’ games, a bounce house, sand art, a huge raffle, door prizes, and DJ entertainment. We added three mascots to the fun this year: Scoopie the ice cream cone, Kase the dog, and a penguin. The look on the kids’ faces when they saw the mascots was priceless! We will definitely have them again.

Each participant received a bag full of goodies including water bottles, coupons, and 3M products. We also had T-shirts and food for the participants. The first-place winners of the 5K event receive a wooden trophy of a running man that represents the event. The second- and third-place winners are given a medal. We are thinking about adding a 10K event next year to help draw in more runners. We are also going to have a committee for the run to make sure we have an adequate number of volunteers and to help things go smoothly each year.

Between donations raised online through First Giving pages and money received the day of the event, we raised over $6,300! We have actually lost track of the exact amount because checks trickled in for weeks afterward! We are extremely grateful to all of our family, friends, participants, volunteers, area businesses and sponsors. This event could not be possible without their support. Thank you for making our event such a huge success! See you on September 21, 2013!

Brazilian Jiu Jitsu Benefit

Dup15q Alliance would like to thank Jeff Rozovics, a black belt in Brazilian Jiu Jitsu who is dad to Riley. Jeff has been training for more than 15 years and was asked to put on a Brazilian Jiu Jitsu seminar for a local academy in his town. He talked to the owner of Threshold Martial Arts, Bill Shimuk, and asked if the money collected could go to Dup15q Alliance. The students donated more than $400 and Threshold Martial Arts matched the contribution for a contribution of $850.

Cocktail Party Fundraiser

By Rylie McHam

Along with my family and a very good friend, I hosted a Dup15q Alliance fundraiser at my mother’s house on October 11. It was a collective effort, and I was completely overcome by the generosity of those involved. We had a cocktail party, and people across the community came together to support the Dup15q Alliance. Everyone was genuinely interested in learning more about chromosome dup15q syndrome and Dup15q Alliance. We received a lot of really positive feedback, and it was truly a wonderful, heartfelt evening.

At first, I was a bit overwhelmed by the idea of hosting a fundraiser. It turned out to be really fun, though, and my friend and family enjoyed being able to contribute to Dup15q Alliance. Local restaurants, distributors, and grocery stores donated all of the food, drinks, and party supplies. People were more than generous with their donations, and we had a seemingly endless amount of delicious food and desserts. We sent out invitations asking for a minimum of a $75.00 donation to Dup15q Alliance, and we raised just over $10,000.00.

Sophie’s Challenge

Dup15q Alliance member Katy Miller has started Sophie’s Challenge, an online fundraising effort. Her goal was to raise $1,000 for the organization. When this issue of The Mirror went to print, she had already raised $2,225—and the total could go even higher!

From Katy’s fundraising e-mail:
I work hard to give my Sophie a better life every day, but there is a bigger picture that she is part of. During the holiday season, many people look for causes to donate their hard-earned money toward. I thought this year, and maybe every year, I could take a little extra time and try to bring awareness and a little help to Sophie’s cause.

Dup15q Alliance is doing amazing things to bring families support and, more importantly, funding research to discover more about dup15q and how we can better treat it in the future. To learn more about Sophie’s Challenge or donate, visit www.crowdrise.com/Sophieschallenge/fundraiser/katemiller.
AGILITY ABILITY CANINE THERAPY

BY CONNIE WILL

August 17, 2005, two days before my daughter Avery's second birthday, we received her diagnosis of dup15q. I remember my whole body became numb. My husband, Gary, and I were in shock. It just couldn't be.

Because she was our first, we weren't overwhelmed with concern about Avery's development until after her first birthday. I remember waiting for her to "catch up" to all the milestones she was missing, but even when she did accomplish a milestone, it was so difficult for her and awkward. I finally demanded our pediatrician help us find answers.

Nine months later we finally had our answer. After her diagnosis, I knew I had to stay positive and try my best to make Avery's life the absolute best it could be.

I am a certified personal trainer and have had my own business for more than 15 years. I knew the great value of working with Avery physically to help her be her best, so I immediately got her involved in every therapy I could find and kept her involved in life. As time progressed, I watched her intense love for animals, especially dogs. We had a dog at home, Barley, our loving and patient yellow Labrador, and Avery clung to him every chance she could. Even though he had never had any formal training, Barley was very therapeutic for Avery.

One day in March 2011 was particularly special for Avery and me. I was not able to find a babysitter, so I decided to take her to work with me. I was training a group of dog handlers at an agility facility to help them work on their quickness and strength. I knew there would be dogs around and thought Avery would enjoy the atmosphere. After the fitness session, one of the agility handlers asked if it would be okay to have Avery run the course with her dog. I agreed because I thought Avery might enjoy it, but I was also a little hesitant. I thought that Avery would not understand the course or what to do. These were competitive dogs, and I didn't know how Avery would handle the situation.

The handler instructed Avery to run alongside the dog as he weaved his way through the complex course. Then the handler took Avery's hand and also directed the dog to begin the course. They took off! The dog weaved his way through the poles, leapt over 20-inch jumps, and ran through a long tunnel and over a teeter-totter. I ran along the outside of the course ready to retrieve Avery at any second.

All of a sudden and with a huge smile on her face, Avery squealed with excitement; then she started giggling. The handler told Avery to yell "jump" as the dog was approaching a 20-inch jump. Avery yelled "JUMP!" as loud as she could, and the dog leapt high over the bar. Avery stopped, looked me right in the eyes with disbelief and the greatest sense of joy and pride, and then started running after the dog joyfully. I had never seen such excitement from her. I stood there frozen for a moment as I watched her jumping and laughing with excitement. When they finished, the handler ran over to me and gushed with excitement along with me.

I started crying and knew I had stumbled upon a new therapy that Avery had to be involved in. I immediately checked with the agility group to see if they had classes for children with special needs. There was only one group that I found in Ohio; it specifically worked with autistic children. I started working with an agility handler on a plan to start classes for more kids with special needs. Within four months, we had a group of
eight competitive handlers and their trained agility dogs, three special education teachers to help train the handlers how to work with the kids, and a bunch of excited dogs that love being around the kids! I was shocked and overwhelmed by the response from the agility community. I believe this was a true miracle from God.

As we started practicing with the kids and handlers, more and more handlers were ready and waiting to volunteer. Within six months, we began a new sports therapy called Agility Ability. We have been overwhelmed by the response from kids and their parents and even siblings. A wonderful mix of children participate, including those affected by autism, Down syndrome, and cognitive and physical delays. We have two classes of six children each back to back on Saturdays. In July 2012, we celebrated our first-year anniversary, and we have received local newspaper and television exposure. We have also started going into early intervention schools, just like Avery was in when she was 2 years old.

My cofounder and friend, Cindy Warren, and I have been humbled by this powerful sport therapy. We have seen children on the autism spectrum come in with no focus, running throughout the building, but once they are set up with their dogs and then shown how to do each skill, the children calm down and run with the dogs in a sequence of runs. We end the sessions by spending calming time brushing the dogs and talking to them. It is powerful when the dogs curl up next to the children and just love them.

We have even seen children who struggle to speak suddenly get so motivated by the dogs that they call out commands to get the dogs to respond. It is motivating and gives children a great sense of pride when they tell the dogs what to do and the dogs respond. Many of the volunteer dogs are retired agility competitors and are very excited to get back on the course under less stressful conditions. They understand that they are a help and joy to the children and love working with them week after week! We are now working to expand and teach more handlers and agility facilities to set up their own Agility Ability sport therapy so that they can bring this opportunity to their community and help other exceptional children.

Out of all the therapies Avery has been involved in, this has most definitely been her favorite. It has created great changes for her and for our family!
Reflections from a Sibling

My Sister Allison

BY MICHAEL GOMEZ

You know, I have many nice things to say about my sister, Allison. She is a 15-year-old who has autism, absolutely loves water, and has broken just about everything in the house. Just to give an example, my mother and father had just bought a new cherry wood-and-glass coffee table. I think you know what happened next. The next morning, we didn’t see a brand new coffee table; instead, we saw a broken coffee table with glass all over the floor and a crack down the center of three out of the four legs. Oh yeah, did I mention she is very strong? She was only 9 at the time.

Today, Allison acts like a race car driver on my grandparents’ lawnmower and knows just about every single path at their farmhouse like the back of her hand. When she was 3, she would express her emotions in a very funny way. When she was happy, she would dance around with the curtains and say “ma ma ma ma ma ma”; however, when she was angry she would say “da da da da da.” In a nutshell, she can be a challenge and also a blessing.

Allison is a very special person not only because she has dup15q but because she is a miracle bringer. She is the light in the darkness of the world. She shows that there is hope in this world. When she was about 14 months old, my mother found out that Allie has autism. The doctors said she might not be able to talk, but they were wrong. She can communicate like nothing ever happened. She uses a program called PECS to communicate. PECS stands for Picture Exchange Communication System. This system allows her to hand a picture to a person like we use our words to ask for something we want. If she wants something—for example, a drink of water—she will hand the person who has water a picture of a cup.

Almost every day, she goes around the block about four or five times on her tricycle no matter what (except for bad weather, of course). For example: Hurricane Sandy—80-mile-per-hour winds and heavy rain. She kept handing my mom her shoes and helmet because she wanted to go on the tricycle. After about three times of receiving the shoes, mom gave up and opened up the back door for just about five seconds. It was enough for Allie. She didn’t ask one more time to go outside.

I am Allison’s brother, and I am three years younger than her. She has been my guide in life. She has taught me how to live and respect my life. She teaches me that I should be very thankful for the things that I have and generous to those that have little. She has taught me how to be happy and healthy.

Allison has a bright future, and thanks to her we also have a brighter one to make a good change in the world by making people more respectful of each other.

MICHAEL AND HIS FAMILY LIVE IN ROBBINSVILLE, N.J.
Reflections from a Grandmother

Our Family’s Precious Gift

BY JUDY THOMAS

I am the lucky “mawmaw” of Riley Baker. She turns 6 years old in December. My husband, her “papa,” and I were both retired when Riley came along three days before Christmas in 2006. The entire family was in awe of this precious gift that was given to us. Because we were retired, we were given the wondrous opportunity to be Riley’s caregivers when it was time for her mother, our Jill, to return to work.

When Riley was six months old, I was feeding her cereal and a bottle when she had what I knew to be a seizure. That was the beginning of our journey with Riley and dup15q—a journey that has taken us from disbelief, pain, and denial to where we are today. Riley was immediately diagnosed with infantile spasms, and then the genetic testing showed dup15q. She later received the diagnosis of autism as well. Looking back on those early days, I have to say that the hardest part for me was knowing that the pain I was feeling was nowhere near the pain that my daughter was feeling. I was lucky to have a best friend that I could share my feelings with because at that time I felt that I needed to be strong for Jill and her husband, Richie; therefore I would not let myself break down in front of them.

Through it all, I have learned more from Riley than I believe she could ever learn from me. I have learned to appreciate all the little ways she can communicate with me. When we dance to Barney or Dora, she hops faster than I can and looks me right in the eye. Her papa and I have helped her learn to recognize actions and activities that Barney does, such as dancing the hula dance or doing the clapping song. When these favorite parts come on, she will search for us to do our part. If something catches her attention that she finds funny, her laughter shakes the house. She has the most beautiful laugh I have ever heard. It comes right from her heart. I am so proud of everything she has accomplished.

When I can get her on my lap, I will whisper in her ear “MawMaw loves you,” and then I kiss her face as she wiggles off. It is then that I catch a small smile forming on her face if I look fast enough. It is like she is saying “I know you do MawMaw, but I have more hopping to do!”

The thing that I believe helped me the most in understanding dup15q was being able to attend the last two conferences. The conferences have speakers from all areas. I was able to choose which sessions I wanted to attend, and my overall favorite one was the extended family session. It was there that I truly learned that I was not alone. Along with other grandparents, aunts, uncles, etc., I talked about Riley and my way of dealing with her issues. I was able to listen to other family members talking about their little ones, too. There were quite a few tears in that session, but they were tears of love, caring, and understanding.

I would not trade any of this journey—the pain, disbelief, or denial. It is only by going through all of those feelings that I have gotten to joy, love, pride, and happiness.
Great news! We now have a calendar on our website so you can keep track of all of the upcoming events. If you have an event to put on the calendar, please let us know!
Visit www.dup15q.org/calendar.html.

2013 CONFERENCE RAFFLE TIME! By Katie Supina

With only a few months left before the 7th International Conference in Minneapolis, it is time to start thinking about what you can donate to the raffle and silent auction.
In Philadelphia we raised over $10,000 at the conference raffle—an amazing feat that we hope to surpass at the conference July 25-27, 2013.
The raffle and silent auction will be held during the reception dinner on Thursday, July 25. We would love to include a basket for each home state and country represented. Think of what you can donate, work together, and be creative!
Donations might include CDs, art supplies, jewelry, foods from your home state, sports memorabilia, toys, DVDs, quilts, shirts, gift certificates, coffee, or whatever you think people might try their luck at winning!
Watch for updates on BigTent to see the list of great raffle items coming in. Either send the baskets to the Supina family in Minnesota or bring them with you to the conference. If you plan on bringing the items directly to the conference, send me a quick e-mail so we know what to expect.
Contact me if you have any other raffle and silent auction questions!
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http://www.dup15q.org