

THE MIRROR

The Newsletter of
IDEAS

IsoDicentric 15 Exchange, Advocacy & Support

FROM OUR EDITOR
BY OUR EDITOR

IT'S COMPLICATED: by Jane True, Editor



What Researchers Have Learned and Are Still Trying to Understand About dup 15q

As part of our mission, IDEAS convenes research roundtable meetings to stimulate research into duplications of chromosome 15q. These meetings are designed to bring scientists together to talk about their interests in isodicentric and interstitial duplications of chromosome 15, and to promote research collaborations. On May 18, 2010, IDEAS convened such a meeting in Philadelphia. This roundtable immediately preceded the annual IMFAR (International Meeting for Autism Research) conference, so many scientists and researchers were able to attend.

This was by far the largest such group we have ever convened, and it was wonderful to see so many knowledgeable people gathered together and discussing how best to understand and help people and families affected by dup 15q. From 8AM to 4PM this “think tank” shared what they have learned in their research, what they wish they knew, and the best ways to find out and use this information. Those of us attending from IDEAS who did not have professional expertise in genetics, pathology, sleep disorders, epilepsy, etc. sometimes felt as if our heads were about to explode. But it was obvious that this was a dynamic meeting and that everyone there came away with some new thoughts about how they could proceed to help unlock the mystery of dup 15q.

This was not a scientific meeting format in which formal published papers were presented. Rather it was more of a “think tank”. Thus the summaries which follow in this issue are just that—your editor’s attempt to let you know the kinds of things that were discussed and some of the thoughts that were shared. So if some of the statistics don’t tally precisely or something isn’t perfectly explained, please don’t blame the researchers. The one comment that came up throughout the day was “It’s complicated”—thus this issue’s theme.

IDEAS is fortunate to have so many brilliant minds working to help our children, and pleased to be able to convene such a group and facilitate their interaction. It is the support and fundraising of our families which made this possible, so thank you all!

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.

jtrue@kc.rr.com

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.

IDEAS 2010 Scientific Meeting

HIGHLIGHTS AND SUMMARIES

The following summary of several presentations was compiled by Jane Pickett of the Autism Tissue Program:

Of the several genetic disorders that have a 'causal' relationship to autism, the duplication of a portion of chromosome 15q (IDIC15q) figures prominently in post mortem brain research. In fact, one out of every ten brain donors to the Autism Tissue Program (ATP-link) comes from this specific population that is represented by the IDEAS organization. A major concern of the group and a factor in the high brain donation rate in this group of only about 650 families is sudden unexplained deaths. Seizure activity in many of the individuals is thought to underlie their apparent vulnerability and the IDEAS group has been proactive in both publicizing recommendations from their physician-advisors as well as promoting brain donation to understand the causes of death and look for developmental changes consistent with autism and/or epilepsy.

Today's meeting that brought together researchers and parent advocates was a significant effort to understand the research to date and fine tune future efforts. Dr. Jerzy Wegiel from the New York Institute for Basic Research described neuropathology in five brain studies completed to date that shows unexpected ongoing production of new brain cells (neurogenesis), a dysregulation of the migration of brain cells and distortion of the cytoarchitecture reflecting an altered course of maturation of brain cells. Accumulations of intracellular protein deposits and mitochondrial inclusions signify a process of cellular damage. Each of these brain anomalies can contribute to or be the result of seizure activity, so the study of brains and clinical evaluations of the donors will continue.

In conjunction with the neuropathologic examinations of brain donors, IDEAS asked its families to participate in a seizure survey. Preliminary results from about 85 participants show various types of seizures and onsets. Results will be posted on the IDEAS website. Since sudden deaths often occurred during sleep, Sanjeev Kothare, MD, of Children's Hospital in Boston was present to provide information on his studies of breathing abnormalities in patients with IDIC15q. He reviewed the clinical spectrum of dup15q: epilepsy, hypotonia, minor dysmorphisms, moderate-severe developmental delay and autistic behaviors. He speculated that the increased risk of sudden death is due to abnormalities of sleep, cardio-vascular function, mitochondrial function and epilepsy. The results of his sleep study on five children with idic15 revealed central sleep apnea that occurs when the brain does not send proper signals to the muscles that control breathing often in conjunction with seizure activity. This very important work will continue and many of the IDEAS families have worked with their own doctors to obtain a sleep study to determine both seizure and breathing activity.

An additional highlight of the meeting was a talk by James Sutcliffe of Vanderbilt University on one of the genes of interest in the duplicated piece of chromosome 15 - the GABA B3 receptor. GABA is the main inhibitory neurotransmitter

Agenda for IDEAS 2010 Scientific Meeting May 18, 2010

Overview of dup15q syndrome
 Carolyn Schanen, MD, PhD

Mortality and dup15q
 Edwin Cook, Jr., MD

Overview of neuropath results
 Jerzy Wegiel, PhD

Epigenetic alterations in
 idic15 brain samples
 Janine LaSalle, PhD

Homologous pairing of
 chromosome 15q11-13
 is associated with significant
 disruption of gene expression in
 human maternal chromosome 15
 microcell transferred neurons
 Shin-ichi Horike, PhD

Breathing abnormalities in
 dup15q
 Sanjeev Kothare, MD

Seizures in dup15q
 Agotino Battaglia, MD, Dped, DNeuro

Interstitial dup15q and Autism
 Lawrence Reiter, PhD

GABR3 Mutation and Autism
 James Sutcliffe, PhD

*Note: Drs. Battaglia and Thibert were
 unable to attend due to last minute
 circumstances that arose.
 Even getting there was complicated!*



Researchers and Assistants:

2nd row left to right: Sara Spence, Shin-ichi Horike, Jerzy Wegiel, Jane Pickett, Lawrence Reiter, James Sutcliffe, Ed Cook, Randy Carpenter
 1st row: Janine LaSalle, Carolyn Schanen, Brenda Finucane, Nora Urraca, Julie Cleary

"There is the possibility that, just as the study of one brain affected by Down syndrome greatly enhanced our understanding of Alzheimers disease, one of our dup15q kids can teach the world how the human brain works."

Dr. Jerzy Wegiel

and any dysfunction in its receptor is thought to INCREASE brain activity and might contribute to seizures. He is studying rare point mutation in this gene that was also found in a condition known as Childhood Absence Epilepsy.

A presentation by Larry Reiter focused on a subset of 15q duplications called 'interstitial duplications'. These are also duplications of genes in the 15q portion of the chromosome but instead of arising de novo in the child, are inherited from the mother or father. The IDEAS group was instrumental in putting out the call to its members for participation and 15 subjects have been identified.

Overall, the future goals are aimed at learning more about the conditions that affect mortality such as hypotonia, apnea and seizures. Further genetic studies on molecular mechanisms to find drug targets will include mouse models and analysis of DNA and brain tissue.

Summary of Presentation by Dr. Shin-ichi Horike

Currently, no beneficial mouse or cell culture model exists for maternal 15q11-q13 duplication observed in 1-3% of autism cases, so our microcell mediated transfers of a maternal chromosome 15 into human SH-SY5Y neuronal cells or mouse ES cells are expected to be a novel and essential experimental system for further understanding 15q11-q13 epigenetics in autism.

Previously we observed that homologous pairing of 15q11-q13 was deficient in human neuronal cells with extra copy of maternal chromosome 15. Interestingly, extra copies of genes are predicted to lead to increased expression, however our study revealed that gene expression can be altered in unexpected ways through epigenetic changes resulting from increased maternal 15q11-13 dosage, similar to what has been previously observed in a human brain sample with maternal 15q duplication and disrupted homologous pairing.

Also, in order to investigate the gene dosage effects of an extra copy of human chromosome 15 on various 15q

dup phenotypes, we used microcell-mediated chromosome transfer to create ES cells containing human chromosome 15. ES cell lines retaining a single human chromosome 15 were used to produce a transchromosomic mouse with human chromosome 15. Thus, molecular investigation of gene expression in our 15q dup model cells and model mice with an extra copy of 15q11-q13 provides insight into the potential complexities of other copy number variations in autism.

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Dr. Carolyn Schanen: Overview of the syndrome

by Jane True

The first step in understanding dup15q is describing what it looks like. Dr. Schanen reported that there is a seizure risk of 50-75% with male bias. All types of seizures are seen. There is a high risk of autism, listed in the literature at 90%. This may or may not accurately reflect the autism rate in our group. Anxiety and hyperactivity are associated with dup15q. We are not sure whether psychiatric disorders, mood disorders, or psychosis are associated. There is cognitive impairment across the board. Hypotonia exists, especially in infancy. Also associated with dup15q are ataxia and cortical visual disturbances.

Physical characteristics include short stature in 25%, the rest are of normal stature. The head circumference is typically normal. Hoarding behaviors are seen (such as in PWS). There are dysmorphic features, joint laxity, hyperpigmentation. Multiple congenital abnormalities are rare. SUD has been associated with dup15q.

The affected chromosomes are almost universally maternally derived. Variable breakpoints are involved, though two forms predominate. There are gross motor delays across the board, mostly attributable to hypotonia.

With respect to phenotypic nuances, does anything stand out differentiating interstitial or idic15 from idiopathic (unknown cause) autism? They have begun looking at interstitial and idic and comparing them to idiopathic autism. Seizures are more common with idic than with idiopathic autism. Cognition is generally worse with idic than with interstitial.

They are now seeing much more breakpoint diversity due to advances in diagnostic technology. Many micro duplications and deletions have recently been diagnosed. It is difficult to counsel people with these new diagnoses as not enough is known.

Conclusion: It's complicated and the scientific group needs to make some sort of statement as to "which ones are not like the others" (Brenda Finucane). Then IDEAS must decide how to proceed. For example, IDEAS could potentially facilitate connecting these families.

Top 3 Priorities for Future Research

As an outcome of the scientific meeting, your IDEAS board has settled on the following three areas of priority for future research:

1. Develop a Registry
2. Promote Seizure Study
3. Investigate Sleep Studies



Researcher, Board Members, and other Attendees :

2nd row left to right: Sanjeev Kothare, Karen Sales, Daniel Lightfoot, Jane True, Rachel Doucette
1st row: Paula Davis, Candace Tietsworth, Cindy Johnson, Carolyn Komich-Hare, Kadi Luchsinger

Changes on IDEAS Board

IDEAS would like to thank Frank Kobuszewski, Paula Davis, and Nicole Cleary for their years of service to the IDEAS board. Nicole in particular has served IDEAS since its inception and provided valuable leadership at some key times, such as incorporation. IDEAS has been fortunate to have their creativity and energy on the board for the past several years.

We welcome new board members Mike Porath, Rylie McHam, Lisa Lightner, Linda Meagher, and Patti Rubel and look forward to working with them. We are also pleased to announce changes for some of our existing board members: Len Poore has agreed to serve as our new Board Chair, Rachel Doucette will be our new Vice President of Communications, Tom Doyle will serve as our new Vice President of Finance and Karen Sales will contribute as our Corporate Secretary. IDEAS is a parent-run organization and we very much appreciate the commitment that our board members and their families make for the support of IDEAS. It is good to know that IDEAS is in strong hands going forward.

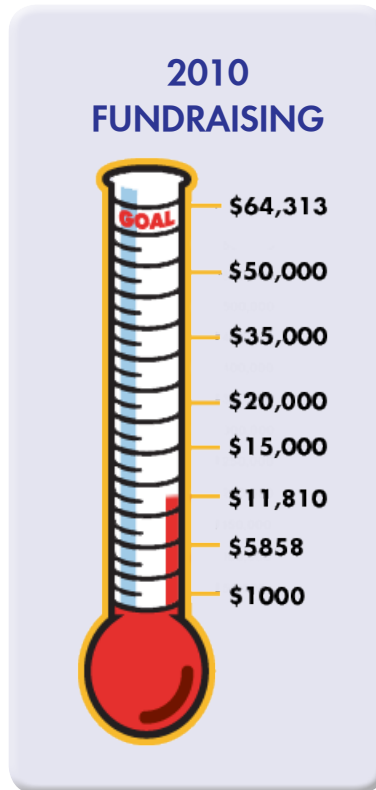


Announcing the First Annual Illinois Golf Outing for IDEAS

Friday, August 6, 2010
 Poplar Creek Golf Course in Hoffman Estates, IL.

Come for golf, dinner, or both!
 More info or register online at www.dup15q.org

For questions contact:
 Ember Burke
ember720@hotmail.com
 773 704-9722



IDEAS need your help to reach its fundraising goal for 2010. Go to the IDEAS web site to see how your donations are used. <http://www.idic15.org/donations.html>

IDEAS

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| RON THIBERT, DO, MsPH Pediatric Epilepsy Program Massachusetts General Hospital; Boston, MA |

Cheers

to our Volunteers



IDEAS gives a very special Cheer to volunteer Nicole Cleary

In this issue IDEAS honors a special volunteer who recently retired from the board after many years of leadership and service to our families. Nicole Cleary became involved with IDEAS in 1999, when her daughter Corrina (idic15) was almost 3 years old. At that time Nicole joined a handful of parents who were communicating on a yahogroups listserve started by Erica (mother of Cheyenne) and Paul Rivard (father of Megan). The listserve was the most helpful resource for sharing the joys, fears, frustrations and unknowns of raising a daughter with dup15q. The knowledge and support of these parents was a lifeline for Nicole and her husband Tim, since no one in Portland, Oregon, had even heard of isodicentric 15 back then.

Two years later Brenda Finucane and Elwyn sponsored the First National Conference for Parents and Professionals on Isodicentric 15 and Related Disorders. Nicole and Tim flew from Portland to Philadelphia to meet other parents and professionals for the first time. It was both an inspiring and sobering experience. At that conference, Brenda asked interested parents to meet with her to talk about forming a board and becoming a parent run organization. Up until this point, IDEAS had been a joint project between Brenda and Donna Bennett, co-founders. Nicole was inspired by the many talks she heard and parents she met, and she knew that for resources and research to really move forward for dup15q, parents were going to have to step up to the plate. As Gandhi said we were going to have to "be the change you want to see in the world". That is as true today as it was in 2001. Nicole had a master's degree in social service and decided then and there to put it to work for IDEAS.

Nicole served as the first board chair for IDEAS. The board met monthly via conference call for many years and in 2004 the board incorporated IDEAS as a nonprofit corporation in Oregon. Nicole quit her job and served as both board chair and executive director until the needs of the organization got so big that we really needed to separate these roles into two different positions. She states that it was some of the most exciting, draining and rewarding work she has ever done. IDEAS has always benefitted from an extremely dedicated group of parents serving on the board and Nicole loved coming together with these parents by conference call once a month over the nine years that she served as board chair. Nicole felt extremely grateful to participate in the elections of the current board as her last formal act with the IDEAS board. She is excited to be turning over the baton to such a vibrant and engaged group. IDEAS has been a huge part of Nicole's life and she is now "cheering wildly from the sidelines" as the board supports the mission of this organization that is so important to all of us. Not being able to completely let go, Nicole is continuing to support the IDEAS seizure survey and encourages any families who have not yet signed up but are interested in helping with this important research to contact her at nicleary503@comcast.net. Three cheers for Nicole, and many thanks for all she has given IDEAS.

My Sister Grace

by Katie Lowell age 10



Do you have a brother or sister with special needs? I do.

Her name is Grace and I love her a lot. She is full of fun. There are a lot of things she does that are different.

My sister Grace has sandy brown hair. She got it from my dad. Grace has brown eyes that are very pretty. They look like chocolate drops. She has messy hands most of the time because she likes to play in the dirt or she has been eating and has messy hands. I don't like it when she touches me with her dirty hands. She loves to wear sweatshirts. Sometimes we can't get them off of her. One time we had just gotten back from a walk and I got Grace out of her coat, but I couldn't get her out of her sweatshirt.

Grace says "gorilla gorilla" a lot because she loves gorillas. They are her favorite animal. We used to not be able to say the word gorilla around her. She also likes to say "ears ears" and comes and plays with your ears. It gets annoying. Grace annoys my mom by saying "want some milk" over and over. One time in the car she kept saying "want some milk" over and over until we got home and got her some milk. Sometimes she is just silly and says "wanna go to bed" and then we have to walk her back to her bed. Then she just lays there for hours. Grace just lays on her bed, even though it is not bedtime. Then she fusses when we try and get her up.

She loves to look at books. Grace doesn't read the books because she doesn't know how to. Grace also likes people to read to her. Whenever Grace is somewhere with a ton of space she just runs and runs and runs. We have to chase her around then.

My sister makes my life different and fun. She is an individual. No one could replace her.



A letter from Heaven *a tribute to Jake Miller*

Dear Mom, Dad, and Sarah,

I know you think that life isn't fair. And you're right, it isn't. I didn't get my fair share of healthy genes. ... But I always felt loved by so many people, most of all by you guys....

I'd like you to know I am free now. And I want you to do one more thing for me. I want you to remember the dreams you had for your lives before you gave them all up to care for me. Please go after those dreams now, even if they are simple ones like sleeping through the night. Know that wherever your dreams take you, I will be with you in your hearts. You will never get rid of me....

You made my life the best it could be every single day. Now go out and live your lives. And whenever you see a pinwheel, if it is turning, know that it is me blowing on it.

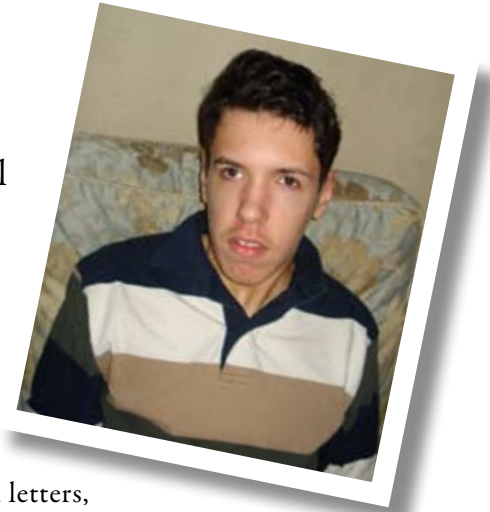


May 4, 1999—February 15, 2010

excerpted from a reading at Jake's memorial service

OUR SON ADAM

by Patti Rubel



It's hard to believe that our son Adam is now 18 years old. We were one of the first families that found each other when IDEAS was first forming around 1994. It was very comforting to know that we were not the only family with a child diagnosed with what was then called "Inverted Dup 15".

IDEAS has been the port in our storm. John and I were so grateful to connect with other families, first by phone and letters, and then on-line. We first met other families at a gathering in Atlantic City about 12 or 13 years ago. Shortly after that a bigger group met in Providence, Rhode Island, and the rest is history.

Adam was born in 1991 in Coronado, Calif. I had a wonderful pregnancy, though Adam was born almost two weeks after his due date. He was a big baby – 10 ½ lbs. The doctor didn't have time to give him an Apgar score, as he was rushed to the NICU for breathing problems. He did go home with us a couple of days later, with a clean bill of health. It wasn't until his 15 month checkup that our doctor noticed some delays. Adam had very low tone and wasn't crawling, let alone walking. We consulted a developmental pediatrician and, after many tests, received a diagnosis of "Inverted Dup 15". I threw myself into researching all I could about what this meant for our family. We were told by his geneticist to expect Adam to have mental retardation and require lifetime support.

"Though Adam is non-verbal, he can always get his point across."

Here in Northern Virginia, they provide early intervention services from birth to two years and then five half days of school from age two through Kindergarten. Adam started hippotherapy at 15 months of age and then speech, occupational and physical therapy starting at 18 months of age. In addition to the therapies our school district provided, we had a private speech therapist and an occupational therapist work with him twice a week. At the age of three, Adam received an additional diagnosis of autism. I was not surprised as I had been noticing a number of things, aside from the fact that he was still non-verbal and would not socialize with peers. He toe-walked, had no joint attention skills and was beginning to "stim".

Now we had more to learn and a lot more work to do. We were one of the first families in Virginia to get ABA (Applied Behavioral Analysis) therapy through CARD (Center for Autism and Related Disorders). We hired local college students and trained them so they could work with Adam for a total of about 30 hours a week for the next two years. Over the next six years I worked hard to get our school district to look into ABA for children with autism in the school setting. I have to say that ABA wasn't as geared to non-verbal kids with autism so the program was semi-successful for us. Even the experts needed time to catch up and gear ABA therapy as much to the non-verbal child as the ones who had some speech. The best thing to come out of ABA training was the realization that Adam COULD learn. Once we realized learning was possible, we were off and running. Toilet training was difficult, but it could be done. It took a lot longer than we expected, but success was possible. That gave me so much hope.

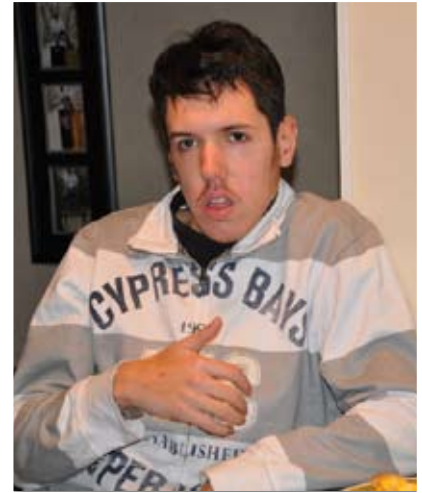
I helped start a small lobbying/consulting company with friends who also have children with autism. We spent many hours in our state capitol lobbying the legislature to make sure that kids like ours were not forgotten. We made sure that when they required a new test to hold teachers accountable for student progress our kids were included with tests of their own. Eventually the state put together a plan to test low functioning kids by requiring that a "portfolio" (work samples, a video of the child in the classroom, etc.) be submitted to a committee for review every two years. Though not perfect, at least our kids had to meet a standard of some kind.

Adam progressed very slowly, but he had some great splinter skills. He learned to manipulate the mouse on the computer quite easily. He loves school and has always had a very pleasant disposition. He takes a long time to learn a skill, but when he learns something he rarely forgets it. Though Adam is non-verbal, he can always get his point across. We have progressed from using rudimentary signs to actual photographs of things, to using PECS (Picture Exchange Communication System). He now uses an augmentative communication device. We still need to have high expectations because he will only give us what we ask for. This is especially true at school, so having a good teacher who expects a lot from him is absolutely vital.

"Adam is healthier now than he's ever been. Read everything you can about healing our kids from the inside out."

We belong to many different associations in order to keep up with the latest research. One of the best I have found is the Autism Research Institute (ARI). When ARI first recommended the DAN protocol, I attended their conference to find out all I could. Adam receives several nutritional supplements and has had a number of alternative therapies such as AIT (Auditory Integration Training), the GFCF diet, nutritional supplementation based on the DAN protocol, etc. We put him on the GFCF diet long ago, when everything gluten-free had to be made from scratch. Thank goodness now for places like Trader Joe's, Whole Foods and Wegman's! I took him to a developmental nutritionist who knows all about what our kids need. Adam is healthier now than he's ever been. Read everything you can about healing our kids from the inside out. I believe in the "leaky gut syndrome" theory. If it turns out your child doesn't have food allergies, you haven't lost much by giving it a try. At a minimum, Adam always takes a probiotic, cod liver oil capsules, lecithin granules, extra calcium, and a multi-vitamin each day. He needs Miralax everyday because he's a "stool-holder" and always has been. I have often had to fight our school

system to get Adam what he needed. When I thought the school district wasn't doing what they should, I would take it up the chain – always starting with his teacher. I have found that special education teachers generally want what's best for our kids. The missing piece is typically teacher training. Teachers are still not being taught "best practices" for children with autism in college, despite the gains in research these past 15 years. My best advice to parents of newly diagnosed children is to stay involved. I wanted to have a voice so I would volunteer every year to be the parent rep in the classroom and the special education representative on the PTA board. If time does not allow you to do this, you can still meet with the teacher regularly. Ask for a meeting when you need an update or when something isn't going well. You don't have to confine yourself to meeting only when it's convenient for the school or when there are regularly scheduled conferences. I also served on a number of county-wide committees, including one that reported back to our school board at the end of each year with recommendations on how to improve special education for all children. Our county has one million residents, so this was a great opportunity for me to make a difference. Our state offered a program



called "Partners in Policymaking" which teaches disabled citizens and/or adults who care for a disabled child to become effective advocates. I attended this course one weekend a month for nine months and it was invaluable. It helped me feel empowered to advocate not just for Adam but for all people with disabilities.

"My best advice to parents of newly diagnosed children is to stay involved."

In the past few years I have been a little less involved so I could work a part-time job. That ended as a result of the need to care for Adam full-time. He began having seizures at age ten. He had the atonic (drop) kind of seizure. Thankfully we were able to get them under good control with Depakote within a few weeks of seeing his neurologist. Last summer, at age 17, he started having them again and it has taken us eight months to get them under control. He was having up to 70 seizures a day. His neurologist put him on four different seizure drugs at once. Nothing seemed to work until she switched him to Banzel. He also had

continued on page 11



HAPPY BIRTHDAY TO YOU!

| | | | | | | | | | |
|-----------------|-----------|------------------|-----------|---------------|-----------|--------------------|-----------|-----------------|-----------|
| Marcel G | 4/4/1987 | Sarah M | 5/3/2003 | Zachary C | 5/25/2000 | Douglas M | 6/26/2003 | Brecon Daniel P | 8/1/2007 |
| Marissa K | 4/4/1988 | Martin C | 5/3/2006 | Kaylor Jade M | 5/25/2007 | Aiden B | 6/26/2006 | Wilson K | 8/2/2005 |
| Shehan W | 4/4/2007 | ✶Jacob M | 5/4/1999 | Kayden E | 5/26/2001 | Jack T | 6/27/1990 | Mary Kate A | 8/3/1983 |
| Matthew H | 4/5/2001 | Shelby L | 5/5/1993 | Joanne W | 5/27/1988 | Holly T | 6/27/1994 | Rachel K | 8/4/1986 |
| Maxwell A | 4/5/2004 | Chris C | 5/5/2000 | Jarrett S | 5/28/1991 | James F | 6/28/1998 | Taylor G | 8/4/1991 |
| Mia J | 4/6/2000 | Emma D | 5/6/1988 | Kayli S | 5/29/2003 | Mikaela O | 6/28/2000 | Ilina S | 8/4/2001 |
| Colton B | 4/7/2005 | Viktoria N | 5/6/2003 | Tiana V | 5/30/2007 | Alec S | 6/29/1996 | Patrick S | 8/4/2005 |
| Chad T | 4/8/1994 | Ruth T | 5/6/2006 | Madison M | 5/31/2001 | Taylor L | 6/29/1999 | James H | 8/6/2007 |
| Christian T | 4/9/2000 | Thomas N | 5/7/2006 | Miranda D | 5/31/2004 | Luke S | 6/30/2000 | Devon J | 8/7/1993 |
| Jeffrey M | 4/10/1995 | Albanelia R | 5/8/1984 | Anna B | 6/1/1999 | Kyle B | 7/1/1984 | Jada B | 8/8/2006 |
| Niklas H | 4/11/1999 | Megan G | 5/8/1998 | James C | 6/1/2003 | Erika M | 7/1/2001 | Chloe J | 8/9/2005 |
| Grace M | 4/11/2006 | Anna M | 5/9/1988 | Alyssa L | 6/2/1992 | Jasper G | 7/2/2007 | Guillermo C | 8/9/2007 |
| Marlena H | 4/13/1999 | Eddie M | 5/9/1999 | Jared L | 6/2/2008 | Benjamin D | 7/4/2006 | Jesse M | 8/12/1994 |
| Bobby W | 4/14/1978 | Graham R | 5/9/2000 | Jordan H | 6/3/2004 | Alexis M | 7/5/1994 | Eli C | 8/14/1992 |
| Stephanie B | 4/14/1999 | Emilie B | 5/9/2007 | Adrian R | 6/4/2007 | Charlotte S | 7/5/2007 | Spencer G | 8/15/1994 |
| Kamika M | 4/14/2007 | Simon P | 5/10/1983 | Colleen B | 6/4/1990 | Madyson P | 7/6/2007 | Austin V | 8/15/1996 |
| Maggie W | 4/15/2003 | Mark W | 5/10/1985 | Kathleen M | 6/4/1993 | Sydney L | 7/6/2009 | Carly P | 8/16/1993 |
| Luca J | 4/15/2004 | Sem K | 5/10/1999 | John N | 6/5/2003 | Elizabeth O | 7/7/1997 | Patrick S | 8/16/1998 |
| Samuel K | 4/15/2006 | Landon C | 5/10/2008 | Shivaun S | 6/5/2006 | Gavin Q | 7/7/2004 | Kathleen O | 8/16/2003 |
| Trevor M | 4/15/2007 | Ashtron M | 5/11/2004 | Isabella G | 6/6/2003 | Emma N | 7/7/2007 | Eric L | 8/17/1989 |
| Cody L | 4/19/1993 | John Paul P | 5/11/2006 | Carol F | 6/7/1991 | ✶Michael B | 7/9/1984 | Gavin H | 8/17/2004 |
| Skylar H | 4/19/1996 | Elisabeth M | 5/12/2009 | Jack R | 6/7/2002 | Samuel V | 7/9/1995 | Parker L | 8/17/2004 |
| Julie R | 4/19/1999 | Austin E | 5/13/1992 | Angel S | 6/9/1993 | Anna Vera F | 7/9/2008 | Stewart L | 8/18/1989 |
| Suzanne K | 4/20/1989 | Skylar P | 5/13/2006 | Abigail T | 6/9/2005 | Blake N | 7/10/2007 | Samuel H | 8/18/1993 |
| Preston B | 4/21/1999 | Ryan S | 5/14/2010 | Morgan S | 6/10/2005 | Charles W | 7/11/1983 | Ella B | 8/18/2003 |
| Ruben & Louca U | 4/22/2007 | Jaylin L | 5/15/1992 | Caitlin K | 6/10/2009 | Andrew H | 7/11/1989 | Alicia M | 8/19/1997 |
| Colcen S | 4/23/1993 | Maille J | 5/15/2007 | Chris L | 6/11/1990 | Lauren C | 7/11/2000 | Avery W | 8/19/2003 |
| Samantha S | 4/23/1993 | Brynleigh B | 5/16/2005 | Massimo N | 6/11/2007 | Adrianna D | 7/11/2006 | Timothy F | 8/19/2004 |
| Matthew R | 4/23/2004 | Nathaniel K | 5/17/2006 | Tori M | 6/12/1992 | Erica S | 7/12/1986 | Annabel P | 8/19/2006 |
| Lucia G | 4/24/2004 | Aidan P | 5/17/2006 | Shadi T | 6/12/2007 | Gabrielle P | 7/12/2001 | Sarah D | 8/23/1998 |
| Bernhard K | 4/24/2006 | Eli F | 5/18/1999 | Nicholas S | 6/13/2006 | Christine D | 7/13/1991 | Colt C | 8/24/1993 |
| Tyler B | 4/24/2006 | John L | 5/20/1994 | Guillaume L | 6/13/2009 | Alec A | 7/13/1999 | Simone C | 8/24/2008 |
| Hannah Rose H | 4/25/2001 | Jack D | 5/20/2003 | Brayan A | 6/14/1996 | Tanner J | 7/13/2006 | Marian I | 8/25/1992 |
| Alexis J | 4/25/2002 | Isabella M | 5/20/2008 | Sophie D | 6/15/2003 | Kira G | 7/15/1998 | Stephen M | 8/25/2006 |
| Elisabeth A | 4/27/1995 | Lindsey Y | 5/22/1998 | Ignacio A | 6/15/2007 | Nicholas D | 7/18/1995 | Reuben B | 8/26/2001 |
| Paige J | 4/28/1992 | John Callum D | 5/22/2001 | Heather W | 6/16/1992 | Jessica M | 7/18/1998 | Chase M | 8/27/2007 |
| Robert M | 4/28/1994 | Bradley W | 5/22/2005 | Messiah W | 6/16/2000 | Elizabeth R | 7/18/1999 | Charlotte J | 8/28/2003 |
| Ava E | 4/28/2005 | Mason M | 5/22/2007 | Andy A | 6/17/2005 | Erin O | 7/19/2001 | Ashley Q | 8/29/1991 |
| Crystal O | 4/30/1987 | Brenden O | 5/24/1991 | Andrew B | 6/18/1990 | Olivia T | 7/19/2002 | Rachel H | 8/29/2003 |
| Maykayla Rae S | 5/2/2008 | Alice Margaret T | 5/24/1996 | Richard H | 6/18/1996 | Travis R | 7/20/1998 | Kevin L | 8/29/2006 |
| | | | | James M | 6/18/1996 | Luke S | 7/23/2007 | Madison H | 8/29/2008 |
| | | | | Isabella D | 6/18/2001 | Lizzie C | 7/23/2007 | Kacey T | 8/30/1993 |
| | | | | Lachlan D | 6/18/2005 | Michell Lilliane K | 7/24/2001 | Shannon N | 8/30/1994 |
| | | | | Yuri P | 6/20/1975 | | | Keshavarudra G | 8/30/2005 |
| | | | | Kyrstyn B | 6/22/1998 | ✶Clare T | 7/25/1980 | ✶Joshua D | 9/1/1994 |
| | | | | Hana C | 6/22/1998 | Zoe N | 7/25/2002 | Harry W | 9/1/2000 |
| | | | | Trevor B | 6/23/1994 | Hunter S | 7/27/2006 | Stephanie C | 9/1/2001 |
| | | | | Carly C | 6/23/1999 | Jacob A | 7/28/2005 | Brenda M | 9/2/1989 |
| | | | | Klara H | 6/24/1992 | Samuel O | 7/28/2005 | Alex K | 9/2/2005 |
| | | | | Jonah C | 6/24/1999 | Colin O | 7/30/1998 | Cara V | 9/3/1992 |
| | | | | Grace L | 6/24/2003 | Emily M | 7/31/1980 | Rylei C | 9/3/2007 |
| | | | | Sara H | 6/26/1993 | Sidney Z | 8/1/2005 | Tom E | 9/4/2002 |

Our Son Adam *continued from page 9*

surgery to have the VNS (Vagal Nerve Stimulator) implanted. We have seen him go from not being able to get out of bed for more than a couple of hours at a time in December to being back in school for a full day by late February.

Now I find myself having to redouble my efforts as Adam begins another transition. He is a 12th grader this year and should be moving on to a new, more intensive program of life and vocational skills. Sadly, our county has two options. One is for very low functioning students (mainly medically fragile or children with difficult behaviors). The other program is for higher functioning students who are ready to go out to work on a job site. Neither is appropriate for Adam, so I'm back in the fight. I plan to work to get the county to develop a new program that fits his needs as well as those of many other kids like him. I want them to dedicate space for an



Happy Birthday to you...

| | |
|-----------------|-----------|
| Claire G | 9/7/1982 |
| Livia G | 9/7/2002 |
| Cheyenne D | 9/8/1992 |
| Elana K | 9/9/1988 |
| Bente S | 9/9/1997 |
| Holdon W | 9/9/1999 |
| Thomas N | 9/10/1993 |
| Dante R | 9/10/1997 |
| Major Jackson R | 9/10/1998 |
| James Andrew S | 9/11/1992 |
| Waawijja W | 9/11/1993 |
| David S | 9/11/2001 |
| Julia W | 9/12/1996 |
| Christina L | 9/12/1998 |
| Thomas Q | 9/12/2001 |
| Casey W | 9/12/2003 |
| Caitlin B | 9/12/2005 |
| Rachel M | 9/14/1994 |
| Raquel L | 9/14/2000 |
| ✧ Breana E | 9/15/1995 |
| Mason L | 9/15/1999 |
| Zachary L | 9/16/2002 |
| Jeremy L | 9/17/1988 |
| ✧ Cameron P | 9/17/2000 |
| Ryder W | 9/17/2005 |
| Conor M | 9/19/1996 |
| Harrison M | 9/20/2007 |
| Lara P | 9/21/1993 |
| Sarah L | 9/23/1975 |
| Paul H | 9/23/1994 |
| Allison K | 9/23/1997 |
| Brenna G | 9/23/2002 |
| Eric H | 9/24/1990 |
| ✧ Brandon J | 9/24/1997 |
| Audrey K | 9/27/2007 |
| Evan M | 9/28/1994 |
| Madison W | 9/28/2000 |
| Kahnee Y | 9/29/2004 |
| Peter K | 9/30/1993 |
| Stephen G | 9/30/1999 |

apartment so that our kids can practice living on their own. They should learn to do whatever is necessary including bathing, preparing meals, cleaning their living space, going to work and enjoying leisure skills during their free time. They should actually go to a job site to learn what will be expected of them when they age out of school. We parents teach them these things at home – our schools should also be teaching these skills. Schools prepare typical children to enter the workforce or go on to higher education after 12th grade. They need to do what's necessary to prepare our children for adulthood. Eventually I expect him to work half days on life skills and the other half of his day on a job site.

We are now Adam's legal guardians, which gives me some comfort. He is also receiving a check from the Social Security Administration each month which helps a lot with on-going expenses related to his therapies and support, etc. I can now see a light at the end of a very long tunnel. I've been preparing for his adulthood ever since we found out he has IDIC 15.

Adam has grown up to be a wonderful young man with many strengths. He is still non-verbal and he still has many stims. He is still not very social. I can now see a light at the end of a very long tunnel. He still wants to play only Disney music. Most of his toys are stuffed animals (Disney characters of extremely well liked by his course). He is, however, I've been preparing for his adulthood ever since we found out he has IDIC 15. teachers and his peers at school. He can sit and work on tasks for 30 minutes at a time which bodes well for future employment. I know that he'll be able to live semi-independently and have a job in the future, even if that means he will always need supervision and a good deal of help.

I have been working towards the end goal, which for us was to come out of school with the skills to have a job and live in a group home. I expect nothing less. Our state doesn't fund programs for persons with disabilities as they should, so we've been thinking about other ways to get Adam into a home of his own. I am now talking with parents about pooling our resources and talents to run a group home ourselves. We have a rental home that we're considering using to house young men with disabilities when Adam is finished with school. We would have to hire people to run it and oversee the program, but I am sure it can be done. I am beginning to visit group homes in the county as well as vendors to see what kinds of jobs are out there for him. We have just a few more years to get him ready for the real world. I plan to make good use of each day so that our dreams for Adam come true.

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.



Save the Date:
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June 23rd, 24th, 25th 2011

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www.crowneplaza.com/philadelphia-centercity

Reserve your rooms by Saturday, May 21, 2011

Reserve under IDEAS for special rate. Room rates are locked in at \$159 per night plus tax. Overnight parking is currently \$33 per night but might increase slightly. Hotel is located in the center of Philadelphia. For questions - contact Cindy Johnson at cynthiaj100@verizon.net

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