

FALL • 2007



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.

FROM OUR EDITOR
KROW ONK EDITOR

Whether your child is 3 months or 30 years old, as a parent of a child with dup15q you have probably encountered a situation which was less than perfect. The frustration you feel when you search for an appropriate experience, whether it be therapy, preschool, or even a post high school job experience, is universal. How often have we heard, "They don't offer that in my community for my child" or "The classes for special needs students at our school aren't acceptable", or "There is no appropriate place for my child to live as an adult"?

In this issue, you will read about the experiences of some parents who live by the philosophy "If it's to be it's up to me." These proactive parents have recognized that if they desire a great situation for their child, they will have to work to create it. There are no whiners in this group—they are too busy envisioning, designing, recruiting, and building!

You will see that the lack of appropriate placement is universal. From Texas to Ireland to the Netherlands, parents advocating for their children are being very creative and in the process developing programs that will benefit many other children with special needs as well. Prosper, Texas, is a community so new that there were no therapies provided in the area until the Gueterslohs worked to change that. In Dublin, educational programming went pretty smoothly until age 13. Read about the process of creating an appropriate secondary education experience in Ireland. And who doesn't worry about the future of their child as an adult?

Appreciate these parents' vision. Admire their energy. Anticipate what your own child will be needing next to grow to be the best he/she can be. Accept that it is up to you to either find or create this situation. Adventure will be in store for you for sure, but what satisfaction you will feel knowing your child will benefit from your efforts.

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

jtrue@kc.rr.com

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DESIGNING A SCHOOL ENVIRONMENT FOR THE TEENAGER

by Fedelma O'Farrell

Fedelma lives in Dublin, Ireland, with her husband Liam, her daughter Evelyn, age 22, and Ruth, age 17 idic15.

One of the hardest decisions parents of a child with special needs has to make is where we will send our child to school. What is available for them, what is the best environment, can they learn, will they be accepted, will they cope if they are accepted?

My daughter Ruth is now 17 and when we started out looking for education for her there were really no choices. Either you went the route of a special school or mainstream school. There were no special needs assistants in schools. At the time, there was nothing known here in Ireland about idic15 and so there were no guidelines or expected outcomes. I thought I wanted to try to get her into a mainstream playschool (like a preschool in the U.S.) and see how it went. This entailed calling to the schools and asking if they would take her. When I think of it now, I don't know how they did it; she had no speech, very poor eye contact, was not toilet trained, could hardly stand up straight, she couldn't walk with ease or run or climb, and had absolutely no interest in other children.

My local playschool took her and they were just amazing in how they worked with her. My offers of help were met with sending me off to "go have a cuppa coffee", "meet a friend", or "get lost – we'll manage and if we can't we'll ring you"! Needless to say, I found this very difficult. I think when you have a child with special needs you are so in tune with them you are them and you can't imagine how anyone else could meet their needs. So at the age of three years the cord was cut and Ruth began her experience of education. She stayed and progressed slowly but really well in

that playschool until she was five, and then the search was on again. She went on to a Montessori school. I went from school to school each time bringing her with me and asking them to take her and again I was lucky and found a wonderful school where she stayed until she was nine.

I then heard of a special class that was being set up in Primary School (ages 4 to 13) for children with a moderate learning disability. I thought that this might be the best of both worlds. Ruth would have the environment of a mainstream school where her role models for language and behaviour would be typical children and have the support of a special class where her individual needs could be met. I was lucky enough to apply for a place for her and got it. This class worked very well. They had integration both ways: typical children worked in the class with the children with special needs, and then the children with special needs went each day to a class appropriate to their age for time in the morning and afternoon. All the children played in the playground together, took part in drama, and any sporting activity they could manage.

There were eight children in the class and the parents of the children became really good friends and were very involved in the school. We had also been brought together when our children were cut off from 'services' (Physiotherapy, Occupational Therapy and Speech Therapy) because our children were in mainstream education and were now under the Department of Education rather



“nothing comes easily when advocating for a child with idic15. If it would be logical and easy and cost effective, then you will have to fight for it. I think we have all experienced this when you have a child with special needs, you spend a lot of time fighting the system. Why they have to make it hard I just don't know”

than the Department of Health. We were of course shocked at this. We ended up in Court to have the services restored to our children and were successful, and had the 'services' provided to the children in the school setting as part of their day or week, depending on the need.

When we saw how well the class was working, and the benefits for both our children and the typical children, we thought, "What will be the next step? Where will the kids go next?" We wanted this experience for our children to go on and yet there was nothing available. We investigated the special schools for children after the age of 13. We were not satisfied with what was available for the 13-to-18 year-olds. If we wanted a better program we were going to have to take charge and create one. Having experienced an integrated setting and seen the benefits, we decided as a group to approach the Department of Education and request that they duplicate what we had in a Second Level environment.

We met with the Department of Education and they agreed that this was the way forward and gave their support and agreement. However nothing comes

easily when advocating for a child with idic15. If it would be logical and easy and cost effective, then you will have to fight for it. I think we have all experienced this when you have a child with special needs, you spend a lot of time fighting the system. Why they have to make it hard I just don't know.

We spent the next four years battling to have this class set up. While everyone in the Department of Education thought it was a great idea, putting that idea into reality was another story. It took endless meetings, phone calls, emails, meeting with politicians, writing letters, threatening court, you name it, we did it. In the end we succeeded. We found a school that was willing and able and had space. We went from having nowhere for our children in February to having a class, teachers, special needs assistants all up and running in September. This was quite amazing as here schools close on 1st June for three months and so the time frame was what most would consider impossible.

A working group was set up of representatives of the Department of Education, Department of Health, Board of the School, PTA, parents of the children to attend the class, Department of Education's architects, school buildings, psychologists and service providers and the class was born.

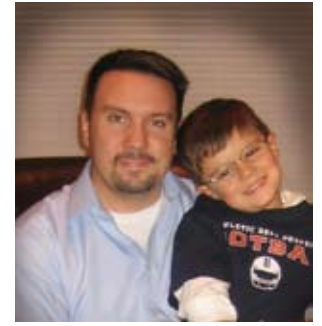
We are now in our 4th year and it has been an enormous success. The class has eight children, a teacher and three special needs assistants. Physiotherapy, Occupational Therapy and Speech therapy is provided as part of the day. The children are taught by mainstream teachers. They circulate around the school at the class breaks the same as the typical children. They are totally accepted and part of everything that happens in the school. Each child has a buddy and again typical children integrate during the school day in the class and work with the children. Each child has their individual education plan. As well as the usual reading, writing and math basic subjects the class is fitted out with kitchen facilities and a large open space and a garden where they can cook, garden, dance, do whatever is best for them on a daily basis. The school and teachers and all concerned were so happy with

CHEERS!

TO OUR VOLUNTEERS!

Will Sales

Will is the father of William Sales, age 5, dup 15q. He recently headed up the note card project on which IDEAS kids' art is displayed. Check out these great gifts at the IDEAS Store soon—they are going quickly!



Attending the Boston Conference was my first real experience with IDEAS. I found meeting and observing other children with the same diagnosis as my son to be very valuable. There was also a fair amount to be learned from the other attending families. Of greatest importance to me was that IDEAS provides me with the latest research.

My son turned five in October. His mother and I are divorced, and as a divorced father, I sometimes find that fathers are overlooked or under-appreciated as parents. I don't believe I need special recognition as a father, but I do want equal recognition as a parent. In my work, I come across many people who are poor or unfit parents who often want recognition of the title without putting in the effort that parenting

the success of the class that they took on a second class last year and now there are two classes of eight children in each in a school of 400 pupils.

This class is now being accepted as the model for the Department of Education as to how best to integrate children with special needs into mainstream education. It doesn't end there....does it ever? We are now looking to the next step and want to have a continuing education environment for our children when they finish in this Second Level setting, the fight goes on..... ■

requires. When I put in the effort, it is because I take my responsibility seriously, not because I want lip-service. My son's needs are met through a large community. On a daily basis, he sees the faces of family, teachers, therapists, and doctors. He doesn't see the faces of IDEAS every day, but IDEAS is working to meet my son's needs by increasing awareness and supporting ongoing research. When I volunteer for IDEAS, I'm just helping to meet my son's needs.

I gravitated to the notecard project because it allowed me a creative outlet. Overall, it was a fun project. Now that I've done it once, I hope that it proves successful so I can volunteer to do it again.

Thanks to Will for getting this project off the ground and showcasing our kids' art!



Sometimes we have to go straight to the top to get what our children need. Ruth O'Farrell discusses her situation with Mary McAleese, the President of Ireland.



Somewhere Under The Rainbow

By Buffie Guetersloh

"All children have hopes and dreams —our goal is to simply lift them up so they can reach the rainbow."

On September 7, 2002, our family was blessed with our perfect gift, Livia (5). Her brother Connor (now 10) and sister Adisyn (now 8) adored her. My husband, Chad, and I could not have been happier. We believe that "Every good gift and every perfect gift is from above... James 1:17" None of us realized the significance of the beautiful angel God placed in our lives.

Livia was always such a good and easy baby. I chalked it up to her being the third, but Chad, being a pediatrician, began to voice concerns around two months old. At four months old, she began erratic breathing while sleeping. She would actually stop breathing and then begin again with forcefulness. Chad's concerns only deepened and by the time she was six months old, his concerns became my concerns as well. At that point, we began physical therapy to address her muscle weakness. Of course, we were always trying to get her to make eye contact or smile, but rarely received a glimpse.

At ten months, Livia began to have infantile spasms. ACTH injections only slightly decreased the amount of seizures she had. Sabril helped, but didn't control. She outgrew infantile spasms and moved on to partial myoclonic seizures at two. We tried everything from no seizure medicine to what she's on today, which is Carbatrol. (We could not be more thrilled with the results of Carbatrol.) As a result of her seizures, Livi has had significant developmental delays. Today, she is progressing with great speed. Every day is an opportunity to witness her healing and therapy is vital to that equation.

Physical, occupational and speech therapy have always been necessary, but the travel involved was exhausting for her. There was a point at which we had to pick and choose what we thought were most beneficial. The therapies we noticed to make the biggest impact were the non-traditional (according to insurance) therapies. Music therapy was amazing. We soon figured out that replacing speaking with singing encouraged her eye contact. Now she seeks music for pure enjoyment and, of course, a great excuse to dance. I'm convinced she will sing herself into talking! Another therapy that was successful was horseback riding. After months of trying to crawl, she rode a horse two times and began crawling. The movement of the horse allowed her to experience the motor planning necessary to accomplish crawling. Due to the positive effects of non-traditional therapies with Livia, we thought Conductive Education would be a wonderful opportunity for her. This form of therapy

is applied daily for several hours a day. Through constant repetition and practice of ordinary skills, Livi made remarkable progress. Her eye contact improved considerably after just two weeks. Within the second month, she started taking her first steps. Although she made huge progress in such a short amount of time, the Conductor (teacher) expressed that she only felt comfortable working with children that had cerebral palsy. We felt as if Livi's hope was undermined.

As I mentioned, Chad is a pediatrician and has the privilege to treat many children with special needs with a variety of challenges. We believe all children should have hope and the opportunity to reach their full and unique potential. This is the philosophy in which we decided to provide such opportunities based on our experience with Livia.

Prosperity Place, "where all things are possible", began in September, 2006. By God's plan, a perfect warehouse facility was available at a great price in our hometown of Prosper, Texas. Volunteers worked relentlessly in restoring the inside and donations kept us on our feet. As a non-profit organization, our first fundraiser raised enough money to keep our doors open and purchase impressive therapy equipment.

In the beginning, physical, occupational, speech, music, horseback riding therapy and Conductive Education were offered. Conductive Education is not covered by insurance, which placed a heavy financial burden on Prosperity Place and, in return, the families. For that reason, we made adjustments with respect to Conductive Education.

Through research and consulting with our therapists, the decision was made to adopt Intensive Suit Therapy Model as Conductive Education's replacement. The same intensive philosophy is used with Suit Therapy only a physical therapist provides treatment allowing a portion of the cost to be billable. The Intensive Suit Therapy model greatly increases progress over a short amount of time. The results are impressive and extremely beneficial. More information on Intensive Suit Therapy Model can be

found on www.suiththerapy.com.

In regards to our therapists, we have a well-established therapy group that provides physical, occupational and speech therapy within our facility. This group is already accepting several different insurance benefits and is capable of billing insurance for the families. Prosperity Place's goal is to one day employ our own therapists and be capable of filing insurance for the families. This is a difficult task that we plan to overcome within a couple of years. Our music therapist is a contract employee and a good example of how we can provide our own therapists instead of using an outside source.

Overall, our therapists work together to provide individual treatment plans for each child. Our team, made up of the therapist, family, and caregiver, determines the goals for the child. This teamwork approach provides the opportunity for our therapists to have consistent treatment plans and co-treat with one another. Families receive the benefit of all therapies being accessible at one location which is also beneficial for the child.

Prosperity Place is very young and still in the learning phase, but our vision for the future is clear. We are preparing scholarship programs to provide financial assistance to children who might not otherwise receive therapy. The foundation is being laid to partner



Livia dressed for Intensive Suit Therapy.

with a private school, so that children who face challenges in the school system can be taught in a therapeutic-centered setting where Prosperity Place will provide the therapies for those students. Overall, our goal is to provide an innovative approach to treating children while

focusing on the individual child. All children have hopes and dreams—our goal is to simply lift them up so they can reach the rainbow.

With respect to wanting to help these children and starting Prosperity Place, I've always said that Livi was the reason, but not the purpose. God gives you a perfect gift—ours is an inspiration! ■

Combining Research and Vacation

by Kadi Luchsinger, IDEAS Executive Director

This August my husband Todd, Ethan and I decided to take a trip to Memphis to participate in the study by Dr. Larry Reiter with the Department of Neurology at the University of Tennessee Health Science Center. It was an absolutely amazing experience. The first day of the study was a 2-½ hour neurological evaluation. The nurses had decorated the entire room in Dora and bought Ethan tons of treats. Dr. Perkins and his nurses are a phenomenal team. They did draw blood and got it on the first try. We finished up the day with a neuropsych evaluation.

Day 2 - Ethan had an EEG, which was his least favorite. He was then invited into the "bunny room", and allowed to pick any toy he wanted. That afternoon I did a 2-hour parent interview with a speech therapist, while Todd went swimming with Ethan back at the hotel. Day 3 - Ethan had a three-hour speech evaluation (with breaks), mostly identifying pictures and observation during play. The speech therapist was great! Dr. Larry Reiter's group paid for our airfare, our hotel, car rental and our meals. Our hotel was a five minute drive to the hospital. Not only was the study easy for Ethan, it will probably be one of our best memories with Ethan. Ethan's favorite trips were to Graceland and our daily trip to the famous Peabody hotel to see the ducks. So, while participating in research, we really got a special gift in return. We had one on one time with Ethan and that is a treasure. We do lots of activities with him, but we rarely take a trip with just him. He was glowing the whole time (ok, maybe not during the EEG), but this was a trip that we will never forget.

I cannot stress enough the importance of getting more families there (he needs 20). As we have found, there is never an ideal time to do this, but we all need to make it a priority if we can. There are not many researchers who are helping our kids and I can attest that this is a great group of people in Memphis. The time we had with Ethan there was well worth the trip, while helping out other families. If you want more specific information, here is the link to his study for interstitial duplications: http://idic15.org/res_cur_reiter.php. Thanks to Dr. Larry Reiter and his group for their interest in our children and for creating such a wonderful memory for our family.

KEEP IN TOUCH...



Please send your change of address to info@idic15.org



Len is our newest board member and is employed by MetLife as a Senior Business Systems Consultant. He lives in Tewksbury, MA with his wife Joanne and their two children, Lisa age 16 (idic15), a sophomore in high school, and Michael, age 19, a second year student at UNC Charlotte.

It was a clear and sunny morning in Killington, Vermont on September 16, 2007 for the 2nd Annual IDIC15 5K Run/Walk. For the 2nd consecutive year Sarah and Erik Rasmussen, along with a committee of volunteers, ran this event. When I arrived at the race it was simply amazing to see how well-organized an event I was about to witness. There were signs and volunteers everywhere directing people where to park and register. There were ropes and chutes set up to keep the runners and walkers organized at the finish line where they would have their official finishing order and time recorded. There was information available on IDEAS along with a table to purchase raffle tickets. Then there was the game area for the children that included ring toss, bean bag toss, a limbo contest, and face painting.

Prior to the 5K Run/Walk, they had a children's race of a few hundred yards where 70 younger children had the opportunity to run down through the roped off area and across the finish line. Next was the main event, the 5K race which had a goal of 300 this year, which was met having 303 registered runners/walkers from 7 states. All were participating on behalf of Sarah and Erik's son Jack (age 5, idic 15) and for the benefit of IDEAS. It was amazing to witness the support of their community as well as the support

of Sarah and Erik's families. I had the benefit of meeting their family who traveled from Washington DC, New York, Connecticut, and Massachusetts to show their support. Some of their family members participated in the run/walk, some volunteered, and some even did both. There were also members of their IDEAS family showing their support including the Rivards from New Hampshire, the Bopps from Massachusetts, and my family, the Poores.



On behalf of IDEAS I want to say a "thank you" to Sarah, Erik, Jack and Kyle Rasmussen, their family, the volunteers, and all who participated in this event. For all of their efforts Sarah and Erik presented IDEAS with a check for \$12,900. As Sarah herself said in a message, "YEAH for IDEAS, hope we can do lots of great things with the money". I second Sarah's comment as we all participate to the benefit of IDEAS and most importantly our children with idic15.

And now that this event is behind them, they are already planning the 3rd Annual IDIC15 5K Run/Walk scheduled for Sunday, September 14, 2008.

IDEAS thanks Heather Bruce and Len Poore who were recently elected and have agreed to serve as Board Members.



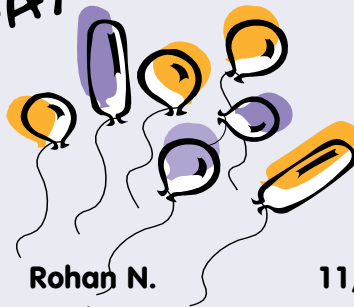
IDEAS families enjoying the day's events include: the Rasmussen, the Poore, the Bopp, and the Rivard families.

10 Ways To Take Charge: How a parent can advocate for their child

by Allison Kalnicki

- Ask yourself: what does my child need, what does our family need
- Inform yourself – ask questions, read and get copies of medical and programming records
- Be organized – keep all information in one place
- Be persistent
- Watch for supporters of your child and use them to their fullest
- Look at things from the professionals’ point of view
- Have a clear head and happy heart; find someone to bounce emotional issues off of BEFORE communicating with members of your child’s team
- Listen to your inner voice
- Be punctual, ready to listen and willing to help solve problems
- Add self-advocacy or independence-building skills to your child’s programming

HAPPY BIRTHDAY
TO YOU!



Sarah D.	10/2/96	Rohan N.	11/8/02	Matthew K.	12/12/96
Joshua C.	10/2/94	Hayley P.	11/8/99	Ellie S.	12/12/96
Adam R.	10/2/91	Will G.	11/11/98	Daniel T.	12/12/81
Riley R.	10/4/03	Taylor P.	11/12/02	Chase W.	12/13/99
Janique W.	10/4/96	William C.	11/14/94	Cody C.	12/14/95
Joseph K.	10/10/01	Stephen L.	11/15/93	Corey C.	12/14/95
Tyler K.	10/12/00	Lindsey K.	11/15/90	Sven D.	12/16/98
Colby M.	10/15/04	Twan W.	1/19/02	Olivia T.	12/16/94
Matthew P.	10/17/81	Melanie P.	11/22/86	Ingvild S.	12/16/86
Giulio Z.	10/18/04	Andrew S.	11/25/01	Nicholas B.	12/18/87
Nathan L.	10/18/01	Chad L.	11/27/75	Aston C.	12/21/02
Makenna J.	10/22/01	Kristina L.	11/28/81	Riley B.	12/22/06
Renate J.	10/22/92	Lisa P.	11/30/90	Austin B.	12/22/95
William S.	10/24/02	Ruth O.	12/2/89	Megan R.	12/22/95
Jarod W.	10/30/89	Jared L.	12/4/02	Caroline W.	12/22/00
Anna B.	11/3/99	Naomi H.	12/7/97	Seth H.	12/23/01
Richard M.	11/4/86	Jimmy T.	12/8/04	Justin O.	12/23/97
Corrina C.	11/5/96	Abigail S.	12/9/97	Chelsi C.	12/23/93
Carrie J.	11/7/83	Ashley B.	12/12/04	Stephanie J.	12/26/96
				Chandler R.	12/27/96
				Ada E.	12/29/99
				Teddy S.	12/29/90
				Joseph T.	12/30/96
				Kevin C.	12/30/95



FATHERING GRACE

by Jeff Lowell

Jeff is the father of Grace (age four, idic15), Katie (age 7) and Megan (age 6). He and his wife Colleen live with their family in Bellevue, WA

For the past five school years, the final assignment for my AP Comparative Politics/Honors English 12 students has been simply titled "Who Am I?" It is a written culmination of their twelve years in school focused by nine months of philosophy, literature, government comparisons, and a great deal of angst as they ready themselves for college life.

Each year as these seniors prepare their written reflection, I prepare my own. I agree each year to share with my students who I am, and in doing so, let them know that life is in many ways the greatest teacher of all. Each time I sit down to write I find that the year passed has afforded me opportunity as well as heartache, joys as well as sorrows, and chances to grow as well as chances to love.

I have completed five - these are excerpts from the past three....

June 2005

Although it may not seem so on the outside, for a great deal of the last two years I have felt like a small rudderless ship floating out to sea. Life has a way of bringing everyone "back down to earth" when they feel as though they know everything.

On June 24, 2003, Grace Margaret Lowell was born at Overlake Hospital in Bellevue, Washington, and my world would never be the same. I assumed having a third daughter would be much like having two. But things were different with Grace. She barely moved when young, didn't make much noise and generally didn't seem interested in us as she never looked us in the eye. Long story short, after a great number of doctor's appointments we found out that she has idic15.

We heard the diagnosis and there were tears and questions, angst and prayers. But from the first minute we heard the diagnosis my wife and I approached things differently. She reads and discusses – and I said I did not want to know what other people thought Grace would do. This is the complete opposite of every other situation in our lives. I have honestly read no articles (except for the few my wife insists I read) about what this "abnormality" means or what limits others believe it may place on Grace. I wanted to know her for her. She has recognizable qualities – she craves ice cream, she is stubborn, she has a fantastic smile, and she has the Lowell eyes. She won't sleep enough some days and remains cranky – constantly needing to be carried around. But one thing hasn't changed from day number one: when she stares at me I forget everything else.

So how does this tell you who I am? I have found that at almost 36 years old there is much I don't know. I am overwhelmed by responsibility – to the point it creates guilt and exhaustion. I need to sleep but can't, need to get things done but lack motivation, and deal with all of it by eating way too much and exercising too little.

I am battling with my career choice, as it takes me away from my family. But I also see the need to teach in order to share a simple message from Grace with every young person I can. Every day is an opportunity and anything you can learn should not be taken for granted. She has to work to balance enough to stand up, work at holding a spoon, work at turning the page of a book, work to try to communicate what she wants to us — simple things that most of us can do without thinking. My wife cried recently when Grace put blocks into a bucket instead of taking them out and I was amazed when she realized that there was a crack under the closed bathroom door as she peaked through it.

With that said, I find that taking advantage of opportunities I am blessed with each day is impossible at times. It is much easier to find the path of least resistance. Easier to avoid responsibility than to take it. Easier to say someone else will get it done. But the world is not easy – life is not easy.

So I can't do that. The path of least resistance is a slippery slope that leads me to dark places that are hard to escape. So I focus on the need to take responsibility for what I do, and to define my existence. The question that keeps surfacing now is how I make it worthwhile. For many years I tied my self worth and much of my identity to what I did, but now I discover that balance is necessary. I don't

know how to do that, and search for an answer. My family needs more of my time. I feel like I let them down constantly. The busier I am outside the home, the more I feel this. So I search for ways to make sure I have the time to give them. But answers are slow, and patience has never been one of my strong suits.

Grace has also helped remind me of the compassion that human beings are capable of; the outpouring of support from families who have offered help in so many ways reminds me that there is good in the world. I have seen this and my hope for the future is that we all remember the need to show compassion for each other daily, not just in times of crisis.

June 2006

I realize now that I spent much of my youth running from responsibility. I showed and expressed cynicism in so many ways. This focus on the dark side of humanity came as I searched for faith – I don't know where I lost it, but I did at one point years ago. I have now begun to find faith once again in the faces of my family.

That discovery is why I wear my bracelet that says BELIEVE – I never take it off. I believe Grace is a walking miracle and that researchers will find out more about her abnormality in order to help her “suck the marrow out of life.” She has been going to school since she hit six months old, and her life full of IEPs begins this summer. She will be starting full day preschool this fall in the Bellevue School District, and my only hope for her is that one day she learns independence.

What amazes me the most about Grace is her ability to find the joy in simple things. As her sphere of influence widens each day she becomes a different kid. She and I are buds. She grabs me when I come home and ribbits, and no matter what else happened that day everything is alright when she pats me on the back – one way she shows affection.

I can tell you now that for the first time I am content with every part of my life – no matter the challenges. I feel as though I am living up to my potential and meeting responsibilities. I connect with all three kids, and when I don't see them for a long time, I think about them constantly. I know my wife well enough after a dozen years that I could tell as she glanced out the car window the other day which tree she was looking at – a frightening thought. I have professionally hit my stride, and am excited about the direction I am heading.

So at almost 37 years old, and although I know that I don't know anything about what will happen in the future, I am comfortable in the present for the first time. I work daily to focus on the present, not worrying about tomorrow nearly as much as I used to while welcoming those same responsibilities that a year ago crushed me. I have lived a lifetime since last June and am ready to experience another lifetime during the next year.

June 9, 2007

This is my fifth time preparing a formal “Who Am I?” I finished last year's with feelings of excitement I had professionally, personally, and spiritually. Now another year has passed.

Grace continues to amaze. Her progress through the school year has been astounding. Her day-to-day leaps in ability have been ridiculous to say the least. She loves books, plays on the playground, explores constantly, and works to carry on a conversation with anyone she can. Katie and Megan are more creative, stronger, more athletic and socially gifted than I ever was in high school. My wife and I are approaching our tenth anniversary. I fall in love with her every day for a different reason, and work to let her know that.

I ran a marathon this year, and am training for another. I have no goal for a time, I just want to take the steps. I joined the Catholic Church and have found calmness

in the spiritual journey I still travel at my own speed, not letting anyone else define what my journey should look like.

Every day as I sit in my office and I look at pictures of my educational past, my teams, my students, and my family, things somehow seem to be falling into place. I love what I do. It is tiring and at times makes me feel emotionally spent, but it is rewarding beyond belief. I want to improve. I feel responsibility to the people who entrust me with the lives of their children. I know what I want for my kids, and don't want to give someone else less than that standard.

As each day passes, I see the blurry whole of my future a little more clearly. However, no matter how excited I am about the future, there is a part of me that is continually reminded that everyone has something to teach. So I silently thank those with whom I have come into contact for their contributions to my life. Most importantly, I remember that life doesn't define us through diagnoses, but through how we choose to live daily. For that lesson I loudly thank my four-year-old miracle.

This fall, just after my 38th birthday, I will head off to my twenty year high school reunion. As I headed off after graduation, I did not know anything about the future. But as I return I am finding myself in my present. ■



IDEAS news flash

IDEAS extends a warm welcome to three new families who have recently joined us from Georgia, Ohio, and Argentina.

Reflections from a Friend

This part of the REFLECTIONS

column shares perspectives from a friend.

Best Friend Ever

by Greg Glosan, friend of Daniel 25, idic 15



I am Daniel's teacher and best friend. While working for a Transition and Assessment Program, I started teaching Daniel, who has an interstitial duplication of chromosome 15, when he was 19 years old. I have been working with Daniel for nearly six years. He is the most amazing person I have ever met.

I have your typical life problems that everyone has. I have good days and bad days. No matter how I'm feeling - stressed out or angry - as soon as I pick Daniel up to start our day, all of that goes out the window. I don't quite understand how this works. It's very moving and rewarding to have such an influence in my life. That one human being, who has so many cards stacked against him, brings such joy to someone else without asking for anything in return is truly a gift from God.

Daniel is the closest I've come to knowing a celebrity. This wasn't always the case. When we first ventured out into the community, the public was unsure about us. Not that they didn't want us around, but they weren't sure what our purpose was. There was a frustration with the unknown. Daniel and I were trying to co-exist with what is considered normal by everyday standards. In most cases I had no problem forcing us upon the public. Not to brow beat anybody, rather to say, "Look we're here, we're not hurting anything, so deal with us. If you have any questions, I'll be happy to talk with you". Now, people constantly tell me that they think what Daniel and I are doing is great. People have accepted us because I make things functional and fun. I joke with the public; I joke with Daniel in public. I'm not afraid to touch, hug and squeeze him. They think, "Hey, those two are having fun, maybe I'll say hello". In return they walk away knowing Daniel is safe and protected. At the same time Daniel is contributing to the community on a daily basis even when it's difficult. They admire Daniel.

There are so many good times. I remember once Daniel and I were walking into a mall. A priest was walking out to his car. As he passed us, he didn't say a word, but put his hand on Daniel's helmet and began to say a short prayer. Now that was nice and all, but I don't like Daniel being treated too different. I want people to treat him

as they would anyone else. He deserves an equal and level playing field. We all do. So when the priest began to walk away, I said, "Hey Father, what about me? I need God's help just as much as Daniel here, even more so." After a look of puzzlement and a smile, he placed his hand on my head and blessed me. I told him thank you and off we went.

Daniel and I are there for each other emotionally and physically. I compare our bond to the great loyalty and friendship between the two Star Trek characters- me being Captain Jim Kirk, and Daniel being my Mr. Spock. Or vice versa. It's not for everyone to understand, but it's really beautiful and maybe even spiritual.

In some ways I'm envious of Daniel. As much as I want to be a good person in life, I could never be half the man Daniel is. All that I have on my plate bogs me down and I forget how to enjoy life as Daniel does. He wants nothing. He asks for nothing, but yet he lives every day to the fullest. I have been rewarded beyond measure for his trust and friendship. His way of life is a lesson I cherish and protect

A note from Barbara Tantaros, Daniel's mother:

Greg is not only an instructor but the truest of friends for Daniel, my 25 year old son. Dan will often give Greg a big hug, something Dan only gives to his closest friends. Greg is an answer to my prayers.

Each morning Greg arrives at Dan's residence and for the next eight hours Greg and Dan go to work sites, stores, restaurants, therapy sessions and medical appointments.

Dan wears a helmet due to having atonic drop attack seizures. I grieved when we had to put that shiny black helmet on his beautiful hair and stigmatize him even further. But Greg suggested he wear one also. So wherever they go they cannot be missed. Everyone knows Dan and Greg.

I wish I could clone him so that everyone with special needs had a friend like Greg.



Farewell to Nicholas Boever:

The IDEAS family says goodbye to Nicholas Boever who passed away after complications from a choking accident. Nicholas was nineteen years old. Our hearts and prayers are with the Boever family.

"The nicest thing you can say to a person with a disability is 'hello'."

Lynn Franery



The United States Spinal Association has published "Disability Etiquette: Tips On Interacting With People With Disabilities." This publication is geared toward the workplace, but could be useful in raising awareness and starting dialogue on how to appropriately relate to any person with a disability. Best of all, it's free upon request.

Call 800-444-0129 or read it online at www.unitedspinal.org.

MIRROR CONTRIBUTORS

Editor:	Jane True Kansas City, MO
Contributing Editor:	Alison Kalnicki
Design and Layout:	PD Graphic Design Kansas City, MO
Printing:	Service Printing and Graphics Kansas City, MO

Reflections from the Listserve

This column is designed to share perspectives from recent Listserve discussions.

Reflections

Proactive Environmental Design

by Mari O'Connor

We have nearly lost Christopher several times from accidents. Before our move to Ireland (September 2006), I swore that I would be proactive rather than reactive. This is what we did to our new home to make it as safe as possible for Christopher.

His bedroom:

- Have plexi-glass placed over his third floor window with tiny holes drilled in the top for air to move through (he nearly fell out of his window once)
- Remove the ceiling light fixture (yep, he yanked one out once by jumping on his bed to grab the flush with the ceiling light fixture)
- Shut all electricity off in to his room and placed plug covers over them
- Shut off the heater to his room (he yanked one right out of the wall once and nearly killed himself)
- Put good locks on the closet doors in his room
- Put a lock on the outside of his bedroom (we lock him in at night so that we can sleep soundly, knowing he is safe)
- Take all furniture out of his room except his single bed (he still has the metal frame but I'm considering taking it out since he likes to stand on the headboard and jump from it). I have also placed a second single mattress on the floor. No dressers to climb on and pull over on himself is best for Christopher.
- We put a large, cut to size, piece of linoleum over his carpeted floor. He still will rip his dirty diaper off and smear it all around so we're hoping to ensure that the carpet is kept clean(er).
- One home had a sink in each bedroom. We didn't remove the sink until Christopher managed to rip it off the wall, flooding the dining room below! Lesson learned.

Throughout the house we have done a few other safety measures. They are:

- Put window locks on all windows above the first floor (we live in a three story house).
- Put electric outlet covers on unused outlets (Ireland has a nice system of being able to switch the outlet off with a tiny switch built in to the outlet...but Christopher has found that switch!)
- Use the back burners on the stovetop. Our current stove is safe but our last stove (an American one) had dials that Christopher could walk past, running his hand over them and turning the gas on! We burned up several items that had been left on the stove top. I finally removed the dials and only used them when I was standing at the stove, watching what was being cooked.

We ask the Embassy to assign us to a home on a quiet street, in case he gets out the door (yep, that too has happened) and with a fenced back yard. We like to have our car parked inside a fenced area but that isn't always possible. We quit using stair gates because he only used them to climb on (and fall from). I have learned that Christopher can never be left alone. His cognitive ability is low but his physical ability is high. He is a great danger to himself so we ensure that he is never alone.

Phew, I'm exhausted just writing about him!

Editor's Note: While not all children with dup15q are Houdinis, we thank Mari for sharing her experiences on creating a safer environment for our children.

To subscribe to the Listserve send an email to: Inverted-Dup15-subscribe@yahoogroups.com



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.

2008 Regional Gatherings

Now is the time to think about whether you would like to get together with other IDEAS families in 2008 by organizing a regional gathering in your state or region. If you would like to talk about how to organize a regional gathering in your area, please contact:
Paula Davis at 978-392-8474 xpdavis@comcast.net.



SAVE THE DATE...
2009 IDEAS Conference

June 25 - 27, 2009 • Crowne Plaza Hotel • Indianapolis, Indiana

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