



The Newsletter of
IDEAS

IsoDicentric 15

Exchange, Advocacy & Support

FALL ■ 2006

COMMUNICATION

in Chromosome 15q Duplication Syndrome

FROM OUR EDITOR
KROW ONB EDITOR

Welcome to our issue on Communication. We want to start by communicating a change in how we describe duplications of chromosome 15q to each other and to the rest of the world. We will now use the term “chromosome 15q duplication syndrome”. This term has been used by researchers for a while, and will now be adopted by IDEAS in all future literature and correspondence. Abbreviated “dup15q syndrome”, it will appear in The Mirror, on our new website (to be premiered later this fall), in conference materials, and in other literature that we produce.

Trying to communicate the name of our condition to others has always been a challenge. Apart from the confusion of trying to distinguish between idic(15) and interstitial dup 15, it has not been clear to many that we were describing a chromosome condition. So the new name, while still a mouthful, should clarify the situation and also be more inclusive. Now when you see the term chromosome dup 15q syndrome, you can feel assured that we are including all of you!

Premiering in this issue is a new feature, “IDEAS Cheers Our Volunteers”, in which we honor outstanding volunteers who have made a significant contribution to our group. Thanks to these wonderful volunteers, we can offer you the many services you value such as The MIRROR. If you have a nomination for a future volunteer who needs to be cheered, please send the name to the editor or to a board member.

Enjoy reading about communicating with the person with chromosome 15q duplication syndrome!

Warmly,
Jane True
MIRROR Editor

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:

- IDEAS Cheers our Volunteers
- Research Update
- Families talk about Communication
- Reflections
- Family Story

Jane True,
MIRROR Editor serves on the
IDEAS Board, and lives with her
husband Jim in Kansas City, Missouri.

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... RESEARCH UPDATE:

Molecular Investigations of Duplications of Chromosome 15 in Autism

N. Carolyn Schanen, MD, PhD, Nemours Biomedical Research; and Nichole Cleary, M.S., IDEAS Executive Director

Speech and language delays are a common characteristic of chromosome 15q duplication syndrome (dup15q), although there is wide variability in the degree to which a child may be affected. Children at the mildly affected end of the spectrum may be highly verbal, but may have impairments of social communication, showing a lack of response to social cues.

At the more involved end of the spectrum, expressive language may be absent or may remain very poor. Speech is often highly repetitive or echolalic with immediate and delayed echolalia and pronoun reversal. Intention to communicate may be very poor or almost absent. In infancy, these children may demonstrate both feeding difficulties and hypotonia. There is often a marked delay in reaching motor milestones. Those that develop speech often experience significant difficulties with communication and social interaction in the first 3 years of life. Some children at the involved end of the spectrum do not ever develop speech.

In our research study, *Molecular Investigations of Duplications of Chromosome 15 in Autism*, we have assessed a total of 65 children with duplications that include the critical region for developmental delays (the Prader Willi Angelman critical region

that lies between 15q11.2 and 15q13). Of these, 58 subjects have maternally derived duplications, one has a paternally derived duplication and six are unknown (because we do not have samples). These also include several forms of duplications: 46 have idic(15), 8 have int dup(15), 1 has a ring(15), and 6 have complex rearrangements that lead to six total copies of the risk region in all or some

Many non-verbal or minimally verbal children with dup15q syndrome successfully use alternative and augmentative communication, including picture exchange, letter boards, and voice output devices.

cells. The age range for the kids tested was 2 years, 5 months to 23 years old at the time of the testing. We had enough kids in the idic(15) and int dup(15) groups to analyze the data from the behavioral testing.

In terms of language development, we found 26 of 47 children (55%) with idic(15) had some language at the time of their participation in the research study. These children's first word was achieved at an average of 28.7 months (range 7-84 months) and phrase speech beginning by an

average of 44.1 months (range 9-114 months). Among the 21 non verbal children, 12 were less than or at 60 months when they participated in the study and may still develop speech. For the eight kids with int dup(15) chromosome, all had some language at the time of testing, with an average age at first word at 38 months (range 14-60 months) and onset of phrase speech at 61 months (range 24-90 months).

Many non-verbal or minimally verbal children with dup15q syndrome successfully use alternative and augmentative communication, including picture exchange, letter boards, and voice output devices.

Because speech is only one aspect of a child's development, it may be helpful for families to consider the other developmental milestones we are seeing in children with dup15q syndrome. For the idic(15) group, the kids achieved independent walking at an average of 25.5 months (range 13-54 months), with 3 kids who were not ambulatory at the time of testing. Only eight of the 47 were toilet trained, with daytime control achieved at an average of 45 months (range 23-60 months). Those same children were dry at night, achieving this at an average age of 43.6 months. Bowel control had been achieved in seven children by

IDEAS CHEERS

OUR VOLUNTEERS!

RESEARCH UPDATE:

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~54 months (range 32-84 months). Notably, six children in this group were less than 45 months and 10 kids were younger than 54 months at the time of testing.

For the eight kids with int dup(15) chromosome, all were ambulatory, achieving this milestone at an average of 16.8 months (range 11-24 months). Four were toilet trained, with bladder control achieved at an average age of 42 months (range 36-60 months) and bowel control achieved by 57 months (range 36-84 months).

Because a number of parents of kids with both idic(15) and int dup(15) chromosomes reported problems with sensory issues, we examined the responses to questions regarding sensory behaviors. Approximately half of the kids had some degree of sensitivity to sound and about 65% of them had other sensory aversions at some point in time.

1. Dennis NR, Veltman MW, Thompson R, Craig E, Bolton PF, Thomas NS: Clinical findings in 33 subjects with large supernumerary marker(15) chromosomes and 3 subjects with triplication of 15q11-q13. *Am J Med Genet A.* 2006 Mar 1;140(5):434-41.

2. Battaglia, A.: The inv dup(15) or idic(15) syndrome: a clinically recognizable neurogenetic disorder. *Brain Dev.* 2005. 27:365-369.

3. Dennis et al (2006).

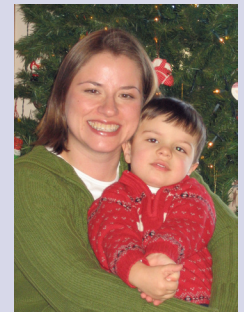
As IDEAS grows, we find our needs are growing as well. As always, we rely on volunteers to meet these needs. Today we honor two moms who have been trailblazers in our fund-raising efforts: **Doreen Gladis and Karen Sales**. These two ladies organized and ran our first IDEAS auction on eBay. They investigated the process, accepted the donations, photographed donated items, listed them on the site, shipped them, and basically did whatever it took to get the job done.

In Doreen's words, "Even though we are scattered geographically it was great that we could come together in this project. Thanks to everyone who bid, donated and got the word out about our auction. Now that we're all set up I can stay on board through June 2007 to post any other items families and friends may want to donate."



Doreen & Son Pavel

Karen adds, "While this auction kept me very busy, it was very rewarding and educational as well. I've been wanting to contribute somehow because this group has given me so much and I've also had a chance to make more friends within the group."



Karen & Son William

Thank you Doreen and Karen for your energy, and for support of IDEAS as we carry out our mission to support families and promote research that will help our children. Because of your efforts we raised \$2,668 and increased awareness of dup15q syndrome among shoppers on eBay.

• • • Please Help Support IDEAS • • •

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

The Highly Verbal Child with dup15q

Tracy & Julie Orton, parents of Allison, Joshua, Mikaela (idic(15)), and Victoria live in Quincy, Illinois.

Mikaela was diagnosed with idic(15) just before her second birthday. The diagnosis made her eligible for the early intervention program. She started speech therapy soon after her diagnosis. When she started she could only say 'Mama', fine for Julie but a little hard on Tracy's ego. She had started biting to get the attention of adults and other children. To give her a means to communicate, her first therapist focused on sign language. She eventually learned signs for: drink, eat, more, please, thank you and all done. The word was always said with the sign, so she got both auditory and visual cues. It took quite a while, but she eventually started using the signs without prompting. When she switched to saying words, she would often sign and say the word.

When she turned three she was using her signs and saying, Mama, Dada and Bye-bye. The day she turned three she started in the Kirksville Community School District early intervention program. At our first meeting they recommend Applied Behavioral Analysis therapy. Mikaela started in the middle of summer. She was at the school 20 to 30 hours per week. The first three days of her therapy were very tiring for both Mom and Mikaela. When we started she would cry at the sight of the school, but after a couple of weeks she started to get very excited about going to school and became

very close to her teachers and the other kids in her class. At the end of the school year she could imitate



sounds, name twenty objects and 8 familiar people.

After that year we moved to Indianapolis. Sometime between the end of the school year in Kirksville and the start of the year in Carmel, Indiana, Mikaela's mind seem to wake up to talking. She started to say words that she had only heard in conversation, not been taught. Julie's most memorable day was when Mikaela said "I wuv you" without being prompted. In Indianapolis we enrolled her in the Little Star School, a private school where we hired a therapist and rented the space from the school. We used the ABLLS program at Little Star since it is easier to self-direct. Mikaela also got quite frustrated at times at Little Star but thrived on the rewards for completing her tasks. She is easy to bribe as she really likes to eat.

Last summer we moved to Quincy, Illinois. We had to have a couple of meetings with the early childhood program staff, but they eventually came around to our way of thinking about how Mikaela learns. She now knows all the uppercase alphabet and can read 30 sight words.

Mikaela is now to the point where she can hold a conversation with other kids and adults. She is able to communicate her needs and desires verbally. She talks non-stop, often asking the same question over and over again. She is a little hard for some people to understand and sometimes needs the Mom and Dad interpreter to help. She orders her own food when we go to a restaurant, usually a hamburger with chocolate milk. Her speech therapy time now is taken up with articulation training. We are not sure if her articulation problems are due to ear infections when she was younger or if they are part of her global delay. She has had two sets of ear tubes and an adenoidectomy.

We feel very blessed that Mikaela has learned how to talk and communicate with her family and others. It has not been an easy journey but it was the path God has taken us down, and we will continue to follow where we are led.

<http://www.idic15.org>

Communication and the Young Adult

Anne Karch and her husband Paul live with Rachel (idic(15)) and her siblings Lydia and Charles in Appleton, WI.

Connecting with Rachel

Rachel turned 20 today. This feels very old for someone who seems so young. A stranger recently asked how old Rachel was, and we encouraged him to guess. He said, "Thirteen? Twelve?" No, twenty. That's a lot of years. Twenty years of daily bathing her, helping her dress, attempting to manage her seizures, and most importantly, trying to communicate with her.

I believe communication is the most important part of caring for our daughter because for me it is the biggest piece of the idic(15) puzzle. We human beings are often described as "social animals," and one of the key parts of being social is communicating. The struggle to communicate with Rachel, and her struggle to communicate with us, defines our parent/child relationship, and it's what makes being able to communicate with her so richly rewarding.

One of our first clues that something wasn't quite right with Rachel when she was a baby was the fact that she didn't start to smile at two or three months of age. In fact, she didn't smile until she was a year old, but what an enormous thrill that first smile was! It was not just that we had been waiting so long for it, but more that it was a form of communication; it told us she was happy.

Rachel's first spoken word was even more delayed than her first smile. She didn't start to talk until she was almost five. But she began to communicate with us much earlier than that, with the smile, and then the laugh, and tugging on our hands to get us to do things. Her early childhood and preschool programs placed a heavy emphasis on communication, both with speech and sign. When she was about three, Rachel would sit in my lap and take my hands, rub them together, and then pry them open. It probably took me a week to realize that she was having me make the sign for "book" so that I would read to her.

During these preschool years, we took Rachel to a speech therapist outside school. She offered Rachel a wide variety of interesting activities, including a Mickey Mouse alphabet computer program that she adored. But I don't think Rachel ever even made a sound during these sessions. The therapist was unfazed; she told me that sometimes you had to "put a lot in before anything comes back out." How right she was. When Rachel did start to talk, she used many of the words that the therapist had worked on with her. I often wanted to take Rachel back to her speech therapist, just so the therapist could have the joy of hearing Rachel talk. Unfortunately, we had moved to another state by that time. A couple of years ago, I used Google to locate that therapist again, and I wrote her to tell her that Rachel could, indeed, talk, that it was finally coming back out. Rachel did

finally talk, and although she only uses two- or three-word phrases, they get the message across: "Help, please;" "Let's go home;" "Hi, Daddy." She often says what she wants to say by giving you your line. For example, she says "Hi, Rachel, how are you today?" to prompt you to say it so she can respond, "Fine, that's nice." Or she'll say, "Let's go home" and not be satisfied with anything else you might respond until you say "Let's go home," so she can say, "O.K." She says a lot through song, too. Rachel knows hundreds of songs. In fact, she probably knows five times her regular speech vocabulary in the lyrics of songs. Paul and she sing songs when they go for walks, and Paul works to think of songs that fit particular situations.

Like most parents of children with a disability, we have to "read" our child. She can't tell us where it hurts, or even that she is in pain. She can't say, "I feel a seizure coming on." So we have learned to watch what she does for clues to what she is feeling. "All behavior is communication," they say, and this is true, although it is often a challenge to figure out what a particular behavior means.

From the time she was four or five until she was about twelve, Rachel had a lot of tantrums, as many as four or five a day. Her teachers and we struggled to help her express her frustration/ rage/ anxiety in other ways. We would tell her to "Use your words," and we would even supply her with the words we thought she wanted to say, although we weren't always sure we were guessing right. This helped

Behavior is Communication

Jodi and Jamie Miller, parents of Jake (idic(15)) and Sarah live in Mount Prospect, IL.

Jake cannot verbally communicate his wants and needs so he sometimes resorts to negative behaviors like hitting his face, cheeks and ears, biting himself and others, and head banging. Most often, these behaviors seem to be related to communication frustrations. At times, Jake will bang his head against walls or floors. This can be a horrifying behavior and we have reacted to his banging by running to stop and comfort him. This can become a reinforcement, as he knows it gets our immediate attention.

Jake currently takes Depakote for behavior control, Prozac (which seems to be less effective over time), and a low dose of Clozapate (which affects his balance and gait). With our doctors' help, we continue to "tweak" his medications.

Behaviors are our biggest challenge in raising our idic15 child. By identifying the source or reason for Jake's behaviors, we have tried to implement specific strategies for coping. Sometimes they are effective and sometimes not. We have found we have to mix things up to keep them fresh and new to help extinguish unwanted behaviors.

To alleviate head banging we proactively use a soft-shell helmet. We padded his bedroom wall with a decorative area rug with foam underneath, as he would wake us up to get him out of bed by head banging the wall. Our goal was safety, while not reinforcing negative behavior. We began to leave his bedroom door open at night so he could get out of his room without head banging for our attention. This has worked to stop the head banging. Now Jake wakes up, comes into our room, and goes back to sleep in our bed. The head banging has stopped and has been replaced with sleeping with his parents! Getting him to sleep in his own bed and through the night is a huge challenge and we are still working on finding the solution.

With the help of our ABA behavioral consultant and our occupational therapist, we wrote a "sensory diet" and helpful strategies that are implemented proactively throughout the day. These strategies help Jake regulate himself during school, therapy sessions and at home.

Strategies

- Acknowledge and verbalize what your child may be trying to communicate. "You don't want to!" "You want to stop!"
- Use picture communications and signs coupled with short simple verbal commands.
- Keeping a chew tube hooked on a shirt for instant access helps with the need to bite others and indicates that your child needs something if they are biting.
- Use affect in your voice when communicating with your child.
- Communication devices like the big Mack switch or Cheap Talk help the child to communicate.
- Have Boardmaker symbols and photos around the house for often-requested items like water, food, bathroom, play outside, etc.
- Social stories and picture schedules help to show the task ahead and when it will be completed.
- For transitions give the child fair warning when an activity is going to end. For example: "we are almost done with water play", count: "1,

HAPPY BIRTHDAY TO YOU!



2, 3", "all done with water play". Reward communication efforts with sensory input when completing a difficult task and for participation.

Do not let the child manipulate his way out of work. If having trouble with a specific task, require him to complete the task successfully (even if hand over hand) by telling him he needs to do "one more time" and then reward with a sensory break away from the work to regulate himself. This is important, as you don't want to reinforce negative behavior.

"We can make our minds
so like still water

that beings gather about us
that they may see,

it may be,
their own images,

and so live for a moment
with a clearer,
perhaps even with a fiercer life

because of our quiet."

W. B. Yeats

Logan K.	10/01/01	Melanie P.	11/22/86
Lucy B.	10/01/02	Andrew S.	11/25/01
Sarah D.	10/02/96	Chad L.	11/27/75
Joshua C.	10/02/94	Ruth O.	12/02/89
Adam R.	10/02/91	Joseph T.	12/03/96
Riley R.	10/04/03	Jared L.	12/04/02
Sem K.	10/05/99	Naomi H.	12/07/97
Joshua K.	10/10/01	Jimmy T.	12/08/04
George P.	10/17/81	Abigail S.	12/09/97
Matthew P.	10/17/04	Matthew K.	12/12/96
Giulio Z.	10/18/04	Ellie S.	12/12/96
Nathan L.	10/18/01	Ashley B.	12/12/04
Makenna J.	10/22/01	Chase W.	12/13/00
Renate D.J.	10/22/92	Cody C.	12/14/95
William S.	10/24/02	Corey C.	12/14/95
Jarod W.	10/30/89	Sven D.	12/16/98
Shay P.	10/31/92	Olivia T.	12/16/94
Anna B.	11/03/99	Ingvild S.	12/16/86
Richard M.	11/04/86	Nicholas B.	12/18/87
Corrina C.	11/05/96	Aston C.	12/21/02
Carrie J.	11/07/83	Caroline W.	12/22/00
Rohan N.	11/08/02	Austin B.	12/22/95
Hayley P.	11/08/99	Megan R.	12/22/95
Will G.	11/11/98	Justin O.	12/23/97
Taylor P.	11/12/02	Chelsi C.	12/23/93
William C.	11/14/94	Stephanie J.	12/26/96
Stephen L.	11/15/93	Chandler R.	12/27/96
Lindsay K.	11/15/90	Ada E.	12/29/99
Twan W.	11/19/02	Teddy S.	12/29/90
Chandler G.	11/20/98	Kevin C.	12/30/95

REFLECTIONS FROM A SIBLING

by David McCoy, brother of 7- year-old Marlena Higgins (idic(15))

As I am getting ready to leave for college I started thinking of all the things I am going to miss. My friends, the life I am accustomed to, my job, the city I live in, but most importantly my family. Some of you who are reading this have more than likely seen me at one of the conferences or have some idea of who my sister is. For those of you who don't, my sister is Marlena.

For those of you who have never had the pleasure (and I mean that in a good way) of meeting my sister, you should know that she has idic(15), and is one of the friendliest and most charismatic people that you will ever meet. If you have met her, you have more than likely shaken her hand and answered one of the many questions that she will ask.

I never really realized it until now but she is one of the things that I am going to miss the most, (sorry mom) even though it is a guarantee that she will be knocking on my door at six in the morning to wake me up on my only day off from work. But with the good also comes the bad.

For instance, when babysitting her she has gone into the kitchen to get some cereal and poured it all over

the floor which is a good ten feet away from any bowl in the kitchen. Or when I am watching my favorite show on TV and she turns it off during the climax because she thinks it is time for bed even though it is only eight and neither of us are going to bed for another two hours.

All of this is worth it when you are laying with her on the couch staring at the blank TV and she turns to you, gives you a hug and says, "Dave, I love you". Even though she is just saying it so I don't get mad at her for turning off the TV this

is what I am going to miss the most when I leave. Not my friends, not the life I am accustomed to, not my job, not the city I live in, not my parents (although they are a close second), but my sister Marlena.



The Mirror

We are looking for siblings who would like to share their thoughts in a future issue of The Mirror . If you are interested please contact the editor at jtrue@kc.rr.com

IDEAS

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REFLECTIONS FROM THE LISTERVE

Communication in our Kids

Hayley started talking to Dora the Explorer. Her most frequent first words were "backpack", "boots" and "map". She has always loved interacting with the Dora shows. Another DVD that my girls absolutely love is the Laurie Berkner Band. It is all music, but music is how Hayley picks things up and learns most of her speech. She can sing most of the songs from the DVD on her own now and walks around the house singing them when it is not on. The worst part is me and Daddy catch ourselves singing along with her.

– Laurie Plate

We have a lot of the leapfrog toys and videos and she started to make most of her sounds when we got the one that stuck to the fridge that you put a single magnetic letter (Fridge Phonics) into and then it sings a song. Then there is one that you put 3 letters in and can spell 3 letter words (Word Whammer). She will watch the videos and then play with the magnets on the fridge and try and make the sounds. Our speech therapist just brought over some new Sesame Beginnings videos. They have caught her attention because they are very repetitive (ie. m..m..m..mother, b.b.b.baby) and have catchy songs. Payton really likes this because then she can try to make the "m" sound.

– Kristina Fowler

Although the behaviors are still present they are far less frequent especially since she has started to use PEC's. Payton uses PEC's (picture exchange communication) for communication and picked this up extremely fast. She is able to even put together compound sentence ideas.

– Sandi, Payton Fowler's grandmother

I think I will start with a real photo of Matt's sippy cup and put it on the fridge and see if he will show some interest. Who knows, he may yet learn to point.

– Julie Kelley

My son Kayden loves Baby Einstein and Teletubbies. The only other videos that will get his attention are Elmo's World (I think because of the high-pitched voice). He is 5 and is still completely non-verbal, but seems to be "absorbing" all of the info. The Baby Einstein videos did teach Kayden lots of classical songs, which he has now memorized and will hum note for note in perfect pitch. He knows songs I don't even know!

– Teana mother of Kayden

Communication and the Young Adult

...continued from page 5

her some, although Risperdal probably helped her more.

Learning to "read" Rachel has become the hurdle that any new helper or caregiver for Rachel must jump. Getting to know Rachel takes a while, much longer than it would take with a regular kid, and often the helper gets discouraged or even thinks that Rachel doesn't like her. But if we can get over that hurdle, then the helper gets very close to Rachel, and Rachel includes her in the select group of people whose lap she will try to sit on.

Understanding what Rachel is trying to tell us is something we never feel very good at, but one thing's for sure: we're much better at it than anyone else, including doctors and nurses. Three years ago, it took us three visits with three doctors before anyone would believe us that Rachel had whooping cough. This was partly because Rachel's regular doctor, who knows that we know her, was not available.

We have always said that our highest priority goals for Rachel are that she understand that we love her and that she tell us that she is happy. I feel pretty good about these goals when Rachel leads me to a chair, sits down next to me or on my lap, pulls my arms around her, rubs her hands through my hair to get a better look at my eyes and forehead and supplies me with the words she thinks I want to say: "Hi, Rachel, how are you today?"

A Military Family Alexis' Story

Andy and Cindy Johnson

and their children Amanda, Shelbie, and Alexis (idic(15)) live in Wrightstown, New Jersey.



Andy and I have both been in the Air Force for 18 years. In our careers we've had many assignments, been deployed and away from home for trips and for training. I'd like to share with you how our military family lives with our daughter with idic(15). Andy and I met in Tampa, Florida, while we were both assigned to an airborne unit where we jumped out of planes together....in our little minds we thought that we were ready for anything that the world brought our way! Little did we know what was ahead of us....

Five years ago while I was assigned in Philadelphia and Andy was stationed one hour away in New Jersey we found out that I was pregnant and we were thrilled. At that time Andy had orders to Korea for a year tour and I had orders to Germany for a 3 year tour. Shortly after our baby was born the girls and I would move to Germany and he would join us after his tour in Korea. We were all so excited about spending a tour in Germany with our new baby! Andy and I have both been stationed over in Europe when we were younger and we were planning all kinds of traveling in hopes of letting our daughters share the same experiences that we had. I prayed all the time for our family to be blessed with good health and safety until we were all together again in Germany. Alexis Marie Johnson was born 25 April 2002.

Weeks prior to Alexis' six month well baby check up Andy left for his one year tour in Korea leaving me home alone with all three of our daughters. During the appointment her doctor became worried and the appointments with the specialist started. They have never stopped; they've slowed down but

are always there. For over 3 months and many doctor visits I struggled and cried, I was terrified that I was going to lose my baby girl. I had seen so many sick little children at every appointment, I became terrified every time the phone rang, scared that it would be a doctor with bad news.

On my birthday we met with a geneticist at the Children's Hospital of Philadelphia (CHOP) and were given her diagnosis of Isodicentric 15.

I had girl friends go with me to almost all appointments for support because I never knew what type of news I would get. After the geneticist gave me the diagnosis, and took the time to explain the symptoms, my only reaction was to hug the doctor and say thank you. I was hugging her because she told me that what Alexis had was not terminal. I think that the hardest part for me was that my husband was gone and I had no family around. I will always be hurt that none of my family could come out for support during this time; however I'm grateful for my girl friends who helped me along. One downside to being a military family is that we've moved often and never around family.

The Air Force (AF) has always impressed me with how they try to help individuals when possible. Now with my personal experience with Alexis I can verify that in our situation the Air Force has gone out of the way to take care of our family. As soon as

Alexis was diagnosed, the AF sent Andy home at his six month mark in Korea. With her diagnosis, I was scared and wanted nothing but to stay at home with her everyday. I was ready to separate from the military. A few wonderful soldiers, fathers and other mentors sat down with us to discuss our situation and our future in the AF. These soldiers melted my heart with their understanding and sympathy for what we were going through. They agreed to try to help us out as much as possible in hopes that we would both try to stay in a bit longer, at least until we had 20 years in service and were able to retire.

Our military insurance covers everything with Alexis. One benefit we will get upon retirement will be the same insurance. Andy worked nights for a year while he kept Alexis home during the day and attended all of her OT, PT and speech therapies. He did this until her second birthday. I was able to go to all of her appointments and make many of her therapies.

“I can verify that in our situation the Air Force has gone out of the way to take care of our family. “

Our assignment to Germany was immediately cancelled upon her diagnosis because none of us really knew what we faced and what type of medical facilities she would need. Twice since our assignment to Germany was cancelled, we were in a must move situation and had to find other bases to transfer to. Again, with no luck on finding facilities that could care for her, we were able to move around locally and were placed

“We have always felt that we were in a perfect place for Alexis. New Jersey has a lot of support for special needs and we are seen regularly at CHOP and yearly down at Bethesda Naval Hospital. “

in different positions at our current base to remain here. Thankfully, it was agreed upon by many individuals who had an impact on our careers that this location had the best medical and school criteria to meet Alexis' challenges. It has been difficult changing jobs so often, but well worth it as it allows us to give back to the AF as it continues giving to us.

We have always felt that we were in a perfect place for Alexis. New Jersey has a lot of support for special needs and we are seen regularly at CHOP and yearly down at Bethesda Naval Hospital. Alexis attends Burlington County Special Services (BCSS), a special needs school for children that is full day/year round, and attends the McGuire AFB Child Development Center (CDC) for two hours after school each day. The ladies in her room, Sue and Tina, have been outstanding and take such good care of her and the other children. This CDC is a five minute walk from my office and I visit quite regularly. Alexis loves it there and I trust the ladies to take loving care of her. Alexis has remained in the 1-2 year old room and is loved and taken care of by her classmates as well! The ratio of care givers to children changed in her room to allow more one on one time with her.

Sometimes Andy or I have Temporary Duties that take us away from home. Fortunately, we have never had to leave at the same time. As a mother I believe that this has been harder on

me than it has been on Andy. I don't know what was harder for me, the fact that I was physically away from my husband and children or the guilt that I had every minute that I was away. I'm very proud of my husband; he never complained, he just pressed forward and did/does everything he can to take care of the girls.

The United States Air Force has been amazing for our family. My grandfather Carl Peterson retired from the Army, my father Ed Thomas retired from the Air Force, and Andy and I will have served 20 each next year. We are humbled to serve in such a great military and for such a great nation. We are also very blessed to have been taken such good care of while having a special needs daughter. A special thanks to Col. DeGraphenreid, Lt. Col. DiMarco, Chief Daigle, Chief Rener, Chief Ayers and Chief Price as these airmen ensured our family has been taken care of.

Tell us your Story

The MIRROR welcomes the stories, insights, and ideas of all parents and professionals interested in idic(15). We'd also like to hear your suggestions for future articles.

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The 4th Bi-Annual International IDEAS Conference

"SHARING THE JOURNEY"

The Conference Team has been working hard and has a great line-up of events and speakers we know you won't want to miss so mark your calendar and plan to attend! Let's make this our best conference yet as our extended families and supporters from around the world reunite once again in fellowship to share our journeys through life with chromosome 15q duplication syndrome.

Registration Forms, Conference Agenda, etc. will be mailed in January 2007 and will also be available on the web site (www.IDIC15.org)

A block of rooms at special rates has been reserved at the hotel so call now to reserve your room (be sure to mention the IDEAS Conference to get your special rate)

Limited scholarship aid will be available - applications (available on the web site) will be accepted beginning in February. In addition, many states provide funding towards this type of event - contact your appropriate state agency to inquire about this possible source of funding.

We hope to see you next June!!!

IDEAS

is a non profit organization that provides information, education and support to families affected by isodicentric and interstitial duplications of chromosome 15. IDEAS promotes research, awareness and understanding of isodicentric 15 and related disorders.

SAVE THE DATE!



IDEAS IS PROUD TO ANNOUNCE:

The 4th Bi-Annual International IDEAS Conference

"SHARING THE JOURNEY"

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 at the

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Coming Soon...

The new and expanded IDEAS website is set to launch in early December. Check out www.idic15.org for:

- more information about chromosome 15q duplication syndrome
- bulletin boards to share information
- monthly updates on IDEAS developments
- resources for European families