

THE MIRROR

SUMMER • 2009

The Newsletter of
IDEAS

IsoDicentric 15

Exchange, Advocacy & Support

FROM OUR EDITOR
KOW ONK EDITOR

CONFERENCE WRAP-UP

by Jane True, Editor



Those of you who were in Indianapolis for Full Steam Ahead know what a rousing success it was. For those of you who were unable to be there, you can get a sense of what went on from this issue. Heather and Ron Bruce, our conference chairs, did a fantastic job of planning. From the moment of arrival at the hotel it was obvious that this experience would be special. The hotel itself was located in the actual working train station for the city, so that was fun for the children. Some of the rooms were even refurbished train cars.

The opening dinner was quite spirited thanks to a spectacular auction and raffle organized by Cindy Johnson. There was something for everyone to bid on and win, and more than one thing for many of us! A petting zoo was brought into the dining area, much to the delight of the children. They were quite excited to pet and perhaps even help to hold a large boa constrictor, and for those who weren't into reptiles there were also soft bunnies.

The Research Round Table was exceptionally well-attended this year. Read details of what was presented inside this issue. There is so much exciting research going on that it was decided IDEAS would sponsor this Round Table every year instead of every other year. One announcement of note was the creation of and arrival in this country of a genetically-engineered dup15q mouse. This will greatly expedite research in areas of interest and relevance to our IDEAS families.

Many interesting sessions were held, including a well-received presentation on Nutrition. Read a summary of the session in this issue. And learn about the experiences of several people attending the conference for the first time in their article, "First Impressions". A number of families made the effort to attend from abroad—how nice to see them again or meet them for the first time! It was especially gratifying to see so many extended family members in attendance. There were enough grandparents present to merit having their own session this year! Rumor has it that this group is creating its own space on BigTent.

As our group grows, so does our board. The board recently altered the bylaws to expand the board to twelve seats in order to better handle the ever-increasing work load that comes with growth. We now have a full working board as we welcome Karen Sales as our twelfth board member. Even though the conference is over, it is still "Full Steam Ahead" for IDEAS as we serve our families.

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 Jim 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.

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Research Into Dup15q Increases in Scope and Complexity



Nicole Cleary is the chair of the IDEAS Board. She works closely with the IDEAS professional advisory board to convene roundtable meetings of researchers working on chromosome 15q duplication syndrome as part of every IDEAS conference. She provided the following recap of the 2009 IDEAS research roundtable.

Dr. Carolyn Schanen, MD, PhD led off the roundtable meeting with an overview of the state of research into chromosome 15q duplication syndrome. She noted that a variety of disciplines are being used to approach the questions regarding dup15q syndrome. **Clinical studies** explore the full spectrum of physical, medical, and behavioral effects of the various forms of duplications. **Neurobiological studies** are examining the effects of dup15q on the brains of affected individuals. **Molecular/Cytogenetic studies** seek to determine whether the type/size of duplications correlates with symptoms. These studies are also exploring whether genes that are not involved in the duplication, but are located next to them, are also dysregulated. The amount of information coming out of these multiple research approaches is accelerating and helping scientists understand how incredibly complex and involved dup15q is.

On the clinical front, we heard about a study of sleep disorders in dup15q, a small scale comprehensive study of interstitial duplications of 15q, and an upcoming study into the seizures associated with dup15q.

Dr. Sanjeev V. Kothare, MD, DCH, FAAP, FAASM sent information regarding children with dup15q who had been evaluated at the Center For Pediatric Sleep Disorders at Children's Hospital in Boston. He noted that night time seizures can trigger a central apnea, and these central apneas can happen at the end of a seizure. Two of their patients with dup15q syndrome and generalized tonic seizures experienced central apneas during their sleep study. These findings underscore the physician advisory's recommendation that an **overnight sleep study** with monitoring of respirations, pulse oximetry and EKG (done as part of a sleep study or polysomnography) should be considered for individuals with dup15q.

Dr. Ron Thibert, DO, MsPH shared information about his upcoming clinical study on seizures in 15q duplication syndrome. The goal of this study is to gather epidemiological data regarding the presence,

frequency, severity, and progression over time of seizures in individuals with chromosome 15q duplications. IDEAS families should have received a mailing inviting them to participate in this study. We are hoping all families will participate, regardless of whether their child is currently experiencing seizures or not.

Dr. Larry Reiter, PhD shared information from his interstitial dup15q clinical study and the related work from fly and animal models that his lab is involved in. He shared exciting news about the development of a new **mouse model for chromosome 15q duplication syndrome**. His lab was lucky enough to get these mice, which are essentially the mouse equivalent to an interstitial duplication on 15q, before they were even published. The mice are breeding nicely now and he expects to begin some molecular studies on protein expression change in the brain soon.

“Our goal is to use these mice to determine the behavioral and molecular effects of 15q duplication. We are also hoping to be able to separate the effects related to duplication of the gene UBE3A from duplication of the other genes on 15q like the GABA receptors. My lab is working with Ed Weeber at the University of South Florida now to construct a mouse that just over-expresses UBE3A in certain regions of the brain. Together these two mouse models will accelerate our understanding of which genes in the duplicated region result in which behavioral characteristics and also help us to understand the underlying molecular and neuronal changes that cause these behavioral characteristics.”

Dr. Ted Brown, MD, PhD presented the neurobiology findings from brains that were donated by IDEAS families to the Autism Tissue Program.

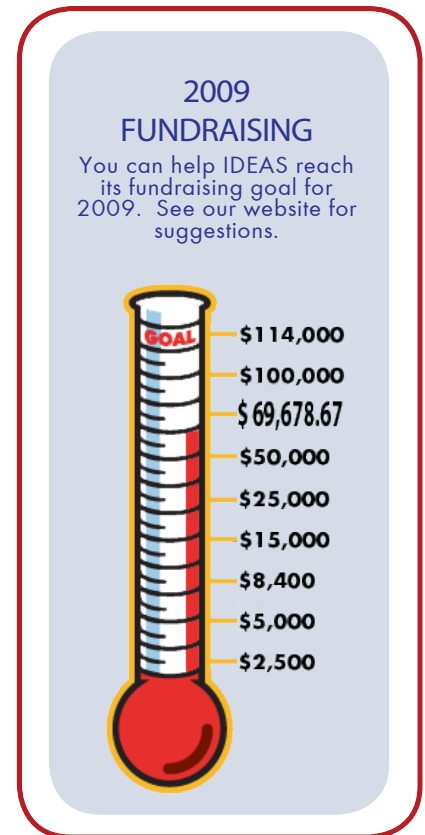
The neuropathological study of the brains of four individuals with chromosome 15 duplication syndrome showed significant developmental changes. Detailed studies revealed clues to both the developmental problems and epilepsy experienced by these individuals. The most notable findings include reduced brain weights, “Microdysgenesis” and/or disorganization of cells in many regions of the brain, hippocampal abnormalities and mitochondrial abnormalities. A reduced volume of neurons and neuronal nuclei was noted in the striatum, amygdala, entorhinal cortex and Purkinje cells. In individuals with chromosome 15q duplication syndrome, reduced size of the brain and delayed growth of neurons appears to be the main contributor to developmental deficits.

On the molecular level, we heard about the quickly advancing rate of discovery among researchers trying to decode the causes of autism by testing molecular pathways deficient in dup15q and other genetic disorders.

Dr. Janine LaSalle, PhD presented information from her molecular research into the overlap of several autism spectrum disorders, including Rett Syndrome and the syndromes associated with chromosome 15q11-13. Although maternal duplications of 15q11.2-q13 are the most common cytogenetic cause of autism, not all individuals with duplications have classic autism, so understanding the molecular basis of the clinical differences is important. Dr. LaSalle is particularly interested in the structure and orientation of DNA copy number variations on chromosome 15q. Her research suggests that it is these copy number variations combined with additional genetic or environmental influences that impact the clinical differences and outcomes seen in the 15q11-13 duplication syndromes. She noted that there has been a rash of discoveries of smaller copy number variations in the last year for not only autism, but also epilepsy. These discoveries help further our understanding of how duplications of chromosome 15q

cause the developmental problems in this syndrome.

Looking towards the future, all attendees agreed that the rate of discovery and number of scientists becoming interested in dup15q syndrome warrants increasing the frequency of research roundtable meetings. The IDEAS board committed to organizing annual meetings. Brenda Finucane offered Elwyn as a potential host site for a one day meeting in 2010 immediately before the annual International Meeting for Autism Research which will be held in Philadelphia. We will continue to keep families apprised of new research developments through the IDEAS website and MIRROR.



How Can I Help Support IDEAS ?

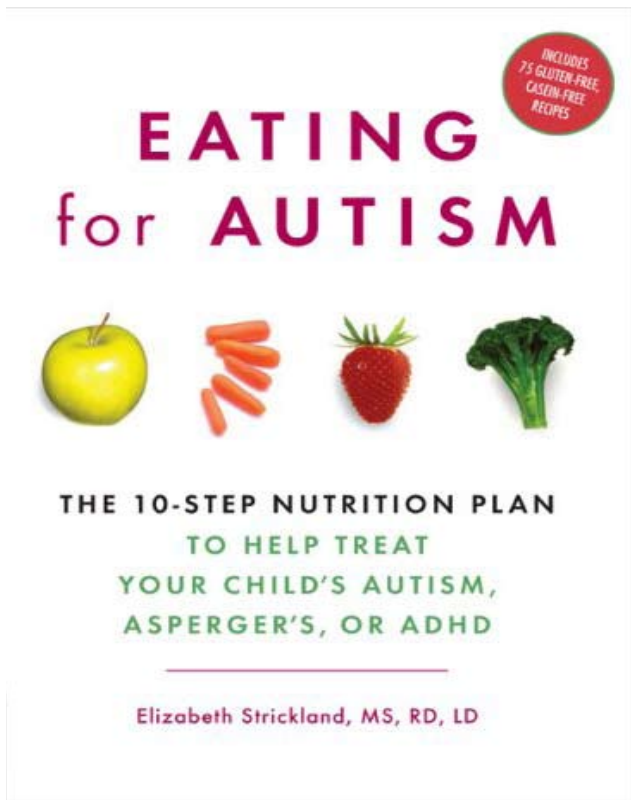
There are many ways you can help support IDEAS. Learn more – go to: http://idic15.org/ideas_supportingideas.php

The IDEAS Seizure Survey is Now Online

You should have received an invitation by mail to participate in the IDEAS seizure survey. We hope all families will participate! If you did not receive the survey materials or need a second copy, please contact Nicole Cleary at nicleary503@comcast.net

The Autism Tissue Program makes post-mortem brain tissue available to as many qualified scientists as possible to advance autism research. Using brain tissue, scientists can go far beyond the constraints of other technologies and study autism on both a cellular and molecular level.

- Brain recovery can be arranged with a call to 877-333-0999
- Call within 24 hours of death
- If you are registered as an organ donor, that does not automatically mean that brain donation will occur; please consider registering your intention at <http://www.autismtissueprogram.org> and/or use the site to obtain a donor card.
- Brain recovery is arranged locally and the brain transferred to Harvard Brain Tissue Resource Center



SUMMARY

of the Nutrition Session at Conference

by Jean House

Elizabeth Strickland wrote the book on nutrition for children with special needs. In *Eating for Autism*, she explains how to remove unhealthy foods and toxins while adding essential nutrients to children's diets. Strickland, a registered dietitian specializing in nutrition therapy for autism spectrum disorders, spoke at the Full Steam Ahead Conference in Indianapolis about the particular dietary concerns of people with dup(15)q syndrome. Working on mealtime behavior and involving your child's team are two keys to improving nutrition.

Tackling Behavior Problems

First, Strickland recommends gradually clearing foods that contain artificial colors and flavors, preservatives, trans fats, and sugar substitutes from the diet, as well as cutting back as much as possible on refined sugars. Once junk food has been removed and a plan has been made for adding nutritious replacements to the diet, parents are faced with the task of actually feeding their child. That can be easier said than done if you have a problem feeder.

Strickland detailed the difference between problem feeders and picky eaters. Picky eaters use mealtime to practice control of their family and caretakers. For instance, a child might refuse certain foods or even entire meals. Her behavior isn't related to the food so much as the control she can wield by not eating, though. Generally, if parents and caretakers refrain from overreacting to a typically developing kid's refusal to eat, she will come around. Problem feeders, on the other hand,

suffer from severe meltdowns at mealtime and ongoing refusal to eat. A host of reasons, such as sensory processing disorder (SPD) or gastrointestinal (GI) sensitivity, may cause or contribute to behavior issues. A child with sensory issues can easily become over-stimulated at mealtime: The odor, taste, feel, and even sight of food can be too much to handle. And if a child has GI tract issues, such as reflux, diarrhea, or constipation, food leads to pain.

Strickland described one child who had such an aversion to a particular food that she would throw herself on the floor, screaming and crying, if she simply caught a glimpse of it. This wasn't a mere tantrum; testing demonstrated that she suffered from severe, painful reflux, so naturally, she associated the food with suffering. Unlike picky eaters, problem feeders like this need feeding therapy, and even after a physical problem has been addressed and resolved, the psychological trauma left by the offending food may need to be addressed.

Finding foods that are both tolerable and healthy for our children can be especially challenging if their choices are already limited due to GI pain, allergies, or special diets, such as the gluten-free, casein-free diet. And food rejection, compounded by an already strict diet, grows even more frustrating when we get bad counsel from well-meaning friends or family. We've all heard this advice about kids who refuse food: "They'll eat when they're hungry." The adage might be fine for typically developing kids, but it's not fine for our children.

In fact, simply waiting it out with special needs kids could be dangerous. If a child already is a problem eater with a limited diet, and a vitamin or mineral deficiency has resulted, that deficiency could affect appetite. Zinc deficiencies in particular can have an impact on appetite. Zinc is a crucial part of the complex chemical reactions by which the body signals hunger to the brain and the brain recognizes that hunger. Our kids' bodies can

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FIRST IMPRESSIONS

our first conference...

Three new IDEAS members share their experiences, thoughts and emotions about attending the conference for the first time.

My husband, Nick, and I landed in Indianapolis late Wednesday, the night before the conference began. We were curious to see another child with dup15q syndrome. At the airport, we were already looking for families with children. Once we got to the Crowne Plaza Hotel and were waiting in line to check in, we saw a grandmother holding the hand of a little boy who was hanging down and lying on the floor. Nick and I looked at each other and knew

right away that he had dup15q syndrome because our son, Nicholas, does the same thing. We smiled and giggled. I knew that this would be a great experience, and I already felt comfortable. We would finally be surrounded by people who understood our situation.

On Thursday morning, my husband and I walked around the hotel, hoping to see other families and children. At 8:00 am we went to register. The ladies at the registration table were very friendly. They handed us name tags and a bag that had a binder in it. This binder included the conference schedule and information about each session. Everything was very well organized.

We decided to go to the new family reception to meet other parents who were experiencing this for their first time too. Nick and I started to mingle

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I remember someone warning me that the second day of the IDEAS conference would be the hardest but the most rewarding. And while there were so many moments during the conference that touched my heart, the second day stands out the most to me. It made me take a hard look at myself and what I do with my child.

The women's session opened my heart during that second day. It was amazing to be surrounded by so many women who fully understood what I was going through. Although I couldn't bring myself to speak of my truth, it was wonderful to listen and just to be surrounded by others who get it. It surprised me how quickly the group opened to one another to share their fears and hopes, to laugh and cry. The group seemed like old friends baring their souls to one another, yet many of us had never met. I've never been around such an amazing group of women. It was a soul-soothing experience for me and something I will never forget.

Another message that came through loud and clear is to take care of

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Our first conference was exciting and emotional. I was also nervous to meet friends I had spoken to on the phone but hadn't seen in person yet. We first met Riley in the lobby of the hotel. She and my son, Brendan, stared at one another as if they had met before. Then we began talking to her parents, so excited to see each other. Everyone was friendly and kind —just as if we have known them forever, just like family.

Sometimes my husband and I went to the same classes and sometimes we went to different ones; afterward we would talk about what we had learned. We were often very tired, yet anxious to learn more. We were so amazed by the information presented at the classes, but more than anything we loved connecting with other parents.

—Ember Burke, mother of Brendan, age 3, idic(15)

Reflections from a Sibling



My name is Holly. I am 11 years old. My sister, Anna, was diagnosed with Idodicentric 15 when she was 7 months old. She is 9 years old now.

Anna !

It is not easy having a sister with Idic15. She often wrecks our rooms by emptying our drawers and throwing stuff off our shelves. Right now she has gotten into going into any room that is not locked and making a mess. It makes me upset when I have to clean up a mess that I didn't make.

My other sister, Ellie, and I are home schooled but Anna goes to school. Every day when she gets on the school bus we can leave the doors open without worry, but when she gets off it is a scramble to lock all the doors again. It is hard having a sister with idic15. Sometimes when we forget to lock the bathroom door, she will get in the bath and turn on the water, then she is a big soppy mess of water. Usually Anna heads straight upstairs towards the bathroom door when she gets home from school.

It is fun, though, when Anna laughs when we tickle her. It's fun to jump on the trampoline with her. She lies on her stomach while Ellie and I bounce her really high and she laughs hard. She likes to get up and jump, too. Anna likes for me to read books to her. Her favorite is *Goodnight Moon*. She sits in the recliner with me while I read.

I'm glad that Anna is my sister. It is hard having a sister like Anna but I still love her.

Nutrition Session

continued from page 4

get hungry while their brains never receive and decode the message, so waiting just won't work.

Involving the Team

Working on behavior begins at home but can extend to the classroom. When formulating your child's individual education plan (IEP), consider how you can include proper nutrition and mealtime behavior in the plan. For instance, the IEP might include "My child will learn to eat age-appropriate foods." Or you might request that your child be taught to sit in a chair—necessary for eating and joining in mealtime with family. Teachers can reinforce skills such as sitting with a reward—but not with food.

If sweets are used as a reward for sitting in a chair for two minutes straight, for example, the resulting sugar rush may cause the child to

Strickland cautions against using food as a reward in therapeutic and educational settings because doing so can actually be counterproductive.

jump out of the chair and take off running. In addition to empty calories gained, hard work has been wasted. If parents ever discover a therapist using food as a reward, Strickland counsels, they should give him two weeks to wean the child off of it and switch to a non-food treat.

Tackling behavior issues and involving your child's team lay the foundation for proper nutrition. The food itself is the bricks and mortar. *In Eating for Autism, the 10-Step Nutrition Plan to Help Treat Your Child's Autism, Asperger's or ADHD*, Strickland provides a detailed blueprint of how to assemble a diet specifically for your child. The correct amounts of carbohydrates,

proteins, good fats, vitamins, probiotics, (and the list goes on) build a healthy body and brain. With those building blocks in place, kids with special needs can reap the greatest benefits from their therapies.

If parents ever discover a therapist using food as a reward, Strickland counsels, they should give him two weeks to wean the child off of it and switch to a non-food treat.

amazon.com

LISTMANIA! Book list

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to check out this book and more IDEAS recommended reading through the Listomania Book List link on the IDEAS website.

FIRST IMPRESSIONS continued from page 5

and meet families. I was a little nervous, but as we started chatting with parents, I relaxed. When I saw the children and adults in the parade at the opening ceremony, I couldn't help but cry. I just felt so proud of those children and families.

Every session we went to during the conference gave us great, helpful information. We learned about current research, seizures, nutrition, potty training, social skills, effects on typically developing siblings, effects on marriage, sensory diets, individual education plans (IEPs), auditory processing, and more. Everything that I learned was information that I hadn't learned from my son's therapists, counselors, or doctors.

We attended the breakfasts, lunches, and dinner that were included in the conference, and the food was great. During dinner, there was a silent auction and a raffle that included baskets that people had donated from each state to help raise money for IDEAS. I donated a basket from Maryland, which was so much fun getting together. It was exciting to see people trying to win it.

Meeting other parents and learning about therapies and tests their children have had gave me great ideas about what could benefit my son. I gained so much from this experience: information, friends, a new family, and hope. Most of all, it felt good to know I was doing something to help my son.

Attending the conference was one of the most important parts of this journey for my family. I now plan to attend every conference. The next is in Philadelphia in 2011. We are bringing Nicholas with us next time so other parents can meet him, and maybe he can give them hope like children we saw gave us.

—Sue Stokes, mother of Nicholas, age 3, *idic(15)*

FIRST IMPRESSIONS - I REMEMBER...

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myself. I over-do therapies with my daughter, yet feel guilty for every second lost. My daughter needs her mom, not a therapist. She needs to feel loved and secure, and she can certainly sense if I'm stressed or unhappy. So I've decided to step back from the mom-therapist role and just be mom. I learned to let myself enjoy our amazing little girl and stop feeling guilty.

Attending an IDEAS conference took inner strength, especially on the second day. The conference revealed my denial and weaknesses, but it also taught me how to address them. I learned to open myself to the journey of raising a special needs child and—most important of all—that I'm not alone.

—Tina Mueller, mother of Grace, age 3, *interstitial triplication 15*



On August 1st, the IDEAS online community moved to BigTent. The IDEAS yahoo group is currently closed to new members

and will not accept new postings. However, the yahoo group archives will continue to be accessible. If you have not joined the IDEAS BigTent Online Community, please join by clicking the BigTent link on the IDEAS website (www.idic15.org). Extended family members are welcome to join the Extended Family Subgroup within the IDEAS BigTent Online Community. Please contact Rachel Doucette at doucette.rachel@gmail.com with questions.



Do you use Facebook? Join the IDEAS Cause Page!

IDEAS now has a cause page on Facebook to create awareness of dup15q syndrome as well as raise funds to support our programs. The cause page has over 1000 members! If you use Facebook, please join the IDEAS cause page and share it with your friends. This is a public group so please use caution if posting personal information. To find the cause search "cause IDEAS 15" when logged into Facebook.



Bon Ton Community Shopping Day November 14, 2009

Purchase coupon book for \$5
100% profit to IDEAS
Coupons include \$10 off any \$10 item or greater, 30% off until 9am, 6 -20% off and more!

Stores include Elder-Beerman, Bergner's, Boston Store, Herberger's, Younkers, Carson Pirie Scott in 23 states (not at NJ locations).

Sell them to family and friends.
Contact Theresa West with questions or with number of books needed.
theresa.west94@yahoo.com



“Rohan is such an inspiring force of nature,

he is unstoppable, despite all the challenges he has. ”

Raising a child with idic15 has been the most significant and exciting adventure of my life to date.

Rohan was born after a very long labour and a little assistance at the end with ventouse* delivery. I can still remember the midwife calling “6lb 10oz, ten fingers and ten toes, isn’t he a handsome baby”. It was then I suddenly had a sudden panic, as I thought I bet she says that to all new parents, was I going to love this baby? My husband held him first and I watched tears of joy roll down his face, he then passed him over to me, that was the moment I truly fell in love for the first time. My little red wrinkled baby was the most beautiful thing I had ever seen, he was perfect!

He had a little trouble breast feeding, over the course of the first couple of weeks we carried him around crying as he suffered from colic and still wasn’t feeding properly. At two weeks he had lost 20% of his birth weight (norm is up to 10%). We put it down to him being a lazy feeder; little did we know this was due to low muscle tone! Over the course of the following two weeks we built him up by syringing drops of expressed breast milk into his mouth until he was back to birth weight and solely breast feeding. We thought the most challenging bit was over!

At about five months we noticed him occasionally nodding his head in the morning, I mentioned it to the health visitor and she thought it was nothing to worry about. Developmentally he took interest in some areas and showed less in others, which was not unusual. The next three to four months were a bit of a blur. Rohan started to plateau and then regress developmentally. The head nods changed to infantile spasms as they were later diagnosed. I felt awful admitting there was something wrong with my baby but at the same time bad for having been in denial for as long as I had. The next few months revolved around trying various anti-epileptic drugs and carrying out tests to establish what was causing Rohan’s epilepsy.

Simultaneously we had started trying for another baby and had also had this good news a few days after Rohan’s EEG confirming the epilepsy. Rohan did not respond to any of the drugs so as a last resort they tried a short course of steroids. By this point Rohan



was having clusters of up to 20 seizures per time and 50-60 per day. He had gone back developmentally, showing no interest in anything, avoiding eye contact, he laid with his arms beside him not wanting to interact. His epilepsy responded to the steroids and the seizures stopped completely. He was sitting independently within three days of starting the steroids. This was at eleven months. We continued supporting Rohan’s physical rehabilitation as much as we could.

All the tests they had run to find a cause had come back negative until a week after his first birthday (I was 17 weeks pregnant with our daughter Serena). The neu-

R

rologist rang from the hospital and delivered the news about his diagnosis and then said we would be offered a CVS** for the baby and genetic counselling. It suddenly dawned on me that there could be other repercussions.

The next week was extremely testing. We are very lucky we both have supportive and loving families who were there for us. Serena's CVS was fine and Rohan's condition was put down to a spontaneous mutation. We started learning more about the condition and also support services such as organised physiotherapy, occupational therapy, speech and language therapy, and portage. Over the course of the next year Rohan started to make progress, started to smile again. We used food and juice to motivate him to use his hands again. We worked with him intensively. By the age of two Rohan started walking.

Serena arrived safe and well, creating a great distraction for me to start with and eventually another person to teach Rohan new things.

At three years old Rohan attended a mix of special school and normal preschool, for about a year. We realised in the first six months that Rohan wasn't making any progress, also his epilepsy had started again. Rohan had begun to verbalise approximations to words before starting school, over this year he became more apparently autistic, more withdrawn and doing more repetitious behaviours.

One very sweet morning after try-

ing to get a response from her brother to her goodbye, Serena hung her head low coming out of the car and said "Mummy Rohan doesn't want to talk to me". I decided that was what I wanted to help Rohan with. I evaluated our other options and found a home schooling programme called Son-Rise® www.autismtreatmentcenter.org It was a home schooling program that focused on loving, accepting and having a non-judgmental attitude. It was such a powerful and respectful way of teaching any child, particularly one with so many challenges. This program changed all of our lives. I finally really learned how to truly love and accept my beautiful little boy but also passionately want more for him and know how to achieve it. We have implemented a number of other therapies within our programme e.g. B.I.R.D., www.b-i-r-d.org.uk and occupational therapy.

I am also using more holistic therapies and approaches to helping him with his epilepsy (e.g. homeopathy and cranial osteopathy) as it is still unresponsive to the conventional drugs available.

As a result of all of this and despite his continuing epilepsy Rohan is making amazing progress. His muscle tone has improved along with his co-ordination, he now verbalises about 10 word-like sounds, he is really enjoying play in his playroom and interacting with his Son-Rise team and now toys too! He is an affectionate little boy who opens his heart to share his love. My aim is to pro-



Rekha lives with her husband David, her son Rohan (dup15q), and her daughter Serena in Cambridgeshire, UK.

vide the most loving and motivating environment I can and let him do the rest.

Rohan is such an inspiring force of nature, he is unstoppable, despite all the challenges he has. I watch in awe at his perseverance with any activity he has set his little heart on. It is a privilege and an honour to be his mum.

Now 5 years old, Serena loves her big brother just like any other little sister and bosses him around the same too! Rohan will be seven years old in November. He too loves his sister's company and has a good giggle at her antics.

** Ventouse is a suction device, attached to the baby's head to help him out, it is an alternative to forceps.*

*** CVS is Chronic villus sampling, an alternative to an amniocentesis. They take placenta tissue for genetic analysis rather than amniotic fluid in an amniocentesis. it is more accurate.*



Cheers
to our Volunteers

IDEAS Conference Chairs - Heather and Ron Bruce Though Full Steam Ahead was a rousing success, Heather and Ron never stood still long enough to be photographed. That didn't keep everyone

else from having a great time, as witnessed by this collage. And that didn't stop us from naming Ron and Heather our Volunteers of the Quarter—three cheers to the Bruces for planning a fabulous conference!







HAPPY BIRTHDAY
TO YOU!

Kyle B.	07/01/84	Erica S.	07/12/86	Jacob A.	07/28/05	Austin V.	08/15/96
Erika M.	07/01/01	Christine D.	07/13/91	Colin O.	07/30/98	Carly P.	08/16/93
Travis R.	7/02/98	Alec A.	07/13/99	Emily M.	07/31/80	Kathleen O.	08/16/03
Benjamin D.	07/04/06	Tanner J.	07/12/06	Rachel K.	08/04/86	Patrick S.	08/16/98
Alexis M.	07/05/94	Kira G.	07/15/98	Taylor G.	08/04/91	David F.	08/17/98
Charlotte S.	07/05/07	Jessica M.	07/18/98	Lina S.	08/04/01	Gavin H.	08/17/04
Elizabeth O.	07/06/97	Elizabeth R.	07/18/99	Patrick S.	08/04/05	Parker L.	08/17/04
Max P.	07/06/07	Nicholas D.	07/18/95	James H.	08/06/07	Stewart L.	08/18/89
Samuel V.	07/09/95	Erin O.	07/19/01	Devon J.	08/07/93	Samuel O.	08/18/93
Michael B.	07/09/84	Luke S.	07/23/07	Dominic L.	08/07/06	Ella B.	08/18/03
Blake N.	07/10/07	Michelle G.	07/24/01	Jesse M.	08/12/94		
Andrew H.	07/11/89	☛ Clare T.	07/25/80	Samuel H.	08/13/93		
Lauren C.	07/11/00	Zoe N.	07/25/02	Eli M.	08/14/92		
Gabrielle K.	07/12/01	Hunter S.	07/27/06	Spencer G.	08/15/94		

Conference Contributors

IDEAS thanks the following contributors to the success of Full Steam Ahead:

American Girl	Price Products	Brian/Susan Gazewood
Around the Block Quilt Shop	Real People Art	Lori George
AudioCraft Publishing	Ripley's Aquarium	Doreen Gladis
Baby BumbleBee	Rutgers University Football Team	Lisa Halsema
Bath and Body Works	Saint Lawrence Saturday Evening	Doris Hellstern
Ben & Jerry's	Choir	Cindy Johnson
Block Buster	Sechler's Pickles	Ruth Kross
Bowers Harbor Vineyards	SCENTSational Soaps	Joan Lammas
Boyne Highlands	Shedd Aquarium	Maria Leo
Brys Estate Vineyard and Winery	Sleeping Bear Press	Rachel Lorkin
Carowinds Amusement Park	Special Olympics New Jersey	Kadi Luchsinger
Cedar Point Amusement Park	Starbucks	Ethan Luchsinger Grandparents
Chateau Chantel	The Henry Ford	Franny Mackling
Cincinnati Zoo	Two Tomatoes Records	Noel Marcoux
Crowne Plaza Hotel and Conference	WITL Country Radio 100.7	Meagher Family
Center, Indianapolis, Indiana	Yoga Kids	Jodi Miller
Crowne Plaza Hotel, Philadelphia		Angie MittelBuscher
Center City	Anonymous donor	Tina Mueller
Macy's	Claudia Allen	Mary Mullen
Marion-Kay Spices	Jill Baker	Julie Orton
Mary Kay	Connie Bist	Sarah Porath
Mid-Ohio Sports Car Course	Lynne Bopp	Ritter Family
New Rencel Pancakes	Tasha Boutselis	Tonya Rodemich
New York Jets Football Team	Charles Brady	Rylie Trueman
N.K. Hurst Beans	Bruce Family	Grandma Sales
Olive Garden	Grandma Bruce	Karen Sales
Oregon Trail Plumbing & Heating	Marisa Martinez-Chapa	Robyn Smith
Organic Valley	Paula Davis	Sue Stokes
Outback Steakhouse	Ellen Doxtator	Sarah Torrance
Panera Bread	Rachel Doucette	Jane True
Plan Toys	Rachel Doucette's mother	Theresa West
Play Away Swing	Fran Dunne	Samantha Sons
Portland Federal Credit Union	Bernadine Mullen	Rutgers University Football Team

Alicia M. S.	08/19/97	Shannon N.	08/30/94	Thomas N.	09/10/93	 Cameron P.	09/17/00
Avery W.	08/19/03	Keshavarudra G.	08/30/05	Dante R. P.	09/10/97	Conor M.	09/19/96
Timothy F.	08/19/04	 Joshua D.	09/01/94	Major R.	09/10/98	Harrison M.	09/20/07
Annabel P.	08/19/06	Harry W.	09/01/00	James Andrew S.	09/11/92	Lara P.	09/21/93
Sarah D.	08/23/98	Stephanie C.	09/01/01	Waawijja W.	09/11/93	Sarah L.	09/23/75
Colt C.	08/24/93	Brenda M.	09/02/89	David S.	09/11/01	Paul H.	09/23/94
Simone C.	08/24/08	Alex K.	09/02/05	Julia W.	09/12/96	Allison K.	09/23/97
Marian I.	08/25/92	Cara V.	09/03/92	Christina L.	09/12/98	Brenna G.	09/23/02
Stephen (Sammy) M.	08/25/06	Tom E.	09/04/02	Casey W.	09/12/03	Paul H.	09/23/94
Reuben B.	08/26/01	Claire G. F.	09/07/82	Caitlin B. H.	09/12/05	 Brandon J.	09/24/97
Charlotte J.	08/28/03	Livia G.	09/07/03	Rachel M.	09/14/94	Eric H.	09/24/90
Ashley Q.	08/29/91	Cheyenne D.	09/08/92	Raquel L.	09/14/00	Evan M.	09/28/94
Rachel H.	08/29/03	Elana K.	09/09/88	 Breaua E.	09/15/95	Madison W.	09/28/00
Kevin L.	08/29/06	Bente S.	09/09/97	Mason L.	09/15/99	Peter K.	09/30/93
Kacey T. S.	08/30/93	Holdon W.	09/09/99	Jeremy L. M.	09/17/88	Stephen G.	09/30/99

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.

“Did you know?”
 “The chromosome 15q 11-13 maternal duplication is the most common chromosomal abnormality identified in patients with autism spectrum disorders.”
 (Clinical Psychiatry, March 2009)

Check out IDEAS magnet ribbons and other holiday gifts from the IDEAS store (at idic15.org) for teachers, family and therapists.



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