THE MIRROR
The Newsletter of IDEAS
IsoDicentric 15 Exchange, Advocacy & Support
SPRING ■ 2007

Travel

and the child with dup15q Syndrome

By Jane True, editor

FROM OUR EDITOR

Ah, the lazy days of summer. Picnics, ball games, travel…. in the words of Garfield, "Aaaargh!". Travel when the family includes a child with dup15q syndrome is not always something to anticipate with pleasure. The change in routine, strange environment, disruption in sleep patterns, and unfamiliar foods can make travel a nightmare.

Some families dread the prospect so much they feel they will never be able to take a vacation as a family again. Others often have to travel not just for fun but to keep medical appointments. Sometimes parents feel a desperate need to get away as a couple but don't feel it is possible to make all the necessary arrangements.

In this issue of the Mirror you can read how some of our IDEAS families have handled these situations. Organization is key, and some time spent in advance researching and getting familiar with what to expect at your destination can make all the difference. Learn how one family prepares to take their child canoeing, adventure flying and camping. Another world-traveling mom shares her tips on how to survive a long plane flight. Even Disney World can be a more pleasant experience if you know how to negotiate the lines with a special child. It is not only possible to survive travel—you may even learn to look forward to making happy vacation memories as a family. Bon voyage!

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

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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.

INSIDE THIS ISSUE

Focus on Travel

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"Traveling tends to magnify all human emotions."
Peter Hoeg

That said, one of the most important things that I attempt to do, when flying with my special needs son, is to keep my emotions under control. Before flying, I ensure that I am well rested (plenty of sleep,

When booking your flight, explain the situation.
I have found that bulk head seats work best with Christopher (either between two family members or next to a window). He can kick, wave his arms and not bother other passengers (much).

Request that the seats be close to a bathroom.
I like to keep the grabbing of other passengers to a minimum.

Request assistance when boarding and de-boarding.
I 'introduce' my son to the ticket agent and ask that we be allowed to 'pre-pre board' (it doesn't always work but sometimes they do allow us on before everyone else). We are always the last to depart the plane. With connecting flights, we normally use an airline supplied wheelchair or the airline golf-cart.

Make sure clothing is easy to manage.
I make certain that Christopher's clothes for the flight are easy to manage for diaper changes (elastic waist and large pants that will fit two diapers). I always 'double diaper' (with the outer diaper tabs not done) him to make it that much easier in the tiny bathrooms on airplanes. There is less leakage. Between flights, in the airport family bathrooms, I start the whole diaper process over with clean, dry diapers. I try to ensure that my son has a bowel movement before the flight or between flights. We did have to change a dirty diaper once on an airplane and it is not much fun. Try to avoid this at all cost (an enema is one option)!

Pack a special carry-on bag for the trip.
I pack a backpack with the following items:
- –**Medications** with a copy of the prescription
- –Tons of wet wipes
- -Extra diapers
- -Plastic bags for soiled clothing and diapers
- -Small cotton blanket to be used to suck on for comfort, act as a bib for feeding or to wipe the drool from his mouth
- -Books that can be destroyed and 'read' alone (the roar of the plane makes it difficult to be read out loud).
- -Earphones and a walkman with favorite music
- -Small toys (my favorites are the mini-electric fan or a vibrator)
- -Small bag to hold the toys and books since the diaper bag will have to be overhead.
- -Portable DVD player with earphones, if you have a child who will attend to it.

Take turns.
If you're flying with a family member, take turns. While I feed our son, my husband eats. My husband then entertains our son while I eat. We take turns resting too. We avoid caffeine and alcohol while flying since jet lag is so much easier to deal with when you don't have those things in your system.

Seek out security checkpoints for "special needs".
The airline wheelchair assistant will take you to the correct security gate where your child is most likely to receive compassion and understanding (for shoe removal, security checks and 'pat downs'). I dress myself in simple clothes (minimum of zippers) that will not set off alarms and shoes that slip off for security checks (Christopher wears 'monster boots' that are difficult but there is no choice).

Lighten up. While it is more complicated to travel with a special child, do remember: "He who would travel happily must travel light." (Antoine de St. Exupery) I carry the backpack and keep passports, tickets and money in an outside zipper pocket or in my zippered coat/pants pockets (LLBean carries wonderful travel clothes for frequent flyers).

Once you arrive at your destination, have fun and let others help care for your child. Christopher frequently takes advantage of his aunts, uncles and cousins, but they certainly do respect me more at the end of the trip!

Mari is the mother of Christopher, age 15, idic (15), and lives with her husband, Chris in Dublin, Ireland, and has two other children, Gabriele (U. of York) and Abigail (U. of Edinburgh)."

From the Research Desk…

A Note from Dr. Schanen

I was working through my clinical data set for the folks in my study and realized that we saw many of the kids when they were young; since then, things may have changed in terms of seizure status. If you are part of our study, can you please send me the following information:

- Does your child have seizures currently?
- Did your child ever have a seizure?
- Did your child have seizures that were only associated with fever?
- What kind of seizures did/does your child have? (infantile spasms, complex partial, myoclonic, tonic clonic, grand mal, petit mal, or mixed)
- How old was your child when the seizures started?
- If they previously had seizures but they stopped, how old were they when they last had a seizure?

I know you all are really busy and already answered this set of questions when the clinical folks came to see the kids, but even looking through the listserve, I see a fair number of folks whose kids started having seizures since we saw them.
Please reply to schanen@medsci.udel.edu .

Thanks a million!
Carolyn Schanen

IDEAS CHEERS! OUR VOLUNTEERS

SUE BURROUGHS

Sue Burroughs from Vermont is the grandmother of Ethan Luchsinger. Aside from being one of Ethan's biggest fans, she has graciously offered to help IDEAS on several projects. Sue's first project was to design and develop the IDEAS for Cooking Cookbook, which was a huge success. Sue also has helped out tremendously by assisting IDEAS with our thank you letters. For the end-of-the-year direct ask, we received many donation envelopes, and each had to be personally acknowledged. Sue took all of the names from the spreadsheet and made sure each donor received a letter on behalf of IDEAS. Her most recent project was the design of the 1st Annual Phantom Tea invite. Karen Sales, another mother, came up with the wording

(Grammy and Ethan Apple Picking)

and Sue created the design and printed out all of the invites for IDEAS. Sue said, "I enjoy doing projects on my computer and this was an easy way for me to show my support for Ethan. Ethan is my driving force and I will do anything to help him. I also enjoyed learning more about IDEAS during these projects. It felt great knowing that I was able to help in some small way. All of your children have a special place in my heart and I look forward to helping out again."

Thank you to Sue for all of your help! IDEAS is lucky to have a Grandmother like you to help our families.

Vacations without Kids

by Nicole Cleary

Nicole Cleary lives in Portland, OR with her husband Tim and their daughters Corrina (idic15), Sierra and Jasmine. She is the chair of the IDEAS board.

When our daughter Corrina was only three months old, my husband surprised me with a trip to Mexico for Valentine's Day. We had a great time and had visions of vacationing there often with our kids. That was before we knew how chromosome 15q duplication syndrome would change our lives.

A vacation is an opportunity to relax and unwind. As Corrina got older we realized it would be completely impossible for us to relax on vacation with her because we have to be constantly vigilant about what she's doing or might do. We have to care for all her needs when she is awake – she has very few self-care skills. Tim and I know the importance of finding time and space to relax with each other. Given the seriousness of Corrina's disability, we decided to try to make "vacations without kids" part of our lives.

Tim travels a lot with his work, so planning a trip for vacation is fun for him! For me, planning a vacation without kids is a somewhat anxious time. We don't have family resources that can fully cover our child care needs, so we always have to hire someone. Finding someone who can care for our daughter who is non-verbal, autistic, cognitively impaired and unable to independently manage her own daily living needs (showering, eating, dressing, etc) is challenging. Planning Corrina's care, and the care of her sisters, is a full time job the weeks before Tim and I go on vacation. Fortunately, I have it down to a pretty predictable routine.

Finding the person who will be the "anchor" child care provider

I usually start looking for a babysitter 6 – 8 weeks before we plan to go. We have used nanny agencies with some success, always being very explicit about Corrina's care needs. In the last year, we have found capable and loving young women through Craigslist, a free online forum for local classifieds for most big cities. I post very explicit ads and have always had several responses. Fortunately we have always been able to find a good match!

Orienting the babysitter

After identifying a babysitter, we invite her to "shadow" me in our home so that she can get a sense of Corrina's abilities and disability. We also visit Corrina's classroom so that the babysitter can establish a relationship with Corrina's school team. I always print some information about chromosome 15q duplication syndrome from the website so that the babysitter can learn more about this rare syndrome. I find this helps them feel more at ease with Corrina's differences. They will say things like "Oh, watching TV with your nose plastered to the screen is normal for these kids".

Enlisting extra help

Caring for our three children by yourself is a lot of work – I know this to be true! We have found that our most successful vacations without kids come when we enlist extra help for the babysitter. We ask our local family members to come and accompany the babysitter on activities or just spend some "special time" with the kids in the house.

Creating a schedule

I have found that most babysitters appreciate a daily schedule. The schedule includes things like "Corrina likes to hang onto a music toy while waiting for the bus" and other routines that feel comfortable and familiar to Corrina. This helps to keep her happy when we are gone.

Letting Corrina know we are leaving

Corrina is completely non-verbal and has significant cognitive limitations. We have found it helpful to pull out our suitcases a day before we are leaving so that we have something to point to when we tell her we are leaving for vacation. We look at a calendar with her and count how many days we will be gone. We think this helps her to understand that we are leaving and will come back to her in a few days.

Staying in touch

Whenever we travel to Mexico, we always purchase a pre-paid calling card so that we can call every day. This gives the babysitter an opportunity to trouble shoot whatever challenges arise with us. We also talk to Corrina every day, even though she can't talk back. It is very **continued on page 5**

Happy Adventures by Alison Kalnicki

The sun sparkles on the lake. The hot dogs sizzle. The kids giggle in anticipation of lunch cooked over a campfire. Darrell, my husband, and I have hiked into the wilderness with our kids Jesse, 3 years old, and Logan, 5 years old.

Plan ahead

Talk to others who have done what you want to do. Phone and find out what services are available for children or adults with special needs. Have a bag ready to go with change of clothes, snacks, medications, toiletry supplies, communication aids and activities to do while sitting. Plan a way for caregivers to get a break during or immediately after the outing.

There are times that after researching an activity Darrell and I decide that it is not right for us. Our family, like all families, has its limitations and we respect them.

Start small and relax

After we bought our canoe we let the kids play in it – life-jackets on - while it was resting securely on the lawn. Then we introduced a basic rule: always sitting. Logan picks up on my apprehensions so it's important for me to stay calm and have fun. Our first trip lasted about 20 minutes and we built from there.

Stick with a familiar schedule, routines and strategies

We do our best to use the same routines and supports while away from home. Anything we can do to help Logan adapt to our new activity we do, even if we get some strange looks from other people. Invest in a mobility aid or ask a support person to come along. I bring visual schedules, use hand drawn social stories to describe preferred behaviors, and continue to give Logan fifteen minutes to sit on a toilet after each meal. It's demanding but it's worth it.

Keep their favorite and least favorite things in mind

Children and adults with chromosome 15q duplication syndrome have particular interests. Logan holds a comforting toy, and I keep an eye open for any way to incorporate his favorite things into our activity. If you see a kid dressed up like cow at an art gallery, it might be us! Logan finds crowded places over-stimulating, so we attend public places at times when there are fewer people. We also give our children a treat at the end of the outing and let them know that they did well.

When things do not go well...

Darrell and I talk about what could make things go better the next time. When Logan started screaming before flight-seeing trips (Darrell is a pilot), we realized that waiting during the preparation time was making him anxious. Now we include him in getting the plane ready by giving him small chores or books about planes.

Look to the future

Whether it's a trip to a local restaurant, a weekend away or a vacation to a foreign country, plan out your travel in baby steps, bring supports from home and happy adventures!

Alison lives in Canada's Yukon Territory with Darrell, her husband, and their sons, Logan (5 years old, idic 15) and Jesse (3 years old).

continued from page 4

rewarding to hear her humming and laughing into the phone when we talk to her!

Thanks

Caring for a child with chromosome 15q duplication syndrome is hard work and we always recognize it with a small gift of appreciation upon our return!

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Traveling to an Out-of-town Medical Appointment

by Alison Kalnicki

Before you depart –

Pack:

- copies of all pertinent health records from your local medical professionals
- address book with contact information for home medical professionals
- all paper work you have received regarding the appointment
- maps for your hospital or medical office, hotel and city
- notepad and a tape recorder (ask for permission to record first)
- a list of your medical concerns and questions
- some of the comforts of home: night light, bath mat, healthy snacks, spill proof cup, comforting music, favorite bedtime toys and blankets

Arrange:

- medical insurance coverage, if possible
- accommodation (see hospital websites for hotels which have medical rates), transportation and meals
- some relaxing time after the appointment

Phone the out-of-town medical office or hospital:

- provide a phone number where you can be reached after you leave home
- confirm place, time and special requirements for appointment
- ask for any information an out-of-towner might need (parking, directions, length of appointment, do appointments often start late)

Explain to your child:

- where you are going and what is going to happen
- some medical offices have photos they can email you to help prepare your child

When you arrive –

- ask questions
- look after yourselves: good food, enough sleep and laughter

Making the Most of a Trip to Disney World

By Ashley Eveland, sister to Shannon (idic15)

What are some of the things that you think about when you think of Disney World? Happiness? Lifelong memories? Family togetherness? These and so much more make up the magic that is Disney. When a family visits Walt Disney World in Orlando, Florida, they are certainly prepared for the vacation of a lifetime and are bursting with excitement as soon as they step onto the Disney World property. However, for a family that includes a child with idic15, there can also be fear about going to such a large, loud and crowded place. Hopefully by the end of this article I will have eased some of that fear.

Being a former Walt Disney World employee and also having a sister with idic15, I have had the opportunity to utilize many of the services that are offered for guests with disabilities. Out of all the services the most useful has been something called the Guest Assistance Pass. This pass will enable you to "skip the lines" for any of the attractions that have this capability. For example, instead of waiting in a line for 90 minutes, if you show the **Guest Assistance Pass** at the entrance to an attraction, an employee will take you into an alternate line in which you will only have to wait an average of 10 minutes. When we use this pass, we don't have to wait in a long line where a large crowd will overwhelm my sister and by the time she gets physically tired and needs to leave we have already had the opportunity to experience many of the attractions in the park.

This pass can be obtained at any Guest Relations location inside of a Disney World Theme Park. Once there, you will have to

Trip to Disney World continued from page 6

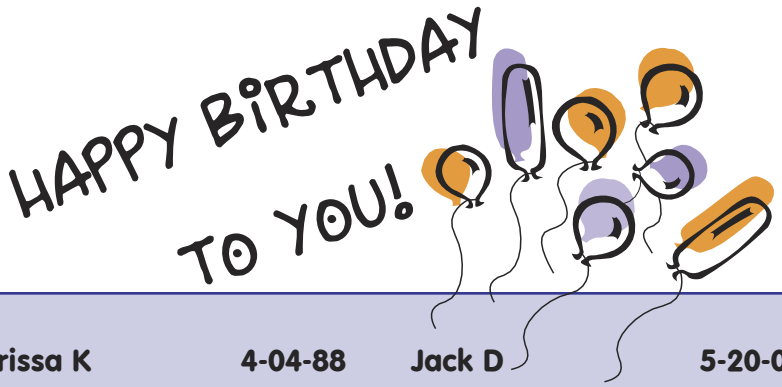
explain what idic15 is and why you need the pass, however once it is issued you will not have to explain why you have it to anyone else. Other employees cannot ask you why you have this pass because that Guest Relations employee already made the decision to issue it to you. In my opinion, this is the best resource that Disney offers its guests and definitely allows families to experience more of the Theme Park than they could without this amazing tool.

Before a guest makes their way to Walt Disney World, they should check out http://disneyworld.disney.go.com/wdw/common/Plain?id=PlainHomePage. This is the website for guests with disabilities and is an incredible resource. It has information about the Theme Parks, Water Parks and Resorts. It is important that guests not only get information about the Theme Parks but also about the Walt Disney World Resort they will be spending their vacation in, if any. The more information you can get before you step onto Disney property the smoother your vacation will go once you arrive.

Walt Disney World offers more resources for guests than I could possibly list here. The most important thing to remember is to become as informed as possible about what your needs are and how the staff at Walt Disney World can meet your needs. If you are honest with them about what would make your vacation a great experience, they are usually quick to help in any way possible. With all of the services provided for guests with many different types of needs, Walt Disney World truly does live up to its reputation as the Most Magical Place on Earth.

"I am Shannons's oldest sister and lived with her until I got married in 2005. I moved to Orlando which is about 45 minutes away from Shannon, but I visit her regularly and make sure to take her to Disney whenever I can. It's one of our favortite things to do together!"

—Ashley Eveland



Marissa K	4-04-88	Jack D	5-20-03
Marcel G	4-04-87	John L	5-20-94
Maxwell A	4-05-04	John C	5-22-01
Mia J	4-06-00	Lindsey Y	5-22-98
Chad T	4-08-94	Brenden O	5-24-91
Tom E	4-09-02	Kayden E	5-26-01
Jeffrey M	4-10-95	Joanne W	5-27-88
Niklas H	4-11-99	Jarret S	5-28-91
Jamie J	4-12-93	Madison M	5-31-01
Marlena H	4-13-99	James C	6-01-03
Bobby W	4-14-78	Alyssa L	6-02-93
Julie R	4-19-99	Kathleen M	6-04-93
Cody L	4-19-93	Jack R	6-07-02
Suzanne K	4-20-89	Angel S	6-09-93
Colleen S	4-23-93	Chris L	6-11-90
Alexis J	4-25-02	Tori M	6-12-92
Elisabeth A	4-27-95	Heather W	6-16-92
Robert M	4-28-92	Andrew B	6-18-99
Paige J	4-28-92	Richard H	6-18-96
Mathew V	4-29-88	James M	6-18-96
Crystal O	4-29-87	Yuri P	6-20-75
Jacob M	5-04-99	Cheyenne J	6-21-96
Shelby L	5-05-93	Krystyn B	6-22-98
Viktoria N	5-06-03	Trevor B	6-23-94
John Paul P	5-11-06	Grace L	6-24-03
David W	5-08-91	Jonah C	6-24-99
Albanelia R	5-08-84	Klara H	6-24-92
Erin R	5-09-00	Douglas M	6-26-03
Eddie M	5-09-99	Sarah H	6-26-93
Anna M	5-09-88	Holly T	6-27-94
Sem K	5-10-99	Mikaela O	6-28-00
Simon P	5-10-83	Taylor L	6-29-99
Austin E	5-13-92	Alec S	6-29-96
Jaylin L	5-15-92		

A Tribute to Frédérique Davidson

Almost 8 years ago, I introduced my daughter Frédérique to the IDEAS families when I wrote a Family Portrait. She was 7 years old then.

Today, I am once again writing in the IDEAS newsletter. This time, it is a tribute to Frédérique, 15 years old, who passed away peacefully in her sleep on March 18, 2007.

Frédérique was a lively, energetic, curious and very outgoing teenager. She was diagnosed at 15 months with a developmental delay, later known as idic15, and with autistic tendencies. Along the way, we learned more than anyone wishes to know about different therapies, treatments, schools, autism, medication, seizures. Frédérique surpassed many of our expectations. Her strengths were definitely human contacts and getting to know people. She especially enjoyed asking strangers for their name and how old they were. She had a love for animals, especially for her own dog Kiwi. Frédérique attended a special needs school. Her teachers were quick to notice her desire to learn, to please and to be treated like a "teenager". Like anyone, she knew her limitations, her likes and dislikes. Fine motor skills were often a struggle for her and a cause for some frustration.

Some of her favorite television shows were "Sesame Street", "Barney" and "Molly and Loonette", while her favorite movie was "Annie". She loved music, singing and dancing to her favorite singer Shania Twain. Over the years, she would go away once in a while on week-ends of respite, and in the summers she would attend a camp for autistic children. She usually had a lot of fun and lots of friends. As she got older she learned to bowl, to ride her adult tricycle and her scooter, to swim like a fish and to ice skate (Canada!). She was a great helper around the house giving us a hand with household chores, gardening and shoveling. She was the family "Cheerleader" at her brother Xavier's (16) hockey games and at her sister Emmanuelle's (13) soccer games.

Like any family, we had our ups and downs, our frustrations and our worries. At 11 years old, Frédérique had her first epileptic seizure. A new hurdle to confront! She would have only 3 more seizures until her death, all nocturnal. Otherwise, Frédérique was a healthy and strong girl who rarely missed school or complained about anything.

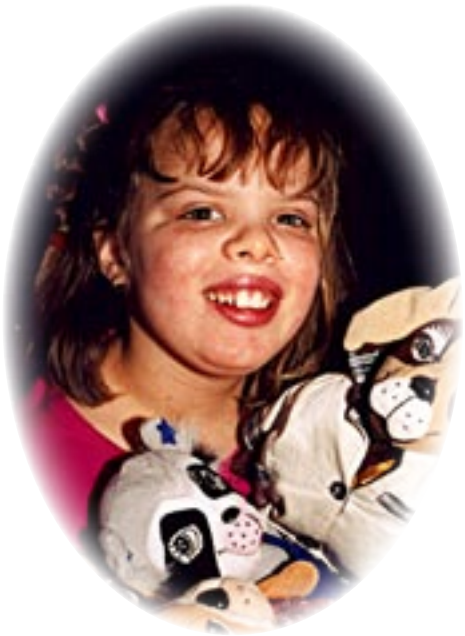
Emmanuelle, Xavier and Frédérique

I believe in my heart we had chosen Frédérique to come into our lives and she had chosen us in return so she could accomplish great things as well as teach us valuable life lessons. Frédérique always lived each day to its fullest no matter the outcome. She loved unconditionally, never judged nor discriminated. Her smile was contagious. I believe she died fulfilled, loved and truly happy. Knowing Frédérique, she is probably counting clouds and pairing them in different sizes and shapes.

She is forever our family's angel.

Catherine Jarrold, Mother

Catherine is Frédérique's mother. She lives with her husband Norman and her two other children, Xavier and Emmanuelle, in Montreal, Quebec.



Reflections

This part of the REFLECTIONS column shares perspectives from a sibling.

Reflections from a grown-up little sister

by Elizabeth Bennett age 28, sister of Josh Bennett idic(15)

Growing up, people always asked me what it was like having a special needs brother. And I always thought we were no different from other families. There was sibling rivalry, we got on each other's nerves, and I felt like I was a nuisance to my older brother as he always had something better to do - like shaking a bottle of water or playing with a shoestring. Granted, his hobbies were a little different from those of most other older brothers.

I am Josh Bennett's little sister. Growing up I never really felt like his little sister. I always had to watch out for him and make sure he was okay. It never really bothered me because that was the way life was from the very beginning. It wasn't like he was normal and then suddenly became mentally handicapped, so I never really knew anything different. In light of that fact, I actually do look up to him as a younger sister would.

Josh has a lot of great character. First of all I admire him for his ability to forgive. It is easy to be upset by the things that hurt us. Josh doesn't hold on to the resentment of the things that others do to him. He is able to forgive but don't think he forgets. Believe me, he doesn't forget anything, especially where Mom hides the cookies. The second quality I appreciate is his honesty. He is not afraid to let you know that he knows when he is not happy. He may not be able to communicate verbally but he gets his point across. Lastly, the trait that I most admire about my brother is loyalty. When one of his staff people was hurt at work and incapacitated on the floor, Josh stayed with her and held her hand until help came.

If you would like to share your thoughts on a sibling with idic(15))in a future issue, please contact the editor at jtrue@kc.rr.com

In the Summer 2007 Mirror watch for Conference and Research Round Table coverage, including:

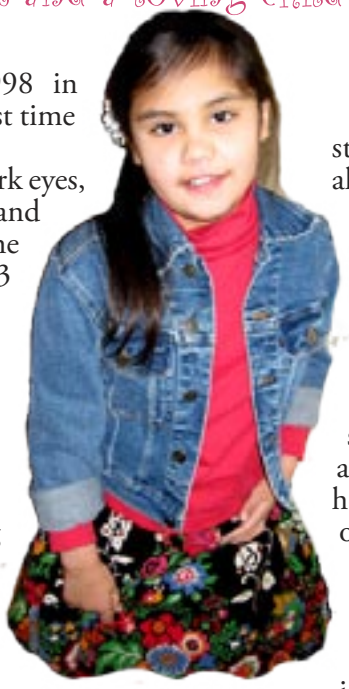
- autism
- the dup15q brain
- death in dup15q
- new research directions

Family Portrait

By Michell Young

Lindsey

a gift and a loving child



Lindsey was born on May 22, 1998 in Barrington, Illinois. I remember the first time I saw her I cried because she was so beautiful. She had dark eyes, chubby cheeks, loads of jet black hair and the longest eyelashes I'd ever seen. She was a seemingly healthy baby of 8lbs. 3 oz.

Bill and I were thrilled. On the advice of the nurses, I tried feeding Lindsey right away and we noticed she wasn't latching on to feed and that she was more interested in sleeping. She was so sleepy she was having trouble keeping her eyes open at all. After talking to the doctors and nurses, they decided to gavage (tube) feed her so as not to confuse her with the bottle.

The first night in the hospital, Lindsey choked after a late night feeding and required oxygen. We were shocked to be told about this the morning after the incident. The reasoning by the staff was that they didn't want to wake us when it happened. They also told us a neurologist would be coming in to see Lindsey to make sure everything was alright. What a trauma hearing that news was. I was sick wondering if something could be wrong with our perfect little girl.

After she was examined by the neurologist, we were assured Lindsey's neurological responses were appropriate- what a relief that was for us to hear. Although we were ready to go home after a couple of days, the doctors decided to keep Lindsey in the NICU because she hadn't had a BM and they noted her stomach was very distended. After many tests and x- rays, they decided to release her. Our baby was finally coming home.

The first 2 weeks with Lindsey were quiet. She slept almost non-stop and it was very difficult to get her to feed. It seemed like she was having trouble controlling her mouth and sucking. After many frustrating hours of consultations with the La Leche nurses, I opted to pump and bottle feed. Lindsey was eating a bit more with the bottle. I remember noticing some things about her behavior- no eye contact, no smiles, staring at lights and so much sleeping. But being a first-time mother I thought maybe I was just being paranoid. I pushed the worries aside, afraid to utter them aloud.

After 2 weeks home, the crying started. Lindsey seemed so agitated all the time and there were days when she would cry all through her waking hours. I would cry right along with her because I felt so helpless not being able to fix whatever was bothering her. It was only when she fell asleep that either of us had any peace. She still wasn't eating well, she seemed to have an upset stomach, and she was having trouble with her BMs. We decided to put Lindsey on a hypo-allergenic formula to see if it helped her stomach- and it did a bit- but she was still irritable. I kept looking at my parenting books at the milestones she should be reaching and she had reached none. I went to the pediatrician with our concerns, but they were brushed aside. The head lag, no eye contact, no pushing up or rolling over were due to the fact that she was a "lazy baby" and she was just a little behind because of it. "What a worrier this new mommy is! There's really nothing other than laziness that is wrong with Lindsey". I remember when Lindsey was 8 weeks old, I had her sitting in her car seat and I was looking at her, talking to her, trying to get her to look at me, smile for me... anything. She was looking through me. It was a moment I will never forget and the first time the word "Autism" escaped my lips. After more visits to the pediatrician, and more brush-offs, we switched doctors.

At 3.5 months we went to see a new pediatrician. In about 5 minutes she

Family Portrait continued from page 10

said there was definitely something wrong with our little girl. She mentioned cerebral palsy, and sent us to a neurologist right away. More trauma, more worries. We went to see the pediatric neurologist where he diagnosed Lindsey with hypotonia. He said that at this young age that was all he could detect. I came home and looked up hypotonia online and burst into tears again thinking my daughter would never have the strength to run with the other kids. Little did we know.

Over the next few months Lindsey continued to miss milestone after milestone. She was eating better and showed some signs of improvement, although not at the rate of expectancy. Her first smile came at 5 months. That was another moment I will not forget- this time joyful. We were advised by our pediatrician to get Lindsey started in physical and occupational therapy, which we did right away.

By the time Lindsey was a year old she was still so far behind, but we had no more answers. Bill and I decided to move to Michigan where our family was and take advantage of my father's medical connections. With the help of some wonderful doctors, Lindsey was finally given a diagnosis. At 14 months we were introduced to isodicentric 15. Not much was known about the diagnosis by our doctors, but we were dealt two words that were devastating... mental retardation. It was a very sad time for all of us.

Less than a year after Lindsey was diagnosed I found IDEAS online. The outpouring of support, validation of feelings, and friendship was almost overwhelming. We learned more about Lindsey's diagnosis and how we could help her from this amazing group of parents than any text book or case study could have taught us. We feel so lucky to have found this family.

The past 8.5 years have been an emotional roller coaster. We've been on a non-stop journey of intervention, therapy, diagnostic testing, home schooling, private schooling, laughter and tears.

Because of Lindsey we have met some amazing people, made new friends, learned valuable life lessons and have discovered the beauty and the ugliness of the world of special needs.

At almost 9 years old, Lindsey is a gift and a loving child. Although severely affected by her condition, she is now attending public school and is mainstreamed part of the day. She loves being around typical children and has greatly improved on her social skills and eye contact. We are hoping the exposure to all of these children will prompt Lindsey to speak her first words. These days, we are struggling with getting her seizures under control. It is a frustrating battle, but somehow, Lindsey always manages to give us hope.

For our family, hope comes in the form of her smile, the joy of her laughter, or a lingering gaze eye to eye, but it is always there for us to hold onto.

Lindsey's favorite pastime is horse back riding. She has been riding since she was 2 years old. We look forward to a time when she will have a horse of her own and be able to spend her days riding with the wind in her hair and a smile on her beautiful face.

Michelle Young is the motherof Lindsey, age 8 idic(15), and lives with her husband Bill in Grosse Pointe, Michigan.

Announcing the

"Circle of Friends"

By Frank Kobuszewski

A "friend" is defined as "a person who gives assistance; patron; supporter". Within our IDEAS family, we have many "friends" we are truly grateful for. It's because of their assistance and support that we are able to carry our mission forward. This summer we are introducing an upper-level giving program called "Circle of Friends". The goal of this program is to allow our IDEAS families and friends to have a larger financial impact to help provide a better tomorrow for children with chromosome 15q duplication syndrome.

The levels of our "Circle" have been set at $150, $300, $500, $1,000 and $2,500.

One of my favorite quotes for business and life raising a child with idic15 is,

"The greatest danger for most of us is not that our aim is too high and we miss it, but that it is too low and we reach it."

—Michelangelo

We are aiming high with our expectations and are looking forward to seeing you in Boston at our conference for the formal kick-off! For more information on IDEAS Circle of Friends, please contact Frank Kobuszewski at fkobuszewski@cxtec.com

Frank is the father of Tyler, age 6, idic(15), and lives with his wife Kathy and other son Collin, age 11, in Camillus, New York.

Please Help Support IDEAS

IDEAS is a completely volunteer run non-profit organization dedicated to providing family support, raising awareness, and fostering research into chromosome 15q dulication syndrome. IDEAS relies on the involvement of families to help us raise money to accomplish our mission.
Go to: www.idic15.org/SupportIDEAS to see how you can help.

THE MIRROR
The Newsletter of IDEAS
IsoDicentric 15 Exchange, Advocacy & Support

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.

Come Share the Journey…

The 4th International IDEAS Conference

"SHARING THE JOURNEY"

is coming up on June 28 – 30, 2007
at the Seaport Hotel in Boston, MA.
Registration materials available at
www.idic15.org

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Northwest Regional Gathering:
September 1, 2007

Come join the Northwest IDEAS families at Maryhill State Park on Saturday, September 1st, 2007. We meet on the bank of the Columbia River and share a picnic lunch and a fun afternoon together. For more information, contact Nicole Cleary at (503) 253-2872

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