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.

Building these networks of support can be a particularly thorny challenge for individuals with dup15q. They often have limited mobility in moving about the world, usually have significantly limited communication skills, and are frequently misunderstood by those who have just a passing contact with them. In this issue you will learn about how a few families are approaching creating such “Circles of Friends”, as they are often called, for their affected children. These circles can be helpful when your child is young and you need support with the challenges of raising your child. At this age and stage often teachers, therapists, and care providers are good circle participants. During these years, much support of the child takes place by supporting the parents and other family members.

As our children grow, the kinds of supports they need change. They need to have a means to get out in the community, to transition to experiencing things in the world without the immediate presence of a parent, to have someone in their lives who can act as a “bridge” between the young adult child and the activities they would like to experience out in the world away from the protected environment. Thus the importance of creating a Circle of Friends becomes even greater.

(continued on page 3)

Jane True, Editor

Jan serves as the editor of the Mirror. She raised Clare idic(15) and her two brothers, Toby and Tyler. She lives with her husband Jim in Kansas City, MO.

http://www.idic15.org
Building Social Connections for Loved Ones with dup15q

by Nicole Cleary

When you sit back and reflect about the things that bring happiness in life, for most of us a feeling of being connected to family and friends is near the top of our list. Our connections with family and friends are what help us get through the hard times when we may lack confidence or find ourselves faced with a difficult challenge. These same people are the ones we run to when we have exciting news or a personal success to share. Beyond our close ties, we have a number of acquaintances and contacts that also play an important role in our lives. Think about the many ways that your connections to acquaintances and contacts provide benefit, from having people to turn to for help when looking for a job to the nice feeling of being recognized in your community when you walk into your neighborhood coffee shop or grocery store.

It is no different for our loved ones with chromosome 15q duplication syndrome (dup15q), with one notable exception: for many individuals with dup15q forming friendships and building social connections is much harder than it is for you and me.

The result of this difference has been brought home to me in my work as a residential coordinator supporting group homes for adults with developmental disabilities. Some of the individuals we support have strong connections to their family and friends, but many of our supported individuals are among the loneliest and most socially isolated adults I have ever met. The only people in their lives on a consistent basis are the people who are paid to be there. This is not the future I want for Corrina, but sometimes I fear it might be where we are headed.

Our daughter Corrina is well loved and supported in our immediate and extended family. She enjoys family gatherings and loves to point to pictures of “her people” all around our house. Beyond our extended family there are teachers and caregivers who care about Corrina. Corrina is known to a very limited number of students in her school because she has been in self contained classrooms with other children with disabilities. I’m not sure that any of them consider her (nor would she consider them) as a friend. If I extend this picture out 20 years I can see the same fate that I see for the supported individuals I work with. If we want a different future for Corrina, we will have to invent it.

A Model For Social Connections

It is helpful to have a picture of the different levels of social relationships in your child's life, both because it helps you understand the social connections that already exist and the relationships that could be expanded or strengthened to create the same kinds of social connections we enjoy.

Assess Current Social Connections

Look at how many relationships your child has for each different level of social connection. It's especially important to look at the outer two circles. Most of us build friendships from social contacts and acquaintances that we spend increasing amounts of time with, especially in mutually enjoyable activities. It's important to have a rich network of contacts and acquaintances because these are the people who are most likely to become future friends.

Find Opportunities To Enrich Social Connections

Be as proactive as possible in involving family and close friends in your child's life. Make special efforts on birthdays, school performances, and holidays to help connect your child to their extended family. As individuals with dup15q become
adults and start to live away from home, you may want to consider new concrete steps to encourage family and close friends to stay involved so that “out of sight” doesn’t become “out of mind”.

As noted previously, friendships most often naturally evolve from repeatedly spending time with other people in activities that both people enjoy. Identify your child’s interests. Building friendships around high interest activities may help your child to reach outside their normal comfort zone for social interactions. Does your child like to go bowling? Is there a typical child in your school/church group/neighborhood who might like more opportunities to bowl that you could invite the next time you take your child with dup15q bowling? Is there a youth bowling league your child could join? Does your community have a Special Olympics bowling club?

Increasing the number of acquaintances in your child’s life may require your active support depending on your child’s social skills. Prompting your child to greet people he or she sees occasionally will help a social relationship to form, even if the acquaintance sees you prompting the greeting.

Getting your child involved in activities beyond their school day will expand their network of acquaintances (ie. boy/girl scouts, swimming lessons, etc). Choosing to frequent the same grocery stores, restaurants, swimming pools, and hair salons can also provide helpful opportunities for your child to make acquaintances and be known in their community.

Increasing contacts may involve proactively introducing your child to anyone and everyone that takes an interest in them, even if that interest comes in the form of awkward staring or talking about your child. For us, a great place to build contacts is our neighborhood community pool. We take Corrina swimming a few times a month and people definitely notice her jumping and delighted hand flapping, and then there’s the opportunity that comes every time I get her dressed. Putting our 13 year old daughter in pull ups in a crowded locker room is a great opportunity to introduce Corrina and help other children see that she is both just like them (loves swimming) and is different (wears pull ups afterwards). Every time we do this with a child from her school or from our neighborhood who has not previously met Corrina, we have just made another contact.

Core Relationships: family & close friends

Friends: people we like & who like us

Acquaintances: people we know socially & see occasionally

Contacts: people we have met but don’t know well

Increasing the number of acquaintances in your child’s life may require your active support depending on your child’s social skills. Prompting your child to greet people he or she sees occasionally will help a social relationship to form, even if the acquaintance sees you prompting the greeting.

Getting your child involved in activities beyond their school day will expand their network of acquaintances (ie. boy/girl scouts, swimming lessons, etc). Choosing to frequent the same grocery stores, restaurants, swimming pools, and hair salons can also provide helpful opportunities for your child to make acquaintances and be known in their community.

Increasing contacts may involve proactively introducing your child to anyone and everyone that takes an interest in them, even if that interest comes in the form of awkward staring or talking about your child. For us, a great place to build contacts is our neighborhood community pool. We take Corrina swimming a few times a month and people definitely notice her jumping and delighted hand flapping, and then there’s the opportunity that comes every time I get her dressed. Putting our 13 year old daughter in pull ups in a crowded locker room is a great opportunity to introduce Corrina and help other children see that she is both just like them (loves swimming) and is different (wears pull ups afterwards). Every time we do this with a child from her school or from our neighborhood who has not previously met Corrina, we have just made another contact.

Be Creative And Committed

Building social connections is a lifelong endeavor. This is not something you do at kindergarten and check off your list. Keep your eyes open as your child ages in school settings, church settings, neighborhood gatherings, and in your community. Help them to make contacts and acquaintances, and be on the lookout for opportunities to transform those relationships into friendships. You never know which ones might just last a lifetime.

Nicole Cleary is the chair of the IDEAS Board. Together with her husband Tim, she is raising Corrina (a 13 year old with idic15), Sierra (11) and Jasmine (7). Nicole works as a Residential Services Coordinator providing supports to 8 group homes for adults with developmental disabilities in Portland, OR.

FROM THE COVER
Learn where some of our families are looking to find candidates for their child’s circle, consider your own child’s specific situation, and then let your mind go. It is surprising where you might find someone who would love to have greater presence in some aspect of your child’s life. Is there a neighbor who seems to relate well? Is there another child who seems curious about your child but perhaps is too shy to ask questions? A parent can take the initiative and see if there are questions that could be answered or if they would just like a window into what it is like for your child to go through a normal day. Perhaps as the parent you can create special activities or occasions that would be enjoyed both by your child and the potential friend.

Much of the success of a budding friendship will depend on how well-prepared the non-affected individual is to do such things as carry on a conversation, even if it is non-verbal, or to guide your child through an upset if one occurs. Often an hour spent in advance by a mom or dad visiting a classroom, scout troop, or church class makes a huge difference in how the others in the group interact with your child. Informing them in advance of your child’s likes and dislikes and helping the group know what to expect can start everyone off on the right foot. Developing and supporting Circles of Friends is a lifelong challenge, but is well-rewarded as you grow the numbers of people who understand and love your child, and genuinely enjoy spending time with them.

INSIDE THIS ISSUE
1 From the Editor
2 Developing Social Connections
4 A Sibling Drama
5 Adult Support Networks
6 Buddies Groups and Individuals
7 IDEAS 3 Year Strategic Plan

In Every Issue
Family Portrait 8
Volunteer of the Quarter 10
Birthdays 11
Fundraising Update 11
MOMENT: INFORMING THE FRIENDS  
By Ben Davis

Ben, brother to Emma, is in the ninth grade at Westford Academy in Massachusetts. He recently wrote the following dramatic scene as an assignment for an "Intro to Stage" class. It is a real interview that he conducted with some of his friends. Next he has to cast people to play the parts, and then he will direct the performance in front of the class.

Thank you, Ben, for sharing this with IDEAS!

BEN: What were your first thoughts when I first told you about my sister’s dis-abilities?

SHAWN: I don’t know, well I wondered how she would be acting with me around...

NARRATOR: Shawn, one of Ben’s friends from down the street.

SHAWN: I was nervous about meeting her and, you know, making a good impression on your parents too, because I didn’t want to mess up or cause a problem. You know? Because I’m not that kind of person.

NARRATOR: Here is Alex, Ben’s best friend for years.

ALEX: My first thought was, well, why didn’t I know this? Should I feel guilty for not knowing and using words like “retarded” badly? I thought about all of the social complications that there were, along with actually meeting her... you also told me that she could die in her sleep any day from a seizure... that part just scared me. I mean, how do you deal with that as a friend?

NARRATOR: This is Riann, the friend Ben tells everything to, because among other reasons, she shows him other perspectives that he wouldn’t have otherwise seen. The real ones. The raw truths.

RIAN: I was, naturally I think, nervous. I was scared as hell to say something humiliating with the word “retarded” because I hear that so much in school and stuff... I was also surprised how you weren’t all defensive about it... seemed you didn’t think too much about it, I thought that was good... you acted like it was just a fact about you.

ALEX: Above anything I was glad that your family was so loving, and like, accepting of it all. I knew that in your family, she would be well cared for, and you wouldn’t be ridiculously over-protective of her, or over-sensitive about the fact that she was different.

SHAWN: I also wondered what type of disability it was. I had no idea what was and was not appropriate or insulting to ask. Was it okay to ask how she would be behaving? If she was in a wheelchair? If she could speak well? I didn’t even know if I was supposed to talk to her like a normal person, because if I did she might not... comprehend or whatever... but if I talked to her a bit more simply, would she think me a jerk?

ALEX: Above anything I was glad that your family was so loving, and like, accepting of it all. I knew that in your family, she would be well cared for, and you wouldn’t be ridiculously over-protective of her, or over-sensitive about the fact that she was different.

SHAWN: I also wondered what type of disability it was. I had no idea what was and was not appropriate or insulting to ask. Was it okay to ask how she would be behaving? If she was in a wheelchair? If she could speak well? I didn’t even know if I was supposed to talk to her like a normal person, because if I did she might not... comprehend or whatever... but if I talked to her a bit more simply, would she think me a jerk?

ALEX: Above anything I was glad that your family was so loving, and like, accepting of it all. I knew that in your family, she would be well cared for, and you wouldn’t be ridiculously over-protective of her, or over-sensitive about the fact that she was different.

SHAWN: I also wondered what type of disability it was. I had no idea what was and was not appropriate or insulting to ask. Was it okay to ask how she would be behaving? If she was in a wheelchair? If she could speak well? I didn’t even know if I was supposed to talk to her like a normal person, because if I did she might not... comprehend or whatever... but if I talked to her a bit more simply, would she think me a jerk?

ALEX: Above anything I was glad that your family was so loving, and like, accepting of it all. I knew that in your family, she would be well cared for, and you wouldn’t be ridiculously over-protective of her, or over-sensitive about the fact that she was different.

SHAWN: I also wondered what type of disability it was. I had no idea what was and was not appropriate or insulting to ask. Was it okay to ask how she would be behaving? If she was in a wheelchair? If she could speak well? I didn’t even know if I was supposed to talk to her like a normal person, because if I did she might not... comprehend or whatever... but if I talked to her a bit more simply, would she think me a jerk?

ALEX: Above anything I was glad that your family was so loving, and like, accepting of it all. I knew that in your family, she would be well cared for, and you wouldn’t be ridiculously over-protective of her, or over-sensitive about the fact that she was different.

SHAWN: I also wondered what type of disability it was. I had no idea what was and was not appropriate or insulting to ask. Was it okay to ask how she would be behaving? If she was in a wheelchair? If she could speak well? I didn’t even know if I was supposed to talk to her like a normal person, because if I did she might not... comprehend or whatever... but if I talked to her a bit more simply, would she think me a jerk?

ALEX: Above anything I was glad that your family was so loving, and like, accepting of it all. I knew that in your family, she would be well cared for, and you wouldn’t be ridiculously over-protective of her, or over-sensitive about the fact that she was different.

SHAWN: I also wondered what type of disability it was. I had no idea what was and was not appropriate or insulting to ask. Was it okay to ask how she would be behaving? If she was in a wheelchair? If she could speak well? I didn’t even know if I was supposed to talk to her like a normal person, because if I did she might not... comprehend or whatever... but if I talked to her a bit more simply, would she think me a jerk?

ALEX: Above anything I was glad that your family was so loving, and like, accepting of it all. I knew that in your family, she would be well cared for, and you wouldn’t be ridiculously over-protective of her, or over-sensitive about the fact that she was different.

SHAWN: I also wondered what type of disability it was. I had no idea what was and was not appropriate or insulting to ask. Was it okay to ask how she would be behaving? If she was in a wheelchair? If she could speak well? I didn’t even know if I was supposed to talk to her like a normal person, because if I did she might not... comprehend or whatever... but if I talked to her a bit more simply, would she think me a jerk?

ALEX: Above anything I was glad that your family was so loving, and like, accepting of it all. I knew that in your family, she would be well cared for, and you wouldn’t be ridiculously over-protective of her, or over-sensitive about the fact that she was different.

SHAWN: I also wondered what type of disability it was. I had no idea what was and was not appropriate or insulting to ask. Was it okay to ask how she would be behaving? If she was in a wheelchair? If she could speak well? I didn’t even know if I was supposed to talk to her like a normal person, because if I did she might not... comprehend or whatever... but if I talked to her a bit more simply, would she think me a jerk?

ALEX: Above anything I was glad that your family was so loving, and like, accepting of it all. I knew that in your family, she would be well cared for, and you wouldn’t be ridiculously over-protective of her, or over-sensitive about the fact that she was different.

SHAWN: I also wondered what type of disability it was. I had no idea what was and was not appropriate or insulting to ask. Was it okay to ask how she would be behaving? If she was in a wheelchair? If she could speak well? I didn’t even know if I was supposed to talk to her like a normal person, because if I did she might not... comprehend or whatever... but if I talked to her a bit more simply, would she think me a jerk?

ALEX: Above anything I was glad that your family was so loving, and like, accepting of it all. I knew that in your family, she would be well cared for, and you wouldn’t be ridiculously over-protective of her, or over-sensitive about the fact that she was different.

SHAWN: I also wondered what type of disability it was. I had no idea what was and was not appropriate or insulting to ask. Was it okay to ask how she would be behaving? If she was in a wheelchair? If she could speak well? I didn’t even know if I was supposed to talk to her like a normal person, because if I did she might not... comprehend or whatever... but if I talked to her a bit more simply, would she think me a jerk?

ALEX: Above anything I was glad that your family was so loving, and like, accepting of it all. I knew that in your family, she would be well cared for, and you wouldn’t be ridiculously over-protective of her, or over-sensitive about the fact that she was different.

SHAWN: I also wondered what type of disability it was. I had no idea what was and was not appropriate or insulting to ask. Was it okay to ask how she would be behaving? If she was in a wheelchair? If she could speak well? I didn’t even know if I was supposed to talk to her like a normal person, because if I did she might not... comprehend or whatever... but if I talked to her a bit more simply, would she think me a jerk?

ALEX: Above anything I was glad that your family was so loving, and like, accepting of it all. I knew that in your family, she would be well cared for, and you wouldn’t be ridiculously over-protective of her, or over-sensitive about the fact that she was different.

SHAWN: I also wondered what type of disability it was. I had no idea what was and was not appropriate or insulting to ask. Was it okay to ask how she would be behaving? If she was in a wheelchair? If she could speak well? I didn’t even know if I was supposed to talk to her like a normal person, because if I did she might not... comprehend or whatever... but if I talked to her a bit more simply, would she think me a jerk?
Elana is our daughter and she is now 21 years old. Right after we were married, my husband Dennis and I moved to Michigan for his job. As we all know life is difficult raising a special needs child and even more difficult when you have no family living nearby.

We are lucky enough to have found a few organizations which we call our family here in Michigan. One is called The Daniel Sobel Friendship Circle. It was started here in Michigan but they now have Friendship Circles throughout the country and even one in Montreal! The Friendship Circle started with a few people and now it is an amazing organization with a building called Lifetown.

Lifetown is an unbelievable building that cannot be put into words. They have different rooms that offer life skills to the children. One walks in there and the “aura” is indescribable. The love, warmth and compassion of anyone and everyone who works for or is a volunteer for the special needs child is so unreal. What is most important is that all the special needs children and families feel that this building is their home away from home – the children can be themselves as well as learn, learn, learn from all the life offerings experiences that they are learning there. Elana loves going there and she is paired with a volunteer. She forms a bond with them and they develop a beautiful friendship.

Besides going to Lifetown, Elana has volunteers that come to the house twice a week. They play with her and give her one on one attention that she truly craves. It gives us some peace and free time and allows us to do the things we need to do and have no time to do!

What is amazing about The Friendship Circle is that they do not turn their back on difficult children. Elana has a lot of behavioral challenges and they just do everything they can do to help. They enjoy helping because they know that is what they are there for. They really love Elana unconditionally. Everyone wins; the volunteers learn a lot from Elana and Elana learns a lot from her special friends.

We also belong to another group called JARC. JARC is an organization that not only helps our family now, but will also help us in the future, as Elana will one day be living with a group away from home. JARC has been such a big help by providing us with respite care for years. They match up respite workers to Elana’s countless needs. Elana has had many respite workers who have helped our family tremendously. Many have moved on and we still keep in touch with them. Not only does JARC provide workers, they also have different activities that Elana attends, such as cooking classes, trips, etc.

We are very blessed to be living in Michigan and to have these two organizations to help us so very much. I always felt that we moved to Michigan for a reason.
Beyond Babysitters: Finding Committed Companions

When families begin the dup15q journey, they are often surprised and relieved to see a dedicated team of therapists, doctors, and special educators quickly form around their children. Government entities such as public schools, departments of Health and Human Services or Mental Health, respite programs, and early intervention programs may lend a helping hand too.

Tending to our kids doesn’t end with medical and educational needs, though. Parents of special needs children often find themselves in a tough spot when searching for caretakers. Garden-variety babysitters and casual companions may not have the dedication and focus necessary for dealing with our children. Instead, we need helpers who are committed to working with our kids’ particular challenges. Here are some ideas for finding special people to care for our special children.

Babysitting Cooperative
A babysitting co-op can be just the respite parents need. In a co-op, families trade babysitting services with one another instead of paying money. While parents enjoy some free time, children benefit from play dates. Co-ops can lead to friendship and trusted companions for parents and children and the price is right: free! If co-ops don’t already exist in your area, you can start one yourself. You might find members in your parents’ support groups, La Leche League, churches, preschool parent associations, or neighborhood associations.

Church Shadows
If you attend a house of worship, you may wonder what to do when your child ages out of the nursery. Parents don’t necessarily have to miss out on church services to accompany their kids who are integrating into religious education classes; a volunteer may act as a “shadow” for little ones or older children. Talk to your church’s religious education director or pastor about finding a volunteer who can accompany your child during religious education, helping him through the classes and taking him to the playground or a quiet place when necessary.

High Schools and Universities
Many districts require high school students to perform volunteer work or complete in-depth senior projects. Either of these scenarios can benefit our families as well as those students who are working toward their diplomas. Contact local high schools to spread the word that you’d like to assist a student who is interested in serving and studying people with special needs. Conscientious and committed young people who are interested in working with people with special needs can become trusted babysitters and caretakers.

Similarly, colleges and universities can be a treasure trove of talent if you’re interested in hiring someone to take care of your child regularly or just occasionally. To find applicants, post advertisements with the university’s career services office and academic departments such as education and psychology. If your child’s condition is more significant, you could even search for a nursing student who is interested in finding part-time work. Consider posting notices on billboards in appropriate academic departments and also sending them to departmental secretaries, who can deliver them to academic advisors and intern coordinators who, in turn, can pass them on to the brightest students.

Local Community Organizations
Finally, think about other organizations that might be able to help you find qualified helpers for your child. For instance, the YMCA and YWCA often have programs for teens and adults with special needs and might be able to offer leads. Another trusted resource that has chapters around the country is the Arc of the United States. Ask around and you may be surprised how quickly you find leads to more potential members for your child’s team.

IDEAS remembers our friend Naomi Gerber who recently passed away at age 39.
In 2009 IDEAS completed its second three-year strategic plan. Because the IDEAS board believes that strategic plans are an important tool for guiding and growing IDEAS, they undertook a second strategic planning process. This process involved reviewing the IDEAS mission, conducting an external analysis with our members and advisors, conducting an internal analysis of the operations of the organization, establishing strategic goals, and developing a budget to support these goals.

The following goals have been adopted by the IDEAS board of directors to guide the growth of IDEAS from 2010-2013. Some of these goals represent an ongoing commitment to activities that IDEAS already engages in, and the remaining goals represent new initiatives for the organization.

- IDEAS will assess and implement an organizational restructuring and strategic succession plan for the purpose of strengthening and maintaining continuity in organizational operations by June, 2010.
- IDEAS will help establish research priorities in dup15q syndrome, and will host annual scientific meetings to build multi-disciplinary collaborative efforts to promote research into dup15q.
- IDEAS will establish and promote family involvement in an IDEAS research registry.
- IDEAS will seek the involvement of a graduate student(s) to develop a “family guide to dup15q” that will assist families in understanding best practices for supporting children with dup15q from birth into adulthood.
- IDEAS will establish a targeted awareness campaign with a focus on pediatricians, neurologists, geneticists, parents of children with autism or epilepsy disorders, and early childhood intervention programs.
- IDEAS will develop, communicate, and provide quarterly status updates to families on a three-year budget that supports the goals in the strategic plan.
- IDEAS will encourage and support families in holding fundraising events to help IDEAS exceed each annual operating budget and support continued growth for the organization.

Families who are interested in reading the entire strategic plan document can find it on the IDEAS website at http://www.dup15q.org/strategicplan.html

MOMENT: INFORMING THE FRIENDS  continued from page 4

I’ve had a long time to adjust.

RIANN: This isn’t something that should always be on my mind, but there come times when I have to see you might think of something differently because of your experiences that you have had with your sister. SHAWN: You know, I don’t think I should think of her as a severely mentally handicapped girl like some people do. Nobody should see her as gross, crude, or whatever else people think of somebody like her. It’s just stupid and anyone who knows somebody like you or your sister would back me up here. It really frustrates me now when people say things and use the word “retarded” like it’s just a word for stupid. Emma is your sister, no less or more important, no better, no worse than my sister. Just different.

THE END
N one of us planned for this. We were OK with picking out nursery colors. Or dreaming about what our children might look like in a little league baseball uniform. But acquiring an expert level understanding of human genetics was not part of the plan.

I was already scared of being a dad. My fear left me paralyzed during most of our pregnancy. Unable to express my feelings I arrived at our December 14, 2004 due date with 9-months worth of pent-up anxiety. I’d love to say that seeing our 8 pound, 15 ounce creation for the first time melted all of that away in a heartbeat, but that of course didn’t happen.

It took us over 24-hours to come up with a name. We did not know if we were having a boy or girl, preferring to be surprised. And we were. All bets were on a baby girl but here was a beautiful boy with big brown eyes looking up at us who needed a name.

In a mash-up of my Swedish heritage and honoring the great jazz pianist we named him Finn Oskar Peterson. We wrote it on the whiteboard in the hospital room and liked the look of these letters together. We had a son. He had a name. And he was going to be special.

Rebecca, my wife of eight years, had been my girlfriend since we were 15 years old. We knew each other well. Like most new moms her adaptation to motherhood was clumsy at first, but quickly evolved into a confidence that I could only marvel at. I still look at her on some days and am overwhelmed with who she has become. Finn meanwhile was doing what babies do, and connecting to us more every day.

About ten months later I was finally beginning to get my footing as a dad. I had started telling the truth about what I was feeling, which resulted in one of the richest periods our marriage had ever known. We really were becoming a family. Finn was beginning to express a personality, exploring his world and absorbing the music from vinyl records we’d play for him most nights. It felt like everything was going to work out OK.

But as all good stories do, ours made an unexpected turn. It became apparent that Finn was not meeting many of the milestones typical of children his age. His muscles seemed flaccid and he lacked the ability to get around like many of his peers. After meeting with our pediatrician it was suggested we visit Vanderbilt Children’s Hospital in Nashville, only a few miles from our home in the city, for some blood tests and an appointment with a geneticist. On the day the tests came back it was revealed to us that Finn had isodicentric-15 and our world changed. Feelings of fear, anger, sadness, guilt and shame pressed in on us and we wept as only a mother and father do. We held onto each other so tightly, and our bond was strengthened in a way only heartbreak can create.

We were blessed to have an incredible nanny at the time, who spent some of the day with Finn while we were working, me for an entertainment marketing firm and Rebecca as a public high school French teacher and part time Vanderbilt professor. We then heard about an excellent, fully inclusive preschool program for children with special needs at Easter Seals of Nashville. The school’s executive director who had a heart for our situation, a student in Rebecca’s French class and a child with special needs of her own, got us in almost immediately. We were able to arrange for much of Finn’s speech, physical and occupational therapy to happen in this world-class facility, and he was making excellent progress in every area. So it was with shock and sadness that we learned Easter Seals was closing due to budget challenges less than a year from our arrival, displacing all the students, staff and families. We scrambled to make new arrangements and eventually found ourselves welcomed at The Adapting to the Surprises of Fatherhood by Andy Peterson

Father of Finn Oskar Peterson, age 5
Susan Gray School, on the campus of Vanderbilt University.

Susan Gray is an on-campus research-oriented school devoted to educational research involving young children with developmental disabilities and was a perfect fit for Finn. Here he would receive expert instruction (many teachers are Vanderbilt special ed grads) and be in an environment that is on the cutting edge of special education and inclusive education. Finn has thrived at Susan Gray, going on his third year in this program. We have found the hearts of the staff and teachers at Susan Gray to be an especially good fit for our family. There are no doubt other excellent pre-K programs for children with special needs in our community, but we think The Susan Gray School is especially unique in the care and compassion they live out daily.

We have also benefited from research happening at Vanderbilt’s Kennedy Center which is one of the nation’s leading institutions of its kind. Its mission is to improve the quality of life for persons with developmental disorders, and to apply scientific research to bring better services and training for affected families. Finn’s participation in a very extensive ‘KidTalk’ speech language development study saw his language skills improve dramatically during 2009 as a result of very intense play therapy and parent instruction. To say that we feel thankful to live a short bike ride from these two world-class institutions would be putting it mildly. And the impact of these professionals has had a profound effect on our family.

Today Finn is participating in a classroom among normal developing peers. He has an increasing vocabulary of at least 200 words and can communicate many of his needs and desires. He loves being in school with his friends who he talks about constantly at home. His gross motor skills have improved to the point where he no longer needs supportive orthotics to assist in walking and can successfully navigate his way through a playground like most any other 5-year-old. Last weekend he joined a few school friends (and moms and dads) at his first NHL hockey game to see the Nashville Predators. He loved it and didn’t want to leave when we dragged him home midway through the third period.

Finn loves to fly on airplanes and gets very upset when either of us goes on trips without him. He has traveled via plane to Chicago, Minneapolis, Midland, Texas and even Big Sky, Montana. We have been known to make special trips to the airport just to walk through the terminal.

He has logged hundreds of miles in a baby jogger over the last few years as we’ve found this is a way to maintain some fitness and time together with Finn. The two-mile run each way to a nearby park and playground is a particular favorite. Unfortunately he is now heavy enough to make these excursions a little less frequent. And he would much rather walk all by himself anyway. He has gained tremendous confidence with his own two feet over the last year and does NOT need to hold hands, thank you very much!

Finn also takes lessons from a Team USA Special Olympics swimming coach who lives here in Nashville. He looks forward to his weekly pool time with ‘Coach Beth’, and we are so thankful to have gotten connected to such a talented coach.

Finn greets Rebecca when she picks him up from school with a running leap of a hug that sometimes puts her off balance. And the highlight of my day is Finn greeting me at the door when I come home from work and immediately asking to play ‘a record’ on the turntable. He helps me pick something out and takes great pride in pushing the play button and watching it spin. We dance until bath time nearly every day.

Finn is unique in Nashville; we know of only one other IDEAs family from here and they sadly now live in Europe. But we were blessed to attend the convention in our home state of Indiana last summer and for the first time met many of you who understand our story all too well. Seeing many of your beautiful children who are older than Finn gave us hope for the journey we are on and thankfulness to be part of a community.

We don’t know why God gave Finn to us. Neither of us would have volunteered for this. But there is no question we are the right parents for this child. We had no idea just how special Finn would turn out to be. We have learned so much about courage, faith and love through this little guy. And we know we are just at the beginning of our story. We look forward to sharing it with many of you as the years go on.

Thank you for reading,
Andy Peterson
www.finnoskar.com
My name is Rachel Segars and I was very surprised and honored to be nominated volunteer of the quarter for IDEAS. I have been a member of IDEAS for 14 months, as my son Luke has dup15q syndrome. He was diagnosed when he was seventeen months old, and he is now two and a half years old. He is my third child; I also have Nathan who is five and Rebecca who is twelve.

We live in the Bay area, but are originally from Cambridge UK. In the UK it is very popular to buy charity cards for Christmas. On our first Christmas here, I was dismayed that I could not support any charity from the purchase of holiday cards. So this Christmas I decided that perhaps an IDEAS Holiday card would be a good idea! Perhaps I should have thought about this in October, as it was November when I and my lovely daughter Rebecca got down to planning how to go about it.

Initially, I would have liked holiday-themed artwork from our special children, but there was just not enough time to organize this. As I am not a graphic artist—more an ‘art and crafter’ with my kids, I knew this idea would need input from specialists! So armed with my laptop and Rebecca, we used Vista Print and adapted the design and changed the saying in the middle to have greater meaning for our families’ situation.

We raised $648.00 for IDEAS and I donated the cost of the cards. The most expensive part of the process is always the delivery costs. I would have preferred a longer lead time as short times increase the delivery costs significantly. The response to the cards was a little slow. I had really not taken into account the cultural issue that many people design their own family cards to send to family and friends. But that would not stop me from doing the project again. I was certainly able to sell a lot of cards to friends and raise awareness. I have a blog about Luke at www.15specialneeds.wordpress.com.

Congratulations Rachel, and a big thank you from IDEAS for your super support!
Plan a Family Gathering!

As winter drags on...

my thoughts are drawn to warmer memories. One of my best memories from last summer was the Midwest gathering of IDEAS families. Over Labor Day, five families met in St. Louis and spent a fabulous weekend swimming, eating, feeding lambs, and getting to know each other.

As I begin to plan a gathering for this summer here in Des Moines, I want to be sure everyone knows that IDEAS has a grant available for these regional gatherings. Because this is a non-conference year there won’t be an international gathering so the IDEAS board would like to encourage families to begin planning get-togethers regionally.

Please feel free to contact Karen Sales at (515)963-0306 or ksales76@msn.com for further information.
IDEAS is a non-profit organization that provides family support and promotes awareness, research and targeted treatments for chromosome 15q duplication syndrome. IDEAS offers help and hope for chromosome 15q duplications.

NEW! in the IDEAS STORE
The IDEAS Cause Bracelet
Made with royal blue lampwork beads, white shell beads, and accented with red and clear crystals. The IDEAS bracelet is finished with a decorative silver oval clasp and a sterling silver “Believe” charm. Available in two sizes: 7” and 8” and costs $35 (includes shipping).
Visit the IDEAS store and order your Cause Bracelet today!

IDEAS families from Italy would like to invite any interested families to join them at their next gathering scheduled for September 10, 11, and 12th in a wonderful old “convent” near Florence, Italy. Their last gathering was featured in the Fall Mirror and you may remember that in addition to exchanging much information they also ate very well!
Contact Christine at acannugi@aliceposta.it for more information.