Chromosome 15q duplication syndrome (dup15q) is a clinically identifiable syndrome which results from duplications of chromosome 15q11-13. These duplications most commonly occur in one of two forms. These include an extra isodicentric 15 chromosome, abbreviated idic(15), which results in an individual having 47 or more chromosomes instead of the typical 46. Individuals with an interstitial duplication 15 are born with the typical 46 chromosomes but have a segment of duplicated material within their 15th chromosome.

In June, the Sixth International Conference on IsoDicentric 15 and Related Disorders was held in Philadelphia. It was attended by 332 people, the highest number yet for a dup15q conference. In addition to research updates, small and large group sessions, and workshops, attendees made new friends and caught up with old ones, networking to make the weekend great and this organization strong.

This conference was a special occasion for attendees who connected in person with their dup15q family—many for the very first time. People gave generously at the silent auction and raffle, raising over $10,000 in just one evening. And those three days in Philadelphia were particularly momentous because of the important developments unveiled: a new name that reflects this organization’s focus, a new multidisciplinary clinic dedicated especially to dup15q, and a new registry that will help us all understand more about the syndrome.

The United We Stand Conference was a success thanks to the dedication and two years of hard work from the Conference Committee, led by Cindy Johnson. The committee’s tireless efforts resulted in a conference that educated, entertained, and joined us all in the common causes of learning about dup15q syndrome, supporting our loved ones, and building community.

This issue is dedicated to the 2011 conference. It includes reflections from a first-timer whose child was diagnosed only a few months before traveling to Philadelphia, as well as highlights remembered by several attendees in the Family Favorites feature. A review of the post-conference survey sheds light on what made the conference a success.

And major developments that will propel our community into the future are explained: the registry, clinic, and new organization name.

Of course, the Mirror wouldn’t be complete without the tried-and-true favorites. If you weren’t able to make it to Philadelphia to share with other dup15q families and hear their stories, please take a few moments to read the Reflections from a Sibling, Family Portrait, and Volunteers of the Quarter.

Through strength, compassion, and love, these families and their loved ones thrive and move forward—much like our dup15q community as a whole.

http://www.dup15q.org
I still remember receiving the e-mail from my husband with three words, “Check this out,” along with a link to the conference in Philadelphia. Could I possibly be reading it correctly? Three whole days dedicated to this condition, which my son had been diagnosed with just one month prior? A month that shook us to our core, not only because we knew our life would neither be the same nor what we had thought it would be, but also because of the helplessness that even in the “Google-It” era it seemed there were few answers to be found. Our doctors knew no more than what we ourselves were finding. How scary . . . how lonely.

On June 23 we arrived in Philadelphia. Cue the emotional roller coaster. The moment we got to the hotel, I went to the ladies room while Fabio checked us in, both rushing to make it to the New Family Orientation. As I washed my hands, a mom and her son came out of the stall. When I looked up and saw the little boy in the mirror, an arrow shot straight to my heart. He looked so much like Santiago. It suddenly became so real, so fast. At the Opening Parade, the reality of dup15q continued to take its form—certainly a varied form, presenting itself in so many shades. Tears streamed down my cheeks. I felt both pride for the kids and their families as they walked past and shock that I had somehow entered a micro-reality.

A day of medical presentations ensued with the appearance of what seemed to be the story’s villain, The Seizure, and we experienced a whirlwind series of introductions to many amazing families living parallel lives to ours. As soon as I got to our room that night—head spinning—I could digest the day with one thought only: we had to enjoy every minute of our life because there would be no other way to get through this, except for right through it, living each and every moment.

On Day 2 a sobering reality set in, but also a strong conviction that we could, and would, get through this, not only in our own families but together across state and national borders.

A registry was in the works. Several brave medical practitioners were curious, committed to helping this group. A new clinic was opening up. Teams were in place to fundraise. Social media sites were set up to spread the word and unite us all. Parents were asking questions and sharing answers. So, no: there were no books written on this subject, or medicines guaranteed to help our kids, or clear-cut answers to many of our questions. Yet, however hopeless things had seemed, it was clear that we were now on the right track.

By Day 3, I felt a deep sense of gratitude to the families of older children that had pioneered these efforts and to the Dup15q Alliance leaders who selflessly offered their time. The energy was powerful and uplifting. We left Philly with tons of names, phone

Continued on page 6...
By Rachel Doucette, VP of Communication

In 1994 a group of 13 families raising children with chromosome 15q duplications was organized by Donna Bennett and Brenda Finucane. In 2004 this group was incorporated under the name IsoDicentric 15 Exchange, Advocacy, and Support. Since its beginning, the group has grown to more than 600 families. Not only has the number of families grown, the understanding of chromosome 15q duplication syndrome has evolved to include more than isodicentric duplications.

At the 2011 International Conference in Philadelphia, the organization proudly announced its name change to Dup15q Alliance along with an accompanying new logo. This change encompasses the different individuals and groups served by the mission of this organization. For more information, please visit the Dup15q Alliance website at www.dup15q.org. For Dup15q Alliance merchandise, visit the store at www.dup15q.org/Store.html.

By Karen Sales, 2013 Conference Chair and Corporate Secretary

The Seventh International Conference on Chromosome 15q Duplication Syndromes will be held in Bloomington, Minn., July 25–27, 2013. Plan to join us at the Hilton Airport/Mall of America, which has a free shuttle to both the airport and the Mall of America.

Not only will there be lots of valuable information, there will also be plenty to keep you busy outside the conference! Minnesota Wildlife Refuge is across the street, the Mall of America (with Nickelodeon Universe and Minnesota Sealife Aquarium) is a shuttle ride away, and several zoos are in the area.

Families traveling from out of town will be interviewed prior to the visit in order to schedule the proper evaluations. Available services include inpatient EEG monitoring, sleep studies, and dietary therapy for epilepsy. Families can call (617) 726-6540 to set up an appointment.

Thank you to Dr. Ronald Thibert and all at Massachusetts General Hospital for creating this first Dup15q Center of Excellence.

Continued on page 4...
questions on various topics including behavior, development, seizures, sleep, general health, and other body systems. The affected individual will not have everything mentioned in this questionnaire, but it is important for us to gather as much information as possible. The first version of the survey is in English only, but we plan to develop the survey in other languages as well.

The information that you provide will be de-identified, meaning no one besides the administrators of the registry will have access to identifiable information. The registry will become a wonderful resource for you. You will be able to house all of the affected individual’s important medical information in one spot and refer back to it as necessary. For example, you will have one location that lists milestones, dates of surgeries, medications used, and medical reports. There will be no more scrambling for medical information, as it will all be organized in the registry for you. Participants will have the ability to look at how the affected individual compares to others in the group by a display of graphs. You will receive an e-mail reminder annually asking for an update to the information.

The security of this information is important to us all. Please read through the terms and conditions of the registry. You will also need to review and agree to the informed consent prior to gaining access to the registry.

There may come a time when a researcher is interested in conducting a specific project. Those who may qualify will receive an e-mail from the administrator informing them of the study. They will be provided with the information to contact the researcher directly. Researchers will not have access to identifiable information in the registry, and all proposed studies are approved through our Dup15q Alliance Scientific Advisory Board and Board of Directors. You may still participate in the registry if you do not wish to enroll in any future research projects.

Our goal is to better define Chromosome 15q Duplication Syndrome. For example, what percentage of affected individuals have seizures, sleep disorders, or autism? What treatments work best for anxiety, seizures, or ADHD? By defining the syndrome, we can better educate our families and, in turn, the medical community about dup15q. We also hope to determine what areas require further research as identified by the information in the registry. These areas may be avenues for future research projects. The long-range goal is to determine effective treatments to provide a better future for our loved ones with dup15q.

Please join with families all over the world to help take this critical step in understanding dup15q syndrome. To participate, you will need to: Continued on page 7...

CONFERENCE SURVEY RESULTS
By Jean House

There were 332 attendees at the conference; of those, 101 responded to the online survey that was posted afterward. A third of respondents were first-timers. Here are a few highlights:

The registration fee, which was cut in half, was a big hit: a huge 80% rated the fee excellent, and 17% rated it good. Other elements that got high marks (good or excellent): 96% for the binder, 97% for the auction, and 95% for the DJ (a volunteer, our own Bob Wiederwax).

Presentations that are standards of every conference—including Seizures, Genetics, Research Q&A, the men’s session, and the women’s sessions—continued to be popular. And attendees were very pleased with the keynote speaker, Robert Naseef, who presented both Stress Busters and First Aid for Relationships. Other sessions that were rated good or excellent by most people who attended them included PECS, Autism Risk & Safety Management parts 1 and 2, Advocating for Your Child, Promoting Independence, Social Skills, the Potty Training Panel, Anxiety & Behaviors, and Animal Therapy.

The opening ceremony is always special to attendees, and this conference was no different: 87% rated it good or better. Not as many people attended the closing ceremony; of those who did, though, the majority gave it high marks. The conference store did very well: almost three-quarters of respondents bought something. Overall, respondents were pleased with the United We Stand Conference: 66% said it was excellent, and 33% said it was good.
Scenes from the Sixth International Conference on IsoDicentric 15 and Related Disorders . . .

Photo credit: Rick Guidotti, www.positiveexposure.org
SHARE SOMETHING YOU GAINED FROM THE CONFERENCE

One of many highlights for me was visiting with Dr. Eniko Pivnick, who sat beside us at dinner on Thursday night. She wanted to know all about Jordan, and while we visited she told me “You know, the parents are the real heroes.” That set a great tone for the rest of the conference for me.

Denis Myers, father of Jordan, 7 (dup15q), and Stevie Rae, 5

My family favorite was hearing the different approaches to potty training from parents who had been there themselves. I think that when parents and family members of children with dup15q present, it gives people hope that they, too, can get there! Thanks.

Jill Baker, mother of Jared, 16, and Riley, 4 (dup15q)

One of my most heartfelt moments of the conference was when Cheyenne was looking for her “best friend,” Rick Guidotti (the photographer). When Cheyenne got to the front of the parade during opening ceremonies, there was Rick with a big bear hug for her.

Ellen, mother of Cheyenne, 18 (dup15q), and Samuel, 17

In a world of strangers’ stares and questioning looks, friends and family who don’t understand, and thoughts of despair and hopelessness, I found a family that doesn’t stare, that understands and gives me hope. More important, I bonded with a group of new-found brothers who know what I’m going through and are there to pick me up when I stumble or fall.

Chris House, father of Jonah, 4 (dup15q)

Our First Conference continued from page 2...

numbers, and friend requests waiting on Facebook, armed with information to help us settle into our new reality.

It’s been nearly two months since we’ve returned from the conference, and we have started to create some structure in our life, with all its new challenges and responsibilities, as well as hopes and dreams. Similar to how my home feels like my stake in this great big world, the Dup15q Alliance and this new extended family feel like a gigantic safety net. We know it’s there to catch us when the going might get tough or when it’s time to rejoice in the “simplest” of victories, such as a good shape-sorting day. Only this group of people, this microcosm, can understand how these are not “simple” feats in the least bit, but rather huge victories.

With this sense of unity and commitment, as well as gratitude and faith, I am inspired by my son and this new force to which we now belong. I credit, in great part, our experience in Philadelphia with so much of the peace I feel. Our life is definitely no longer what we had thought it would be, but it’s proving to be more rewarding and enlightening than we could have ever imagined. Blessings abound.

Coco is the mother of Santiago, 2 (dup15q).
The Philadelphia conference was a great success. Thanks to Cindy Johnson and her conference committee for their awesome planning and hospitality while we were there. The conference grew over our projections to be the largest we have ever had. The final financial report for the conference is not yet complete as some bills are still coming, but it appears that we hit the budget target on the income side ($39,962 actual vs. $39,000 projected) while missing it on the expense side because of about 50 more attendees than originally projected ($66,743 actual vs. $61,900 projected). You may remember that the registration fee was cut in half for this conference because of the success of our family fundraisers last year, so we covered the costs with that income. By the way, if you are still looking for a copy of the binder from the conference or any of our other conference store items, they can be found on the website (www.dup15q.org/store.html)!

As of August 1, the Dup15q Alliance balance sheet indicates that we had $23,629.75 in our checking account with just under $262,000 in our money market accounts for a total of $285,628.04 current assets.

The board decided to move ahead on starting a dup15q registry this fiscal year as well. The costs for that will be significant, but the rewards will be priceless. We made the down payment ($10,000) for the registry in July and will have significant other expenses related to the project as the year goes on. Families will be receiving more information on the registry with requests to participate soon. Please help us make this a valuable tool for Dup 15q Alliance.

We continue to be grateful to the many volunteers who make Dup 15q Alliance work and to our families who so generously support our efforts. Thank you for all of your efforts on behalf of Dup15q Alliance.

Financial Report
2011 Second Quarter
By Tom Doyle, Financial Officer

International Registry continued from page 4...

♦ Go to www.dup15qregistry.org. Read the participation tab and if you agree, at no cost, you are ready to create a username and password. An e-mail will be sent to the administrator, who will approve your admission to the registry. You must be registered with Dup15q Alliance to gain admission.

♦ Once you have gained access, you can start the survey. The first section is Diagnosis. You will need to upload a copy of the affected individual’s genetic report. Instructions are provided regarding how to upload your report. You can send the report via e-mail, fax, or mail. If you participated in the Seizure Survey with Elwyn, you can agree to have Elwyn release the report to the administrator, and it will be uploaded to your record. You will then proceed to answer the questions section by section.

♦ It is important that you answer as accurately as possible. If you do not know the answer to a question, skip it—do not guess—and go back to it later. You can stop and save anytime during the process, so it is not necessary to answer the entire survey in one sitting, although it is preferred.

♦ If you forget to answer a question or forget to upload a report, you will get a reminder from the administrator.

♦ There is a glossary for you to use if there are certain terms that you are not familiar with.

♦ Other medical reports that will need to be uploaded include a MRI, sleep study, EEG, EKG/ECG, and echocardiogram.

♦ If you did not complete the survey, you will start where you left off when you log back on at a later time. You will need to go through the entire survey in order to go back to the beginning of the questionnaire. It is also important to note that you will not have access to compare your answers to others until you have completed the survey.

♦ If at any point you have questions, there is a help link or you can e-mail the coordinator. A coordinator will verify all of the genetic reports and the answers for accuracy. Therefore, if there is some confusion you may get an e-mail from the coordinator for clarification.

Creating this medical registry has been an extensive project for Dup15q Alliance. It would not be a reality without the fundraising and volunteer efforts of families and friends of the organization. Thank you for participating in the Dup15q Alliance International Registry. You are helping to build a brighter future for those affected by chromosome 15q duplication syndrome.
Our Dreams for Emily

By Maria Santarpia

In June 2008 we decided that we wanted to add to our family. Our daughter, Melissa, was a senior at Coyle and Cassidy Catholic High School, and Michael was a sophomore at Taunton High School, so it was now or never. By the end of August, not only were we pregnant, we were blessed with twins. Wow, twins! Us!

Because I was pregnant with multiples, I began seeing a high-risk specialist from Boston along with my local obstetrician. Things were going well until one ultrasound when the specialist thought that Baby A’s head was a little large and might have hydrocephalus. An amniocentesis was done, and a week later we were off to Children’s Hospital in Boston. Our appointment was the day before Thanksgiving at the Advanced Fetal Care Unit for lots of testing, including an MRI of baby A’s head. After a long day, we were told to have a seat in a conference room and wait for the specialists to come in to go over the results of the exams with us. We were so nervous. What were they going to say about one of our babies? Well, the results were in and they were negative; there was no hydrocephalus! What a wonderful Thanksgiving we had with our family. Our babies were fine!

Within weeks, however, we had more “bad” news: the amnio had come back with an abnormal fifteenth chromosome, dup15q. I will never forget the specialist’s words: “This baby is going to be very sick.” We believed that no matter what our baby had, it was our baby and God would get us through. I remember sitting there crying that our baby was sick: Why, why, why? We were good people, didn’t drink, smoke, or do drugs. Why our baby? Why us? Eventually, we decided to stop seeing any specialists and avoid talking about the “sick baby.” We just enjoyed our pregnancy, as there was nothing we could do to change it. From that point on we took control of the situation and had a wonderful pregnancy.

On March 18, 2009, my water broke. My older children drove me to the hospital a couple of towns over, and Jack left work to meet me there. We were so scared about what was about to happen. Everyone wants a healthy, “normal” baby, and here we were having two babies, one of whom we knew was going to have issues. At 4:54 p.m. our beautiful Emily Mae was born at 6 lbs. 1 oz., as healthy as can be with an Apgar score of 10, and two minutes later our beautiful Kimberly Ann was born at 8 lbs. 9 oz. We just cried; they were finally here, and both looked healthy and were beautiful! The hospital stay went well, and four days later we all came home. There appeared to be no difference between the girls.

Shortly thereafter, we met with Dr. Jeff Milunsky from the Boston University School of Medicine Human Genetics Department. Dr. Milunsky and his assistant, Sema, are amazing, but that was truly the day our lives changed forever. We got all the details on what Emily and our family were to expect with a diagnosis of dup15q. There was no more “Well, she could be fine.” Instead, it was, “OK, what are we going to do to help our daughter?”

As with most kiddos who have dup15q, Emily’s (as well as Kimberly’s) first friends have been her therapists and medical staff. In her 28 months of life, she has had lots of testing: numerous EEGs, hearing and eye exams, EKGs, echocardiograms, LTMs, sleep studies, X-rays, MRIs, and the list continues. Emily started Early Intervention when she was five months old. Currently, she receives OT, PT, speech, and hippotherapy from EI. We also got her services at The Schwartz Center for Children, where she gets aquatic therapy and additional PT. While there, she uses a treadmill, rides an adaptive tricycle, and uses a Kidwalk twice a week. We also have her enrolled in a music therapy class, where Kimberly also participates as a “model child.” In January of 2011, Emily received a diagnosis of
PDD-NOS and began ABA therapy five days a week. In total, she receives approximately 25 hours of therapy a week, Monday through Friday, yet she rarely complains as she pushes through every session with a smile.

At home, everything we do has therapy incorporated into it. Emily uses a PECS communication book I made for her and an iPad alongside the PECS. She uses a stander for five to seven hours a week, a Rifton Pacer gait trainer walker, and she wears AFOs. Additionally, she wears a rhino brace at night for hip dysplasia and has had bilateral casting done three times because of increased spasticity in her heels. Emily is on a sensory diet: she has parallel bars, two trampolines, and a sensory room we’ve converted for her and Kimberly.

In the short span of two-plus years, we have already realized that we are the ones, 98 percent of the time, educating the doctors about Emily and dup15q. We have already had to and are going to continue to fight to get the services Emily needs and deserves. Last year, Jack and I decided we wanted to do something positive for our daughter and bring awareness to this very rare chromosomal condition. At that point, we made a big commitment and started an organization called “Dreams for Emily.” Our mission is to educate people about Emily and dup15q, do all we can to get her what she needs, help other children, and donate financially to research. We are small and new, but our hopes are to make a positive difference for Emily and other kiddos and for the future of the yet-to-be diagnosed. We have met some wonderful people along the way with children who have dup15q—over the Internet and, recently, at the international conference. What a blessing it has been to have the support of our dup15q family.

We have adopted the concept of “one day at a time”: We live in the present and try to enjoy the little things in all of our children. Life is very hectic with four kids, including 2-year-old twins, not to mention one who requires so much care, therapy, and attention. Do we worry about the future? Of course, we are terrified of what will happen to Emily when we are old and gone. It scares me to death! But we will not let it consume us. It is beyond our control; we can only control today, and today is a miracle. Our dreams for Emily include that she be physically healthy, be happy, have the ability to communicate her needs and wants, and have all the possible opportunities for medical care, therapies, education, and equipment that will help her achieve independence and become all that she is capable of.

We as individuals and as parents have been transformed into better people because of Emily’s diagnosis. Emily has taught us what determination and happiness are all about. When she wraps her arms around my neck, smacks those tiny lips together, looks in my eyes like I’m her whole world, and says “Mama,” nothing else matters. She’s Emily Mae, our family’s special gift from heaven.

Maria and John (Jack) are the parents of Emily (dup15q) and Kimberly, 28 months, Melissa, 20, and Michael, 19. The Santarpi family lives in Taunton, Mass.
Reflections from a Sibling

Reacquainting Ourselves Through Song

“I was sittin’ on a fence post chewing my…”

“Bubblegum!” Rachel chimes in, sometimes loudly and clearly, sometimes as a whisper so soft you have to watch her lips move to be sure she’s talking. We’re walking through the park near our house on my first day back from college for the summer. At 25, she’s five years older than me but a good nine inches shorter. Although we haven’t seen each other in two months, Rachel and I sing this song together just like the last time I was home.

“Playing with my yo-yo…”

“Whoo whooo.”

The song of choice is “Hermie the Wormie,” which Rachel sings at the camp she attends on weekends and for a week in the summer. The choice really is mine because I like singing the song with her, even though she would probably be fine with walking in silence. Also, I’m tired of singing “Mr. Sun.” Since talking to Rachel gets mixed results, I like to sing to her when we’re together. She joins in when I’m singing more often than not, hitting the last word or two of each phrase.

“When along came…”

“Hermie the wormie”

“And he was this…”

“Big!”

Her favorite words to sing are “Home” and “Hey!” usually shouted at the end of a line to add excitement. Rachel also has a bunch of taglines she likes to say. An example of a conversation you can have with her several dozen times a day is:

“Hi, Rachel. How are you today?”

(Silence from Rachel. I continue.)

“I’m fine how are you?”

And then she says, “That’s nice!”

This was something her teachers in high school said every day, and it has stuck. These catch phrases change from year to year, and their ranking on the Rachel Karch Billboard Chart shifts depending on the day. I usually try to use as many as I can each time I see her to keep them going.

“And I said, ‘Hermie…”

“Baby”

“What…”

“Happened?’”

Even though her familiar phrases and songs get a response far more often, I still try talking to Rachel as I would to anybody else. Who knows if she’s listening or if she cares, but it can’t hurt. We usually go a couple months at a time not seeing each other, and it’s hard to tell if she is excited to see me when I come back because she’s often focused on some very important toys or trying to nap. You can tell the people in her life are important to her by the way she lights up when my parents come in or when she sees old babysitters again.

“And he said, ‘I ate my…”

“Sister!‘”

The dosage of Rachel’s medicine or recent seizures can really affect her willingness to talk. As long as you don’t take anything personally, hanging out with her is usually pretty fun. I don’t even think twice about how I talk to Rachel because this is how we’ve always done it. Her smiles and laughs are so genuine and seen just often enough that they immediately lift the spirits in a room. And as far as older sisters go, I really like how Rachel doesn’t tell me to buy different clothes or cut my hair each time she sees me.

Chas, 20, is a student at Carleton College in Minnesota. The Karch family—parents Anne and Paul, Chas, sisters Rachel (dup15q), 25, and Lydia, 22—is from Madison, Wis.

http://www.dup15q.org
Changes on the Board

By Len Poore, Board Chair

At the June board meeting held at the 2011 conference in Philadelphia, the following board members were re-elected for two-year terms: Kadi Luchsinger as executive director, Rachel Doucette as VP of communications, Karen Sales as corporate secretary, and Linda Meagher as a board member. Dup15q Alliance was very fortunate to have a number of people submit their names and applications as candidates for the two open board positions. At the July board meeting, Paul Karch of Wisconsin and Guy Calvert of California each were elected to two-year terms on the board, and we look forward to Paul and Guy adding their energy to the board. We very much appreciate the commitment that board members and their families make of their time and efforts in supporting Dup15q Alliance.

Write for the Mirror

Do you have a story to tell? Share it with other members of Dup15q Alliance! We are accepting article submissions for upcoming issues of the Mirror, including Reflections from a Sibling, the Family Portrait, and a new feature told from the point of view of extended family members. We’re looking forward to hearing from parents, brothers, sisters, and now aunts, uncles, cousins, and grandparents. Even if you have just enough time to jot down a couple of sentences, you can contribute to your newsletter. Every quarter, we ask a question via Big Tent; members’ answers appear in the Family Favorites feature. For more information about writing for the Mirror, contact Jean House at jeanh@editorhouse.com.

How to...

Go Paperless
If you would like to receive your copy of the Mirror via e-mail rather than through the U.S. mail, please visit www.dup15q.org/Mirror.html to sign up for the newsletter online, or send an e-mail to ideasadministration@gmail.com.

Update Contact Information
Don’t miss out on messages from Dup15q Alliance. Please e-mail any changes to phone numbers, mailing addresses, or e-mail addresses to info@dup15q.org.

Buy Dup15q Alliance Items
Check out the store at www.dup15q.org/Store.html, where you’ll find a limited number of conference binders, new awareness cards, and much more!
Dup15q Alliance is a nonprofit organization that provides family support and promotes awareness, research, and targeted treatments for chromosome 15q duplication syndrome. Dup15q Alliance offers help and hope for chromosome 15q duplication.

JOIN BIG TENT TODAY!

Please join Big Tent today! Big Tent is our online forum where families can connect, ask questions, learn from each other, and—last but not least—support each other. Go to the Web site at www.dup15q.org for the link to Big Tent. IDEAS has a restricted group, so the general public cannot join; you must be a registered family within IDEAS to read and post to the forum. This restriction is important to make the forum a safe and secure site for our families. It is imperative for you to sign up, as Big Tent is our means of transmitting important information quickly to our members. Please don’t delay; sign up today!

http://www.dup15q.org

BIG TENT TIP

Has your e-mail address changed? Do you need to change any other contact or personal information? Keep your information up to date on Big Tent and keep informed and in touch with Dup15q Alliance.

To change your settings:
1. Log onto the Big Tent online community.
2. Click the “settings” link on the top right of the page.
3. Change personal information, contact info, etc. by choosing the link on the left of the page.
4. Be sure to click the “save” button at the bottom of each page to save your changes.

Address Service Requested

Repertible, NY 13066
P.O. Box 794
Dup15q Alliance
877-IDEAS-15