

THE MIRROR

WINTER • 2009

The Newsletter of
IDEAS

IsoDicentric 15

Exchange, Advocacy & Support

FROM OUR EDITOR
FROM OUR EDITOR



IDEAS Encourages You to be a Part of Our Conference

Hop Aboard — It's Almost Time for Full Steam Ahead!

Our 5th International Conference in Indianapolis is fast approaching. IDEAS encourages all families to make an effort to attend this biennial event. We realize that times are very challenging for many of you, and refer you to the Fall issue for possible sources of help with funding. In this Winter issue, in addition to getting wonderful insight into grandparenting a child with dup 15 q, we highlight some of the new and different things that will be taking place at this year's conference.

Read about a much-needed new research study on seizures in dup 15q which will be starting up in the near future. Get up to date on the latest in research on dup 15q and get a hint of what will be discussed at these Thursday sessions at conference. We look forward to our first-ever sessions on nutrition focused specifically on dup 15q syndrome. These Friday plenary sessions will be presented by noted dietitian Elizabeth Strickland.

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.

She provides a preview of what she will discuss in her article in this issue. Check out the playbill for the Friday night premiere of "Slow Children Playing".

Rest assured that we have kept some of the popular "oldies but goodies", like the individual sessions for moms and dads. The entire list of sessions is in the registration brochure, which you should have received in the mail by now if you are in the U.S. If not, it is available online on our website: www.idic15.org. Your session selections may be changed when you arrive at conference, but serve as guidelines for us in assigning appropriate rooms for presentations. Please be sure to fill out your form as completely as you can, and don't forget your meal counts!

We eagerly anticipate everyone coming together in Indianapolis to renew old friendships, begin new ones, and learn how to improve quality of life for our children with dup 15q and those who love them.

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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.

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PREVIEWING THE RESEARCH NEWS AVAILABLE AT THE 2009 CONFERENCE

Dr. Ed Cook and Dr. Carolyn Schanen are members of the IDEAS Professional Advisory Board.

There have been many exciting developments on the research front since we met with families at the 2007 conference. We want to provide you with a preview of the information we will be sharing in the research plenary session, and encourage those of you who have questions to join us at the research Q & A breakout session at the 2009 conference.

AN EMERGING FRAMEWORK FOR THE STUDY OF DUP 15Q SYNDROME

The last two years have seen an increasing scientific interest in chromosome 15q duplication syndrome (dup15q). The interest in dup15q comes from many disciplines, including clinical studies, molecular/cytogenetics, and neurobiology. To help move our research forward, the IDEAS advisors have created a framework with which we can organize and track developing research. We will be presenting this framework more fully at conference, but want to give you a preview of both the framework itself, and the exciting research that is underway.

I. CLINICAL STUDIES

There have been many case studies and some cross sectional behavioral data on individuals affected by dup15q. The new studies of note in the last two years include a comprehensive phenotyping study of individuals with interstitial duplications, conducted by IDEAS Professional Advisory Board member Dr. Larry Reiter. A second new study comes from a team at Boston Children's Hospital which has reported on sleep study abnormalities in two patients with dup15q syndrome. Their findings might help us get closer to understanding why some individuals with dup15q experience a sudden, unexpected death in sleep.

There are also exciting clinical studies coming in 2009. The first is a comprehensive survey on seizures in dup15q which will be carried out through a collaboration between IDEAS, Elwyn and the Pediatric Epilepsy Program at the Massachusetts General Hospital for Children. The second is a collaboration between IDEAS and the Interactive Autism Network (IAN) which will provide an opportunity for IDEAS families to join IAN. IAN will soon have the capacity to identify individuals with dup15q, and it will serve as the long awaited registry for individuals with dup15q.

II MOLECULAR/CYTOGENETIC STUDIES

The most common forms of duplications that have been studied are the classic idic(15) and int dup(15). Over the last two years there has been an explosion in microarray technology, allowing us to identify and study interstitial triplication(15) and other rare variants of dup15q. New microarray technologies, which are detecting a wider spectrum of duplications, have moved into clinical practice. We may be able to start asking questions about the involvement of genes that are not involved in the duplication (but nearby) and discover if they can also be abnormally activated or inactivated by the duplication. Two studies

were done by Dr. Daniel Geschwind (UCLA) and Dr. Jeffrey Gregg (UC Davis) in collaboration with Dr. Schanen, which compared the expression of genes from "white blood cell lines" from cases with idic(15) to chromosomally normal cell lines. These studies revealed that not only were genes that were included in the duplicated region affected, but that a number of other genes found throughout the genome were also differently expressed in individuals with idic(15).

III. NEUROBIOLOGY – FORMATIVE STUDIES


Donations to the Autism Tissue Program over the last two years have provided a resource to explore the neurobiological consequences of dup15q. A team of researchers from the NYS Institute for Basic Research has performed neuropathology exams on several of these brains and is interested in continuing to work on dup15q. The pathology from the existing cases suggests a number of developmental effects from chromosome 15q duplication syndrome. Dr. Ted Brown and his colleagues report the most consistent finding is a reduced size of the brain and smaller size of the nerve cells, with cells in particular areas of the brain being involved (neuronal nuclei in the amygdala, accumbens, entorhinal cortex and Purkinje cells).

Their findings suggest that dup15q may involve a problem in development and maturation of the brain. The developmental abnormalities may mean that the nervous system did not form normally from the beginning. There are some abnormalities seen in cells in a region of the brain involved in learning and memory called the hippocampus. Hippocampal abnormalities can be developmental or seizure related and we do not know the cause of the abnormalities seen in these individuals. One other notable finding was a change in the structure of the mitochondria (needed for producing energy in cells) seen in many regions of the brain. None of these findings directly provide an explanation for the sudden and unexpected deaths, but our understanding of what happens

in the brains of individuals with dup15q has taken a quantum leap forward.

In addition to the neuropathology exams, several researchers, including IDEAS Advisory Board member Dr. Janine LaSalle, are conducting important studies using these tissues. Dr. LaSalle has begun looking at gene expression using these samples and is discovering that the number of copies of gene sequences in the duplicated region does not necessarily equate to expression levels in the brain.

In February, 2008, there was a talk presented by a Japanese research team which has been working on a mouse model for dup15q. Their talk suggested that the mouse model for human 15q11-13 duplication displays autistic behavior. We will be keenly watching the work of this scientific team.

As you can see, research into dup15q is exploding. We are working hard to prioritize and try to coordinate efforts as much as possible. We look forward to sharing a more complete research update with you in Indianapolis, and to the questions and discussions that can take place during the research breakout session. 

New Research Study on Seizures in Dup15q Coming Soon...

IDEAS is excited to announce an upcoming research study of seizures in dup15q. IDEAS is working with Brenda Finucane, Executive Director of Genetic Services at Elwyn, and Dr. Ron Thibert, DO, MsPH, member of the Pediatric Epilepsy Program at the Massachusetts General Hospital for Children and Co-Director of their Angelman Syndrome Clinic, in the development of this study.

In 2003 IDEAS and Elwyn conducted the first survey regarding seizures in chromosome 15q duplication syndrome. While that study provided a helpful preliminary characterization, one of the conclusions was that additional studies are urgently needed to better characterize seizures in dup15q and to study the effectiveness of seizure medications.

A few years ago Dr. Thibert and his colleague developed a comprehensive seizure survey for the Angelman Syndrome Foundation. This survey collected very comprehensive data about seizures and medication in individuals with Angelman Syndrome. Eileen Braun, Executive Director of the Angelman Syndrome Foundation, has generously granted permission for Dr. Thibert to use this research instrument with IDEAS. Not only will this survey help to better characterize seizures in chromosome 15q duplication syndrome, it is also a first ever opportunity to compare the seizures in chromosome 15q duplication syndrome with the seizures in a population affected by maternally derived deletions of chromosome 15q.

This study will be a web-based questionnaire study. This means families will be able to fill out the survey online and there is no treatment involved. The IDEAS professional advisory board has asked that we collect the clinical genetic diagnosis for every child involved in the study so that we can be sure to accurately characterize the seizure profiles of individuals with isodicentric duplications, interstitial duplications, and rare variant forms of chromosome 15q duplication syndrome. Brenda Finucane, IDEAS Co-Founder, has agreed to provide coordination for the collection of genetic diagnoses.

All research studies must be reviewed and approved by an Institutional Review Board (IRB) to ensure that proposed research protects the rights and welfare of research subjects. The study of seizures in Dup15q is currently undergoing IRB review. Once it has passed the review, IDEAS will inform families how to participate through our website, listserv and direct mail.

We are grateful to the Angelman Syndrome Foundation for sharing this survey instrument with us and excited to work with Dr. Thibert and Brenda Finucane on this urgently needed study.

IDEAS Proudly Premieres SLOW CHILDREN PLAYING

A ONE-WOMAN, ONE-ACT PLAY ABOUT
LIFE WITH DUP 15Q SYNDROME

Featuring: Anna-Marie Bushlack
as
Playwright and Actress

Opens Friday, June 26, 2009
Indianapolis, Indiana



To reserve tickets, please indicate how many would like to attend on your conference registration form.

(If possible, please make other arrangements for your young children during this time.)



Nutrition makes a difference

by Elizabeth Strickland

Any child with special health care needs is more prone to nutrition problems compared to a typically developing child; children diagnosed with chromosome 15q duplication syndrome are no exception. Many of the characteristics of dup 15q contribute to nutrition problems, for example:

Growth Retardation – twenty to 30% of children with dup 15q suffer with growth retardation.

Seizure Disorder – drug and nutrient interactions are a potential side effect hindering the absorption of certain nutrients leading to deficiencies. Certain seizure medications can negatively impact calcium, vitamin D, magnesium, vitamin B12, and folic acid.

Hypotonia – low muscle tone can impact the gastrointestinal tract, slowing down bowel movements, resulting in constipation, and often can lead to an impaction of stool in the colon, megacolon, and encopresis. Gastrointestinal problems such as this can create malabsorption of nutrients, and result in further nutrient deficiencies. Unresolved gut problems cause the child discomfort and/or abdominal pain which can exacerbate his behavioral problems. Low muscle tone can also involve the oral cavity resulting in overstuffing of food in the mouth at mealtime and result in other oral/motor feeding problems.

Behavior Challenges – behavior problems especially surrounding mealtime can pose a major challenge to get the child to cooperatively sit down and eat a meal, affecting his overall food intake and nutritional status.

Sensory Processing Disorder – consuming food is a complicated sensory experience using all five senses - smell, sight, sound, touch, and taste. A child with sensory dysfunction may avoid certain foods and have a very limited variety of foods or textures he is willing to consume. Sensory dysfunction can lead to severe feeding problems resulting in nutritional deficiencies.

Attention Deficit Disorder – medical treatment of ADD symptoms with stimulant drugs may result in loss of appetite, poor food intake, nutritional deficiencies, and negatively impact the child's ability to reach their potential genetic height.

Autism Spectrum Disorder – three to 5% of children with ASD are diagnosed with dup 15q. Children with autistic characteristics have their own unique set of common nutrition problems such as gastrointestinal problems, feeding problems, nutritional deficiencies, chemical sensitivities, and food allergies. A large percentage of autistic children appear to benefit from a Gluten Free Casein Free Diet so a three month trial response of a GFCF Diet is usually suggested.

It is critical to look at each dup 15q child individually, determine which nutritional problems are a concern for your child, and resolve each one of them. Identifying and treating nutrition problems is critical because without proper nutrition, your child's body and brain will be deprived of critical nutrients and he will not function at his full potential. You cannot expect your child to fully benefit from his physical therapy, occupational therapy, speech therapy, special education services, and other therapies until his nutritional problems are resolved.

A registered dietitian can assist parents with developing a nutrition care plan that should include the following basic nutrition steps:

1. Clean up the diet (eliminate chemicals and artificial additives)
2. Provide adequate basic nutrients (protein, vitamins, minerals, omega 3 fatty acids, water, and fiber)
3. Select a high quality vitamin and mineral supplement
4. Resolve the child's feeding problem
5. Heal the child's gastrointestinal tract

I will discuss each of these basic nutrition steps in detail at the Fifth International Conference on Isodicentric 15 and Related Disorders on June 27 in Indianapolis. My book, "Eating for Autism ... The 10-Step Nutrition Plan to Help Treat Your Child's Autism, Asperger's, or ADHD" is also an excellent resource for parents to learn how additives, foods, and nutrition affect their child's behavior, mood, and ability to learn and focus. You'll also learn how to heal your child's gut problems and improve his feeding problems.

Elizabeth Strickland, M.S., R.D. L.D. is a registered dietitian and may be contacted via email: ASDpuzzle@aol.com or visit her web site: <http://www.ASDpuzzle.com> This presentation at conference will be sponsored by the Clare True Research Fund. To all of you who so generously contributed to this fund, thank you for making this possible.



Celebrating Michael by Charlie Brady



Our remarkable son Michael was with us from July 9, 1984, until January 12, 2009. He passed suddenly in his sleep but he made quite a mark in his short time on this earth. I would like to share a few things about who Michael was.

He was an Olympic athlete, participating in three Special Olympic competitions.

He was a graduate of Northview High School, where he attended Senior Prom and went with his date in a limo. He was so excited on graduation day he made his mom and me walk across the stage with him when he accepted his diploma.

Michael was an artist. His favorite medium was the crayon. He used yellow for leaves and orange for faces, and colored in both a realistic style and an abstract style.

Michael was a film critic. He was not fond of movies using real people; he favored animation. Some days he had to watch the same movie many times in a row to make sure they did not make any changes he did not approve of.

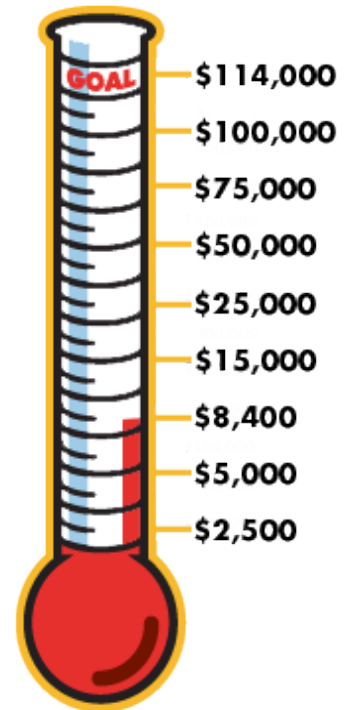
Michael was not the best at remembering a person's name after meeting them for the first time but, upon seeing them again, he would tell you it was the lady with the green shirt. Of course the lady would not be wearing a green shirt then, but she had been the first time he met her. That was how he remembered new faces and friends—by the color, style, and specific items they were wearing.

Michael was a bookworm. He was not very big on all those words, but he did love the illustrations. He would set his alarm after his mom put him to bed and quietly stay awake looking at books for hours.

Probably a teacher is the most important thing **Michael was.** He showed us what pure joy and happiness are and what giving 100% means. He showed us the true meaning of patience and that forgiveness is a way of being. He showed us that doctors are human and do not always have the right answer, procedure or pill, but that it is OK not to always have an answer. Michael showed us that a person is who they are on the inside, not what they look like on the outside. Michael showed us to live in the moment because it is where all the fun is happening; he showed us that moms and dads are the most important people in everyone's life; and Michael taught us that every day is a blessing and to never take it for granted.

2009 FUNDRAISING

You can help IDEAS reach its fund-raising goal for 2009. See our web-site for suggestions. Let's head into our conference year financially strong!



HOW CAN I HELP SUPPORT IDEAS ?

There are many ways you can help support IDEAS. Learn more — go to: http://idic15.org/ideas_supportingideas.php

Growing up with Christopher

by Gabriele O' Connor

Christopher just turned 17 years old and sometimes I find it hard to remember what teenagers are usually like at that age. I remember how mature and worldly I felt at 17, going to bars with friends in Portugal (where the drinking age is 16) and piercing my nose. Sometimes, rather than thinking about what a sweet kid my younger brother is, I'm saddened by the thought of all that he's missing or won't experience, as with these silly rites of passage.

Christopher was born to my diplomat father, Chris, and music teacher mother, Mari, in Santiago, Chile, when I was six years old and my sister three. All was well until, at six months old, he contracted pneumonia and we were medically evacuated to our grandparents' house in Minnesota so Christopher could be brought to the Mayo Clinic. Our next posting was due to be Bogota, Colombia, but at eleven months old he was diagnosed with seizures and two months later with idic 15. It was determined that we remain in America for the next few years for the better healthcare and cleaner cities, and our diplomatic postings since then have, probably happily, been shaped by this diktat.

Over the years it became apparent that Christopher would never mentally progress beyond the age of an 18-month-old. People's rudeness when they stared at him always appalled and embarrassed me, though it later turned into a fierce protectiveness (and still later into a nonchalance - maybe it doesn't happen anymore or maybe I just don't notice). The crassness and superficiality of some people made me more aware of how great he actually was. He's obviously inherited my mother's singing voice and musical aptitude, because it's astonishing how large his capacity is for remembering songs. There's nothing he loves more than to sing and strum along with my mother as she plays her guitar. Over the years my sister and I learned that this was the way to bond with Christopher - she with the piano and me with my violin.



It's hard sometimes, the older he gets. While small for his age, he's still surpassed me in strength, which makes it difficult to babysit him sometimes. He occasionally gets into wicked moods in which he likes to pinch or pull the hair of those he least respects (i.e. me) and my mother's the only one able to calm him down. You see flashes of the mischievous teenager now and then, but most of the time he's the most wonderfully sweet kid who just loves to be read Mercer Mayer books.

Moving from country to country (nine in my lifetime so far) is as difficult as you might imagine but with the added element of Christopher, becomes exponentially so. We're luckier than some because the U.S. government is so good to its Foreign Service employees, and this enables us to have a live-in carer for Christopher and to have the right house chosen and safety-proofed for us. But with a condition as rare as idic 15, it's easy to feel somewhat isolated. One of the most valuable experiences for me, as Christopher's sister, has been meeting the O'Farrell's here in Ireland. A wonderful family, their daughter Ruth is the first idic 15 child, aside from my brother, I have met and, while higher-functioning, their similarities are striking. It's been invaluable in understanding Christopher and the condition more completely, and provided insight into a lifelong desire of mine to know what Christopher would say if he were higher-functioning.

Life is complicated with Christopher but, at the same time, wonderfully uncomplicated. In a lifestyle that's characterized by continual changes and mutable circumstances, he's the one constant in all of it - the often exhausting but very special nucleus of our family.

WINTER MAY BE FADING...



but Emma D. squeezes the last few flakes of fun from winter on a family weekend outing to Saddleback, Maine. Emma's Mom Paula said, "Emma's favorite parts of skiing were "doing it by herself!!!", the ride on the ski lift, and wearing the ski boots. When we got back into the lodge, she wouldn't take the boots off, she just wanted to walk around in them. In Emma's attempts to "do it by herself", she only skied into a tree ONCE. I thought that was pretty good. After she hit the tree (a small soft pine tree), she looked up at her Dad and said "it's okay Dad, I'm fine". It was actually quite cute."



Share your pride and show off your state or country by donating a raffle basket with items that represent where you live. When you solicit and receive raffle donations you help put a smile on someone's face and assist IDEAS in keeping the conference fees down! Check out our website for a current listing of what we have or contact cynthiaj100@verizon.net. A solicitation letter is available upon request.

Reflections from the Listerve

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

Reflections

IDEAS has recently become aware of the need to reassess our means of internal communication via listserves. Issues such as security, feature availability, and ease of use have arisen due both to the growth of IDEAS as a group and the growth of traffic on the internet in general.



The IDEAS Board is evaluating a new online community called BigTent which, if selected, may replace many of the functions currently provided by the yahoo group. IDEAS members are encouraged to explore and give feedback on the IDEAS BigTent group.

BigTent offers all of the same functionality as the Yahoo group plus has these additional features:

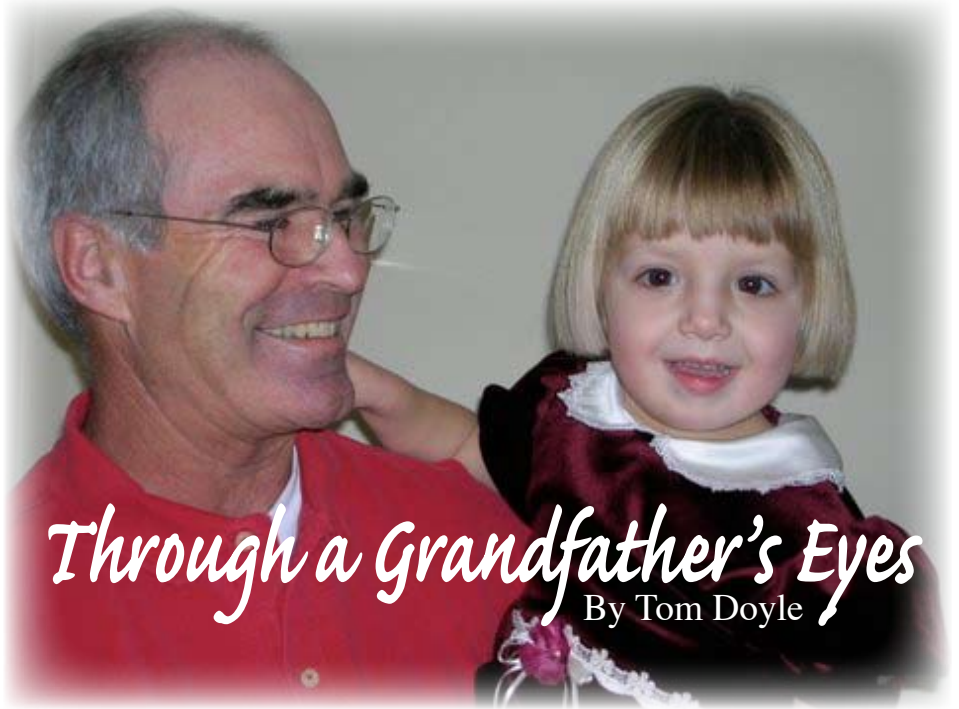
- Calendar
- Photo Sharing
- Event RSVP
- Event Location Google Map
- Group-Only Classified Listing (Like A Private Craig's List)
- Group News
- Sub-Groups
- Auto-Updated Group Roster
- Ability To Manage Multiple Group Events And Communication In One Integrated View
- Personal Settings/Journals/Photos
- Security That Prevents Group Messages/Data From Appearing In Web Searches

The capability exists to move our archives from the yahoo listserve to BigTent, so all our valuable years of history and information sharing on such topics as medications, etc., could be preserved. Big Tent can also sit behind the main IDEAS website directing members to see what is new at IDEAS.

To explore the IDEAS BigTent group go to www.bigtent.com/groups/dup15q and request to join the group. After completing the registration form you can customize your settings allowing you to personalize the way you receive information. Once you explore and experience the IDEAS BigTent online community, please provide feedback to the Board. You can contact Rachel Douchette at doucette.rachel@gmail.com with any questions about the BigTent group.

Today I hope to be able to offer some insight as a grandparent of a beautiful child with dup15q syndrome.

Whether you are a grandparent, an uncle or aunt, family friend, or some other relationship, you have the ability to make a difference in the life of one of our IDEAS children. By being involved in their lives, you bring joy and strength that holds tremendous rewards for the child, for his/her parents, and for yourself.



Through a Grandfather's Eyes

By Tom Doyle

Our story is about Grace, born in 2003 with dup15q syndrome. Grace was the third child born to Jeff & Colleen (our daughter) Lowell. We remember the joy of holding Grace and dreaming about all the possibilities. We also remember the anxiety that we each felt, and kept to ourselves, about something being “not just quite right”. It took some time and some courage before my wife Marilyn and I verbalized our concerns and realized we all had the same thoughts. We discovered that Colleen and Jeff were also agonizing over Grace’s lack of eye contact and interest in human touch. We didn’t want to believe that what we were watching was really seizure activity – we explained it away, assigning it to other issues. We debated the low muscle tone that we were experiencing. I am not sure “it takes a village” to raise children, but I do know that it sure helps to have grandparents and others like them around. Our experience of raising children helped us to recognize there were some problems, talk about them, provide moral support, babysit as needed, drive to doctors’ appointments, and lend a hand in whatever way was necessary.

As a grandparent, how can I help Grace’s parents? I believe we provide Colleen and Jeff with a great resource. They can bounce things off us whenever they need to. Their instincts are great, but it is just nice sometimes to have someone who is available to listen and ask questions. Most often when we talk with them about Grace, they have great ideas on how to work with her and help her to develop to her greatest potential. But they have doubts and, sometimes, just need a little reassurance. We often ask clarifying questions which help them to confirm their instincts are accurate. We will offer suggestions of other possible alternatives of approaching issues if asked. We make ourselves

“After her initial diagnosis, I spent a lot of time trying to figure out how I might “fix “ things for her and change her life. What I found out is that She changed me!”

available for taking the kids for an hour, a day, or over night when needed. I love participating in the doctors’ appointments, both because Grace and I have a great relationship and because I get more insight into what she is dealing with by being there. I imagine our experience doesn’t work for everyone, but Colleen and Jeff and both sets of grandparents feel that the more we know, the more we can help.

How can I, as a grandparent, have some impact in Grace’s life? I might be one of the luckiest people in the world because Grace and I are bosom buddies. Grace’s sisters have learned that I love them very much and would like to spend more time with them, but when Grace is around she is literally “all over me”. We learned early on that the autism related to dup15q means that whenever we can make a connection with Grace, we need to take advantage of that moment. So I sit on the floor with Grace and

we interact in every way possible. I spend most of my time mimicking everything that she does, then trying to get her to react to my response to her. We make everything into a game and most things into a song. I have lost most of my inhibitions when I am with Grace. I would never be seen in public singing or dancing, crawling on the floor, and so many other things until I discovered how much she needed that. Now, I don't want to make you think I am totally crazy, but I no longer care whether I look like a fool to some stranger watching me interact with Grace at the mall. Grace needs that, so I do it. She crawls all over me and pulls my ears, takes off my glasses, kisses me, and most importantly looks me in the eye!

What does being a grandparent to Grace do for me? I remember jogging one morning after we had heard about the diagnosis of dup15q. I agonized over the diagnosis and how it would affect the family, Grace, and me. How would I explain this to my friends? How do I explain to that stranger who acts disapproving of Grace's behavior? How would I explain that Grace wasn't "normal"? I had no idea what to do with those thoughts till I had the funny sensation that I was being given an answer – "Grace will be OK; she'll do just fine." To this day, I don't know if a voice spoke that to me while I was running or my brain just figured out that it didn't really matter. Grace was all that mattered, not how I felt about it or how some outside observer felt. Grace would be OK; she would be the best she could be; we would compare her with her "best self", not with other children or other's ideas. Suddenly, things were so much clearer. My role was to help Grace grow into the beautiful person she is meant to be – whatever that looks like. Grace has the ability to change the world. By changing me and her other grandparents, her siblings, her parents, her uncles and

aunts, and all those who come in contact with her, she does make the world a better place. Before Grace, I had no idea what it was like to interact with a "special needs" child. Now, where I used to not be aware of their presence, I see them everywhere I go. There is a special place in my heart for these "differently-abled" children. My world is different because of Grace.

As a grandparent, I want to be able to help with my presence, my insights, my love, and my finances. I want to know more about dup15q and what is in store for Grace. I want to know what can be done to help all those with this chromosome duplication issue to lead better lives. I want to be involved and know how I can make a difference. I want Grace's parents to let me be a part of her life, to keep me informed as to what is going on medically and educationally in her life. I appreciate the IDEAS website and newsletter because it provides me with information, insight, and inspiration. I envisioned that the IDEAS title must remind grandparents that what our children and grandchildren need are:

I — interdependence...they need us to be involved because sometimes life with their "Graces" is overwhelming. They need a shoulder to cry on, a voice of reason to talk to, or a person just to give them a break for an hour or a night.

D — dedication...there is nothing more powerful than the model of love and duty that a parent of a "special needs" kid provides for the rest of us. We need to support that by being there for them. All the statistics and studies point to how difficult it is for a couple to stay together when there is a crisis in their lives. That is when they especially need we grandparents to stand by them, encourage them, love them, push

them to keep some focus on their relationship as well as the "Grace" in their lives.

E — energy...it takes so much energy everyday to deal with our dup15q kids. The demands of time and commitment are amazing. Every now and then, it is wonderful when we grandparents can step in and give them a break.

A — attachment/affection...especially since autism seems to be one of the side effects of dup15q syndrome, it is critical that we work with our "Graces" to help them to have meaningful human contact with more people. Moms and Dads and brothers and sisters make a huge difference in this area. But grandparents and other relatives and friends can help broaden the child's perspective by developing strong personal attachments with them

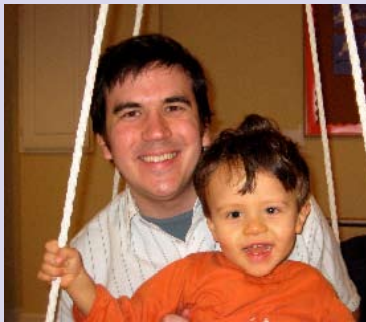
S — service...as we grandparents age and find we have more time, we find that we want to find ways to "give back". Helping our children and grandchildren deal with the difficulties in their lives that result from dup15q is really an awesome way to make a real difference in the world.

I taught for 30 years before "retiring". When I started teaching, I hoped to change the world. It wasn't long before I realized that wasn't going to happen. I realized the only person I could change was myself. And if I did that, it might make a difference in the world. So I continue to grow, to learn, and to marvel especially where Grace is involved. She fascinates me every time I am with her. She enjoys such little, simple pleasures. She gets joy out of things that others would label as "goofy". She learns in her own way and amazes me with what she says or

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Cheers to our Volunteers

Much goes on behind the scene to make our international conferences possible. IDEAS has friends who help in many ways sharing their talents and skills. Sometimes these people don't even attend the conference so we don't get to meet them face to face and thank them. This quarter we shine the spotlight on three hard-working volunteers who prepared our registration materials and conference logo.



Greg Stein with his nephew J.P. (idic15)

Greg Stein is the uncle of J. P. Peters. He designed the logo for "Full Steam Ahead" which will appear on our conference t-shirts and all conference materials.

Jodi Miller diligently coordinated all the information for the registration brochure, entered the data, and worked with the layout person to make sure it all looked professional and was accurate. Jodi is the mother of Jake (idic15) and Sarah, and chaired the conference in 2005 in Chicago.



Danielle Wagner is a friend of the Miller family and graciously agreed to do the layout for the registration brochure. Danielle also helped greatly with the Chicago conference. Both Jodi and Danielle are former IDEAS board members.



Three cheers for three very dedicated volunteers. Because of friends like you we are able to present wonderful conferences for our families.

Through a Grandfather's Eyes, continued from page 9

does on a daily basis. After her initial diagnosis, I spent a lot of time trying to figure out how I might "fix" things for her and change her life. What I found out was that she changed me!

I hope that you have the opportunity that I have, to be involved in the life of the "Grace" of your family. I hope that you can provide support for your children as they parent a child with dup15q. I hope that you can find time to spend with the "Grace" in your life so that you can expand her horizon and make her laugh and maybe even look you in the eye. I hope that you can experience the change that your "Grace's" love will bring to your life.



We are collecting pictures for the Smile CD which will be shown at the conference. Please choose one picture of your child and send it to Heather at rhbruce@yahoo.com. Even if you won't be able to attend the conference this year, we would love to have a photo to include in the slide show. Please include the following information: child's name, age and state or country in which you live. We will only be able to use one picture per family.

Editor's Note...

With IDEAS' recent rapid growth there is more demand than ever for support. There is a huge need for more Parent Match mentors. IDEAS will train you! To help with the Parent Match Program contact Kadi Luchsinger at 888-64-IDEAS or email info@idic15.org.

SAVE THESE DATES!

If you are in the New Jersey area, mark your calendars for **Sat. July 25th** and come barbecue and swim with the Johnson family. If you think you can make it, RSVP to cynthiaj100@verizon.net or call her at 609-723-7731.

Also another New Jersey event will take place on **August 14th at 1 PM**. The Second Annual IDEAS Golf Outing will cost \$100 to play and eat. If you wish to just take part in the Italian Buffet, the cost will be \$30. Watch for more details to come!

The 4th annual IDIC 15 5K Run/Walk will be held Sunday, **Sept 20, in Killington, VT**. For more details of the race go to www.idic15race.com.

IDEAS is in need of items for the raffle at conference. In particular, we would like to have baskets from different states. We will also be looking for people who can obtain sponsors for the conference on the business level \$500-\$5000 and also for individual session sponsors in the \$100-\$200 range. Also remember company matching programs and to check out the IDEAS store on our website

CHECK OUT

WHAT'S NEW...



IDEAS store



Winter Birthdays

Jeremy K.	01/01/89	Matthias W.	02/09/00
Joseph B.	01/02/84	Lily T.	02/11/03
Khalid E.	01/03/95	Robin R.	02/13/85
Naomi G.	01/05/71	Nicholas D.	02/14/05
Shane R.	01/07/00	Thomas Q.	02/15/00
Frederique D.	01/08/92	Callum S.	02/15/03
Ethan L.	01/08/01	Noah H.	02/16/99
Sarah G.	01/09/90	Johnathan P.	02/16/99
Chris O.	01/09/92	Johanna C.	02/17/82
Mason B.	01/12/96	Tristan W.	02/17/98
Angela B.	01/13/94	Ben I.	02/20/85
Emily S.	01/14/03	Hailey M.	02/21/06
Pavel G.	01/17/91	Connor L.	02/22/94
Genevieve M.	01/17/91	Morgan T.	02/22/05
Nathan L.	01/18/02	Christian K.	02/23/94
Ryan O.	01/21/04	Aidan L.	02/23/04
Sarah B.	01/24/94	Ivy Rose O.	02/23/06
Alexa and Matthew V.	01/25/87	Marvie C.	02/25/97
Nicholas L.	01/25/89	Stuart H.	02/25/99
Jonah H.	01/25/07	Brendan B.	02/27/06
Kian S.	01/26/94	Kathryn G.	02/28/93
Matthew B.	01/26/89	Raphael G.	02/28/06
Katy B.	01/27/98	Payton F.	02/29/00
Ryan M.	01/27/86	Allison G.	03/01/97
Avery S.	01/31/04	Dylan M.	03/01/94
Alyscia D.	02/01/82	Fabio C-R.	03/01/93
Elleni P.	02/01/03	Aina N.	03/01/06
Andrew K.	02/02/02	Kameron R.	03/02/04
Eli G.	02/02/04	Jacob C.	03/03/03
Emma G.	02/02/05	Lis R.	03/06/98
Jacob F.	02/03/98	Samuel R.	03/08/83
Riley M.	02/04/04	Shawn K.	03/09/93
Ryan T.	02/07/02	Rylei M.x	03/09/07
Nathan H.	02/08/85	Laura C.	03/12/04
Nicolas S.	02/08/04	Benjamin R. W.	03/13/98
Joshua B.	02/09/76	Kathryn B.	03/14/00
Abby E.	02/09/90	Christopher S.	03/14/96
Kiersten P.	02/09/95	Patience V.	03/15/99
Emma D.	02/09/99	Gabrielle G.	03/15/02
		Jacob L.x	03/16/00
		Michael H.	03/17/80
		Jacob G.x	03/19/99
		Christina M.	03/20/85
		Megan S.	03/20/08
		Joey G.	03/21/88
		Joshua R.	03/21/96
		Jason K.	03/23/90
		Dylan K.	03/25/03
		Jon B.	03/26/07
		Katherine C.	03/29/97
		Cody K.	03/31/99



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.



IDEAS International Conference in
 Indianapolis, Indiana,
 June 25 – 27, 2009.
 Please join us!

IDEAS

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