FROM THE EDITOR
By Jean House

Our Dup15q Family
When dup15q is part of your family’s reality, you can expect plenty of challenges: therapies and doctor’s visits, restricted diets and special equipment, sleepless nights and jam-packed days. Those of us who care for people with dup15q must navigate the mazes of healthcare, insurance, education, and government bureaucracies, and we also must learn how to speak all of their languages. At the same time, we must figure out how to communicate with our children—and how to teach them, assist in their therapies, even how to feed them. All the while, we face sensory processing disorders, seizures, autism, and other medical and developmental issues. It takes a toll—on the wallet, on relationships, on the body, mind, and soul.

But as difficult as it can be when your loved one has dup15q, there are beautiful bright sides to the syndrome. Every single breakthrough, every milestone reached, is a cause for celebration.

Jean lives in Wilmington, N.C., with her husband, Chris, and son Jonah, 4 (dup15q). E-mails are welcome at Jean@EditorHouse.com.

Our incredible family members who have the syndrome work as hard as we do (often harder); they also play hard and love unquestionably. It’s common knowledge in our dup15q family: our children are sweet and precious people.

That dup15q family I just mentioned is another bright side of the syndrome, and it’s the focus of this issue of The Mirror. Throughout, you’ll find myriad ways members of Dup15q Alliance are here to support one another. At a grassroots level, members organize races, benefits, and other fundraisers for research that will benefit our loved ones (and an added benefit of these exciting events is the opportunity to get together with friends in the dup15q community). The Sunshine Committee, our volunteers of the quarter, brighten birthdays. And members around the world hold informal regional gatherings simply to meet fellow families and spend time together in fun and fellowship. Respondents to a survey taken at the International Conference in Philadelphia in June were especially enthusiastic about regional gatherings: 40 percent said that they have been to a regional gathering and 95 percent want to go to one. It’s a rewarding way to get to know your local dup15q family in person.

Also be sure to check out the Family Portrait, Reflections from a Sibling, and Reflections from a Grandfather. These stories from other families within this larger family are reminders of how much we all have in common. And don’t miss the exciting updates on the registry and current scientific research into dup15q.

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 isodentric 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.

http://www.dup15q.org
There are several ways to keep up with your dup15q family: participating in the parent match program, phoning and e-mailing friends all over the world, and posting to BigTent and social networking sites such as Facebook. Getting together in person is a special treat. One place to catch up with friends old and new is at the international conference held every other summer. But how can families get together more often, close to home? At informal regional gatherings, like those recently held in Italy, Spain, Ohio, Minneapolis, Seattle, and Los Angeles. Here are some reflections from organizers and tips for planning your own regional gathering.

**California**

On October 2, we hosted the first and what we hope will become annual dup15q California gathering at our house. The conference in Philadelphia last summer inspired us to bring together some California families. I admit, I was also a little envious of the other regional gatherings that happened over the summer and wanted in on the action! I reached out to all the families in the state as a group, and I also posted the event on Facebook and BigTent. My husband, Mike, and I were excited as the RSVPs started coming in. We ended up hosting five other families, most of whom we had never met. Everyone contributed to the meal by bringing a side dish or a dessert, which made things pretty easy. We had several activities for the kids and spent a great afternoon outside getting to know each other. The age range of our children affected by dup15q was 2 to 17, so it was great to be able to talk with some of the parents who had “been there, done that” as well as get some fresh perspective from the parents with younger kids. There was talk of organizing a group to walk at the Autism Speaks walk in April 2012 and lots of sharing of experiences. I think everyone was happy to have someone to talk to who “gets it.” I know I was.

Thanks to all the families who made our first regional gathering wonderful! We hope that in years to come we will have more and more families and that we can enjoy watching each other’s children grow up. We are already looking forward to next year’s gathering, so California families, we’ll see you next October!

**Sarah Porath**  
Mother of Annabel, 5 (dup15q), and Isaac, 2½
**MIDWEST**

The Midwest regional get-together was held in Minneapolis on Labor Day weekend. The annual gathering started at Minnehaha Park for a potluck picnic dinner. Ten families arrived to ride bikes, walk the trails, and enjoy the views of the river and waterfalls while getting to know each other and catching up with old friends. After dinner, we went to the hotel to continue visiting and go for a swim. The next morning, some of the families took a trip to the Minnesota Zoo, where they had lunch and enjoyed each other’s company while visiting the animals’ exhibits and the children’s petting zoo. A trip to the Mall of America and some rides at the amusement park were next on the agenda. The evening brought a pizza party around the pool at the hotel. Too soon, a wonderful weekend was over and we had to say our goodbyes—always the hardest part of the weekend.

The Midwest get-together has become an annual event. We meet in a different place each year, allowing families to vacation in a new setting. A family volunteers to find a hotel in a particular state, to be used as our home base. We all know the kids like to swim, so as long as we have a pool, we are set. The host family usually makes suggestions for group activities. Each family takes care of its own needs, but we have the support of each other and there is always an extra hand when needed—no one needs to worry about criticism or questioning looks because we are an awesome group! The very nicest part of the regional gathering is the low-key, family-friendly, casual atmosphere. We all enjoy meeting old friends and new families each year.

**Deb Lindgren**  
Mother of Chad, 36 (dup15q), and Robb, 34

**OHIO**

Planning a regional gathering does not have to be difficult or time consuming. In fact, it can be easy and fun. In May 2010, I hosted an Ohio gathering. I teamed up with Connie Will, another local mom, who was a great help. We decided to have a relaxed gathering in my backyard, divided up the responsibilities for food and party supplies, and planned some simple outdoor activities for the kids.

We posted a message on BigTent to see who might be interested and then picked a date and time. Connie and I decided what food we wanted and had family and friends contribute. We wanted the kids to have activities they enjoyed, so we incorporated the trampoline, water play, and some additional party supplies. We also arranged for child care, with the hopes that parents could have a chance to share and connect. It was really wonderful to spend time with other families living with dup15q and to see the kids together. The families who were in town the next morning met at the Columbus Zoo, which was really fun as well. We are hoping to have another Ohio gathering soon!

**Rylie McHam**  
Mother of Jimmy, 6 (dup15q)
How has your dup15q family been a help to your family?

Our Dup15q Alliance family always sees the best in Corrina, and that helps us see the best in her too! Alliance families can be counted on to celebrate Corrina’s successes and notice her joyful spirit, and in so doing they magnify our pride and happiness in our oldest daughter.

Tim and Nicole Cleary
Parents to Corrina, 15 (dup15q), Sierra, 13, and Jasmine, 9

The dup15q family has been such a help to us by providing info on all sorts of things from adapted equipment to dealing with sibling issues. But the biggest help is to go from hearing “your child has something we have never seen” to finding a family that helped us understand that, while Chloe isn’t typical, she’s not the only kid out there with this syndrome. We understand that we don’t just need to “get through it” but can really enjoy our sweet girl for all she brings to our lives!

Sarah Johnson
Mother of Chloe, 6 (dup15q), and Sadie, 3

I am a MOKK (Mother Of Older Kid). When I found out in 1995 that Kathleen has dup15q, she was 2 years old. Her doctor said he knew nothing about it. I found this group and answers to many of my questions. There were 65 of us then throughout the United States, and look how we have grown! Thanks to this group, I have met so many parents who can laugh, cry, and tell very similar stories. I have gone to Kathleen’s doctors over the years with medication advice I’ve received from reading information that members of Dup15q Alliance share. I’ve learned that the quirky things she does are just typical of our sweet children. Thanks to Facebook, The Mirror, and Big Tent, I never feel alone. This is a support group that never judges, only helps hold me together when I feel I’m going crazy and walks this path with me with such acceptance and warmth. I love our dup15q family!

Bernadine Mullen
Mother of Kelley, 22, and twins Kathleen (dup15q) and Lucas, 18

Fundraising Gatherings

CRIM RUN

My husband, Corey, and I organized a fundraising run at the Crim Festival of Races on August 28 in Flint, Mich. We recruited people to run for Team Grace (our daughter), and these volunteer runners collected pledges on her behalf. We also created a webpage on the FirstGiving website as an easy way for friends and family to donate online. While falling just short of our goal, Team Grace raised $3,300 for Dup15q Alliance.

For us, fundraising is the single most important thing we can do to give back to Dup15q Alliance. Our contributions will have a direct impact on future research by way of the genetic registry. The more money we can raise as a group, the better outcomes we will see for our children.

Tina Mueller
Tina is the mother of Grace, 5 (dup15q), and C.J., 1

KANSAS CITY FOR KILLINGTON

This year, the IDIC15 race in Killington, Vt., was cancelled due to Hurricane Irene. The True family felt the pain of having to cancel the race; we attended this event last year and had such a fun time. So at the last minute we decided to organize a walk in Kansas City in support of our friends in Killington.

The 10k walk took place Sunday, Sept. 18, along one of our late daughter Clare’s favorite walking routes. Those who attended were treated to a slide show of last year’s race in Killington, some tasty snacks prepared by our son Tyler, and some great Clare stories. We can’t believe she has been gone for nearly five years.
Due to the last-minute planning and the opening of the skies that morning, attendance was not what we had hoped it would be, but a number of people who don’t care to walk in the rain supported the event with financial contributions. A total of $520 was raised for Dup15q Alliance. Kansas City for Killington was a heartfelt day of fun and raising awareness of dup15q.

Jane True
Jane raised Clare (dup15q) and her two brothers, Toby and Tyler. She lives with her husband, Jim, in Kansas City, Mo.

1ST ANNUAL KAYJAY 5K
A HUGE SUCCESS

On the chilly morning of Sept. 24, Dup15q Alliance families from around the Midwest gathered together in Wheeler, a little village in west central Wisconsin. My husband, Todd, and I live there with our two sons, Marik and Kayden. Kayden was diagnosed with dup15q when he was 1. He is a very happy little guy and has this uncanny ability to get people to fall in love with him without speaking a single word. When Todd got back into running a couple of years ago, he wanted to put on a race to raise money for Dup15q Alliance. He was inspired by the IDIC15 Road Race, an event put on by the Rasmussen family in Vermont. He wanted to bring an event like that to our community, close enough for some of the other Midwestern families to attend. The race was named the KayJay 5K in honor of our son Kayden Jayce. Even though it is named after our son, it is still a representation of all of our amazing, wonderful children who have dup15q.

The race featured a 5K and 1-mile walk/run. We wanted to keep it family friendly, so we also had kids’ games, barrel train rides, bounce houses, raffle and door prizes, DJ entertainment, and food for the participants. We received full sponsorship for the event thanks to Wisconsin Industrial Sand Co. Many businesses came forward to donate money or raffle prizes. My sister’s craft shop had closed, so she donated tons of fun Christmas décor, which I combined into many gift baskets that we raffled off.

Word quickly spread via advertising, Facebook, the newspaper, and television. Todd and Kayden were interviewed on TV together and are now local celebrities. We had a total of 90 participants that day with countless others volunteering their time. The event raised $6,444 for Dup15q Alliance. Considering our goal was $5,000, we couldn’t be happier for our first year!

Including our own, 10 Dup15q Alliance families attended: the Lindgrens, Supinas, Morgans, Morans, Matuzas, Bussians, Paul Karch, Ruth and Marlena Kross, and Karen and William Sales. A few of the families arrived the night before the race and stayed at a hotel close to the event. We all went swimming and had dinner together that evening. After the race on Saturday, most of the families gathered together for lunch and laughs.

We are already planning next year’s KayJay 5K for Sept. 22, 2012, and hope that even more families will make the trip. Thanks to everyone who donated, participated, or volunteered their time. We couldn’t have done it without you!

Teana Ebensperger
Teana is the mother of Marik, 6, and Kayden, 10 (dup15q).
**Fundraising Update**

Mike Porath  
Fundraising Committee Chair

Good news! We’re on pace to exceed our goal of raising $65,000 for Dup15q Alliance in 2011. To keep up that pace, please consider contributing to the year-end direct ask letter that you received in the mail. The funds we raised this year helped us launch the Dup15q International Registry and put on a wonderful conference in Philadelphia.

Since the conference in June, several families have taken it upon themselves to raise money for our group. In the last few months, more than $20,000 has been raised by the following families: Ebenspergers, Muellers, Wests, Rasmussens, Saleses, Supinas, Krosses, and Quinlans. Thank you!

Because of this momentum we’re building, we’ve set next year’s fundraising target at $100,000. I have no doubt we can exceed that amount.

To help us reach the goal, we’re starting a fundraising incentive program. Anyone who raises money for Dup15q Alliance can earn free registration for the 2013 International Conference as well as free nights at the hotel, depending on the amount raised. We’re still working on the details of the incentive program, and we’ll post them soon on BigTent and in the next issue of The Mirror.

There are several ways you can help us reach our goal next year. Please drop me a line at mikeporath@yahoo.com if you’d like to hold a fundraiser or if you’d like to join the Fundraising Committee.

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**Registry Update**

Kadi Luchsinger  
Executive Director

The Dup15q International Registry was created to better understand dup15q and identify areas for research. The registry has recently been upgraded, so when you log in you will see a slightly modified version. Around 175 people have signed up for the registry, but not all of them have completed the information yet. If you’ve signed up, please complete your registry before the end of the year.

If you have not signed up for the registry yet, please go to www.dup15qregistry.org and sign up today. We are hoping for 200 families by the end of the year. It is important to answer each question accurately, as we will use this information to better understand dup15q syndrome. This is a very important step toward creating a better tomorrow for our children, and we need your participation.

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**Financial Report: 2011 3rd Quarter**

Tom Doyle  
Financial Officer

Things are pretty quiet in the third quarter after the conference and all the preparations leading to it. We have been fortunate to have several fundraising events throughout the country that have helped us to remain on budget. Thanks to everyone who participated in the fundraising events this year. Special thanks to all those who participated in various ways after Hurricane Irene put a damper on the Vermont Fun Run event. Many people generously donated their registration fees even after the event had to be cancelled, and many more participated in the “virtual” run that took place as well. Thanks to all who have contributed their time, talent, and funds to these events this year and to Mike Porath and the Fundraising Committee for leadership in this area of our budget.

As of the end of August, the Dup15q Alliance balance sheet indicates that we had $30,571.14 in our checking account, with just under $262,000 in our money market accounts for a total of $292,664.56 current assets.

As I indicated in the second quarter report, 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 hope every family will participate. Please help us make this a valuable tool for Dup15q Alliance.

We continue to be grateful to the many volunteers who make Dup15q Alliance work and to our families who so
RESEARCH UPDATES
Rachel Doucette
VP of Communications

Collaboration Meeting
On October 17, 2011 a scientific group from Boston collaborated at a meeting that was held at Massachusetts General Hospital with representation from Massachusetts General Hospital, Boston Children’s Hospital, and Beth Israel Deaconess Hospital. This group discussed collaboration amongst these three medical facilities as it relates to dup15q, the multidisciplinary approach at the Dup15q Clinic at MGH, and current and future research on dup15q.

Attendees included:
- Ronald Thibert, DO, Pediatric Epileptologist, Dup15q Clinic, Mass General Hospital
- Amy K. Morgan, PhD, Pediatric Neuropsychologist, Mass General Hospital
- Janette Z. Lawrence, MS, CGC Genetic Counselor, Mass General Hospital
- Sarah J. Spence, MD, PhD, Neurologist, Center for Pediatrics, Children’s Hospital Boston
- Kiran Maski, MD, Neurology, Sleep Disorders, Center for Pediatrics, Children’s Hospital Boston
- Matthew P. Anderson, MD, PhD, Assistant Professor and Principal Investigator, Departments of Neurology and Pathology, Beth Israel Deaconess Medical Center
- Dr. Kenneth Sassower, Sleep, MGH
- Rachel Doucette, VP of Communications, Dup15q Alliance
- Len Poore, Board Chair, Dup15q Alliance.

Another meeting is planned for March 2012.

Boston Clinic
The Dup15q Clinic, facilitated by Dr. Ronald Thibert at Massachusetts General Hospital, is proud to report a successful beginning. To schedule an appointment at the Dup15q Clinic at MGH, please call (617) 726-6540.

Sleep Study
Very soon, we will announce a new study involving sleep disorders and dup15q conducted by Dr. Kiran Maski, Boston Children’s Hospital. If your child has had or is scheduled to have a sleep study, please ask the sleep center for a copy of the sleep data on CD. Having this data in hand will expedite the time taken to complete this study.

Dup15q Study Published
Matthew Anderson, an assistant professor of neurology and pathology and director of neuropathology at Beth Israel Deaconess Medical Center and Harvard Medical School in Boston and senior study author, has genetically engineered mice whose symptoms closely mimic autism in humans. In the study, published in the Oct. 5, 2011, issue of Science Translational Medicine, mice were engineered to have abnormality in the Ube3a gene on a region of the chromosome called 15q11-13. The mice in the study were bred to have triple copies of the Ube3a gene (the same as chromosome 15q duplication syndrome). “Now that we have a good surrogate, we can test medications to see if their communication and social interaction improves,” he said.

Other Current Research Projects
Molecular Investigations of Duplications of Chromosome 15 in Autism, N. Carolyn Schanen, MD, PhD, Principal Investigator, Nemours Research Programs, Alfred I. DuPont Hospital for Children, Wilmington, Del.

Autism Phenotype in 15q Interstitial Duplication Patients, Dr. Lawrence T. Reiter, Principal Investigator, University of Tennessee Health Science Center. For more information on research projects, please visit www.dup15q.org/current-research-studies.html or e-mail research@dup15q.org.

Patient Number One at the Dup15q Clinic
William Sales, 8, was the first patient of the new Dup15q Clinic at Massachusetts General Hospital in Boston. Facilitated by Dr. Ronald Thibert, the clinic offers a range of services and specialists for people diagnosed with dup15q. Be sure to check out Karen Sales’ article in the next issue of The Mirror to learn more about this exciting new center of excellence!
The Journey with Janelle
Finding Understanding and Acceptance
by Stephanie Barmann

Five years ago I looked down upon the most beautiful baby girl I’d ever seen. She was born at the tiny weight of 5 pounds, 15 ounces, over a pound smaller than any of her siblings. People would tell me I was blessed to have such a good baby. Because she never cried, we’d feed her on a schedule and check her diapers often. It would have been easy to agree with everyone and say, “Yep, she is just a good baby!” but I knew better. I knew from the day she was born that something was wrong. I felt it deep in my soul, and I wouldn’t give up until I knew what it was.

When Janelle was three months old, we noticed her eyes were shaking back and forth. I knew newborns’ eyes sometimes did crazy things, but this was very odd. It was as if her eyes were on pendulums. A few weeks later, she was diagnosed with nystagmus (a condition that makes the eyes shake involuntarily). When the doctor told me they didn’t know how well she would see, if at all, I started to cry. These were the first of many tears I would shed for my daughter over the years.

In Janelle’s first year of life, she was diagnosed with four eye conditions and several severe delays. At 10 months old she started working with occupational and speech therapists as well as a vision teacher. I waited patiently to see her first smile, which wouldn’t come until she was 11 months old. I longed to hear her speak, but she couldn’t say the words she wanted to say. It was nearly three and half years before she really spoke to us. She did everything very late, and it broke my heart. I wondered if she would ever have a normal life, if she’d be accepted into society. I mourned daily for what should have been but wasn’t.

There were misdiagnoses along the way, such as neurofibromatosis, but I never stopped looking for the right answers. Every time the doctors said “sometimes there are no answers,” I searched harder. Every time people said “just stop and deal with the problems at hand,” I knew I had to find out why the problems were there. I knew the answer would lead me to helping her. I knew somewhere out there someone could tell me why it seemed Janelle had more things wrong with her than right. It took four years, but I finally got those answers from her geneticist.

I’ll never forget what Dr. Robinson said to me. He said his job wasn’t to find out that my daughter has this issue or that problem; it was his job to find the one thing that is causing everything. I swear I could have kissed the man. Those words were the ones I had been seeking all along.

Eight weeks: that’s how long it took for Janelle’s blood work to come back. That test was on my mind every day, and I carried my phone with me everywhere. I’ll never forget the day the call finally came. We were in the car in the mall parking lot, about to go to the shoe store. Janelle was quietly sitting in her car seat behind me. Dr. Robinson told me Janelle did in fact have a chromosome issue. I asked him what it was called, and he said there was no name for it, it was a duplication on 15q 11.2, but then it was just a series of numbers I didn’t understand. (I now understand more about that series of
numbers than I ever thought I would.) He then went on to say “I know I promised you one answer, but there are two.” He explained that Janelle also has a deletion on her nineteenth chromosome, which is even rarer than the duplication on the fifteenth. The geneticist said he doubted there was anyone else who had both of these genetic anomalies.

I hung up the phone and cried. For once I didn’t cry because of the answer, but because we had an answer. I cried because I knew I could now try to find people who had been there and done that—and boy did I! I went home and found IDEAS (now Dup15q Alliance). The first person I met was Vicki Couch, who has been my lifeline through it all. She was the first person I met in what I call my Fifteen Family, the people who have guided me and led me to understanding and acceptance. Every time I saw their beautiful children, I saw my own. Every time their children achieved a milestone, I was there cheering with them. We truly are a family, even if we may never meet in person.

I immersed myself in doing all I could to help Janelle be all she could be. I fought to get her into the best school for her, and she thrived. I stood outside hugging her and sobbing. It was as if I’d heard the sweet voice of an angel.

Things have only improved since then. She is going to a typical kindergarten and doing well. I know she’ll never do things exactly the way others do and she’ll always have her own way of saying things, but she will form real relationships with people and have a full life. She won’t ever let her disabilities hold her back. I once said to someone that I truly believe she is meant for great things. People—and I mean everyone—are drawn to her and always say the same thing: “I love Janelle.” She’s like this little magnet of innocence and sweetness that draws you in. When she meets someone who takes the time to get to know her, Janelle will say “I love them, they are so beautiful.” She only sees the beauty inside; Janelle sees their soul.

My husband and I have six other children. I became pregnant with my youngest while my husband and I were going through genetic testing to determine if we were carriers. If Janelle’s syndrome was due to a parent being a carrier, I had fully expected it to be me, since she was so affected by the duplicated fifteenth chromosome. It wasn’t though; it was my husband, Mathew, our youngest, does have the duplicated chromosome. He was born with hypotonia, but was otherwise fine.

When I was asked to write this Family Portrait, I knew I couldn’t leave out the extended family we’ve acquired because of this condition. As I mentioned before, there are my wonderful Fifteen Family members, who I adore. There are so many others, though. There are a whole lot of doctors and nurses. There are therapists who I’ve spent more time with than I’ve spent with friends, and there are wonderful teachers who believed in my child as much as I did. These people all hold a special place in my heart, and I will never forget any of them.

Yes, I have shed many tears over the years—some happy, some sad. I have fought and I have felt defeated, but in the end I wouldn’t change Janelle. As crazy as that sounds, she is who she is and that’s what makes people love her. I look at what a blessing she is and what a wonderful life she will have because she does not recognize all the bad and evil in the world. Yes, I am truly blessed!

Stephanie is the mother of David, 13, Sara, 12, Leanna, 10, Emma, 8, Janelle, 5 (dup15q), Devony, 2, and Mathew, 1 (dup15q).
Reflections from a Grandfather

by Roland Rivard

What do I like best about spending time with my granddaughter Megan? Megan is very loveable and loves to give kisses. At times we just sit together and enjoy each other’s company. She is so easygoing, and she doesn’t get into trouble.

Also, I love taking her for walks. Whenever I go out with the family, I love taking care of Megan by either walking with her or pushing her stroller. While her siblings are exploring, in a gift shop or other store for instance, I love to escort her around. She is always very cooperative and has no inclination to touch anything in the store.

Megan is always willing to give me an energetic high-five. She doesn’t have any ill feelings about anyone. Since she has always been in a safe environment, she is a very loveable, loving, and trusting person. Megan is a very happy and content child.

Megan reminds me to have no expectations and no desire for greatness—just to be a simple, loving, and content person. She is an example to me of what it means to be trusting, leaning on God.

Roland lives in Berlin, N.H. He enjoys spending time with his family: his wife, Lillianne, three sons and daughters-in-law, and eight grandchildren. Megan (dup15q) is 15 years old.
Reflections from a Sibling
by Kaitlin and Melissa Markwell

My name is Kaitlin. I’m 15 years old and my little sister, Hailey, who is 5, has dup15q. My little sister means the most to me. She has changed me for the better and opened my eyes to life and love. She is the most beautiful, strongest, bravest little girl I have ever seen, and she has accomplished more in the past five years than I will in my whole life. She has proven all the doctors wrong and continues to do so.

Hailey makes you look at life in a whole new way; she makes you realize the importance in the smallest things. She doesn’t need fancy things or even to go to the fanciest places—only to be with the people who love her and care for her. Her smile and laughter are contagious, not only to family and friends but to people who have never seen her a day in their life. She has a pure soul, which not many people do. She goes through life with her eyes wide open and tries so hard every day.

Things that are so simple to me are so hard for Hailey. Most days are not easy for her, but she always has a smile at the end of the day. I am only 15 years old, and she is my inspiration to be somebody in life. I am blessed to have her in my life. How many people can say that a 5-year-old is their inspiration? She is my inspiration to show people how to open their eyes to kids like Hailey, to show people that life is precious and not to be quick to judge, stare, and whisper.

Hailey loves music. She loves it when we sing to her and dance with her. Times like that are priceless. It brings tears to my eyes when I think of her. I wouldn’t ask for a better little sister because there couldn’t be someone better than her. She is my angel here on earth, put here for a special reason, and I thank God every day for picking me to be her sister.

My name is Melissa, and I am 18. My whole outlook on life has changed since my family has had the honor of having Hailey in our life. I have changed a lot of my ways and also what I want to do with my life. I will be teaching special education and also will be working with Hailey because that is when I am the happiest. Recently I have lost friends and family because of mean words people say, and I feel it is my fight to stand up for people who can’t stand up for themselves.

Hailey gets so excited when she rides along to pick me up from school; she giggles and smiles so big it would make the meanest person in the world melt. We have special things we do and special books we read; I have One Fish, Two Fish

memorized.

Family time has so much more meaning than it ever used to, just because Hailey has opened a whole new world to us, especially to me.

My mom the other day said there was a breakthrough with some scientist stuff that could change Hailey. Think what you want of me, because I got mad, really mad. I love Hailey like she is; she is: sweet, innocent, and pure. She is not a brat and doesn’t have a mean bone in her body. Why change that? I love Hailey just like she is, and my job is to protect her, and that is what I will do.

Melissa, Kaitlin, Hailey, and their parents, Lori and Larry, live in Wilmington, N.C.

How to . . .

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If you would like to receive your copy of The Mirror via e-mail rather than through the 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.
Join BigTent Today!

Please join BigTent today! BigTent 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 website at www.dup15q.org for the link to BigTent. Dup15q Alliance has a restricted group, so the general public cannot join; you must be a registered family within Dup15q Alliance 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 BigTent is our means of transmitting important information quickly to our members.

Please don’t delay; sign up today!

BIGTENT TIP

**BigTent Blink:** Receive a summary of news, events, and postings delivered to your e-mail.

1. Click the “Settings” link on the top right of the page.
2. Click the “BigTent Blink” link on the left side of the Settings page.
3. Check the box next to “Please e-mail me a BigTent Blink.”
4. Check the box next to the day you would like to receive your Blink.
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