

# THE MIRROR

The Newsletter of  
**IDEAS**

IsoDicentric 15

Exchange, Advocacy & Support



If you are reading this, you have likely already asked yourself (probably many, many times), “What is it that is affecting my loved one’s health and development so profoundly? What is going on here? And why?” Maybe it was recently or perhaps it was years or even decades ago that you first asked those questions, but if you are reading this, you found the answer: chromosome 15q duplication (dup15q) syndrome. For most families affected by dup15q, IDEAS is one of the first—if not the very first—stops on our journey to understand and help our loved one. And it is a stop we return to again and again.

This leads us to ask, “What exactly is IDEAS, this group that helps those affected by dup15q, and how did it come into existence?”

This grassroots, all-volunteer organization is a safe place (and often a second family) for members. It is a trusted

source of information: We can turn to IDEAS for practical advice from families who have walked this road before us as well as the latest scientific information from experts in the fields of neurology, genetics, and more. It is an invaluable educational resource for both families and medical professionals. And, of course, it is an oasis of support. This issue of *The Mirror* will take members on a short tour of this organization that means so much to so many people.

Visit IDEAS’ past with “The History of IDEAS,” and then learn about our present and future with “IDEAS Committees & Services” and “Corporate Officers and Board Members.” The article “Celebrating Twenty Years of the Americans With Disabilities Act” explains the history of the civil rights legislation and introduces the new assistive device tag. The tag can be attached to strollers and other devices to alert others (such as, business owners and employees) of the necessity of the device for the disabled person. Also in this issue, readers can get a glimpse of Italian dup15q families’ endeavors in “The IDIC 15 International Conference in Italy: Hope and Answers for Families.”

Also, two new ongoing features are being added to *The Mirror*. “Family Favorites” is a list of tried-and-true winners recommended by members. The “Quarterly Financial Report” fulfills the strategic goal of providing members with quarterly budget updates. Finally, be sure to check out the very important information on page 3 about the Pepsi Refresh Project, which could award IDEAS a \$50,000 grant to fund the upcoming research meeting and reduce the cost for families to attend the international conference next summer. You can vote for IDEAS three times daily.

To learn all about dup15q, visit the official IDEAS website at [www.dup15q.org](http://www.dup15q.org). To learn all about IDEAS (and how you can get more involved with this very special organization), just turn the page!

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JEAN, A FREELANCE EDITOR, LIVES WITH HER HUSBAND, CHRIS, AND 3-YEAR-OLD SON, JONAH (DUP15Q), IN WILMINGTON, N.C. E-MAILS ARE WELCOME AT [JEAN@EDITORHOUSE.COM](mailto:JEAN@EDITORHOUSE.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.

<http://www.dup15q.org>

# The History of IDEAS: How Did It All Begin



by Kadi Luchsinger, Executive Director

IDEAS is a grassroots support and advocacy group for families affected by chromosome 15q duplication (dup15q) syndrome. Today, it is a thriving and growing international organization of hundreds of families. But less than 25 years ago, it began with a genetic counselor and a mother who were determined to find families living with dup15q syndrome.

In 1987, Donna Bennett enrolled her son, Josh, at Elwyn Institute in Elwyn, Pa. There they met Brenda Finucane, a genetic counselor. Together, Brenda and Donna made a powerful advocacy team for people affected by dup15q syndrome. Although they knew Josh's symptoms well, they could not find any information in the literature about the disorder, and they couldn't find any other people who had a similar diagnosis.

One day, Brenda noticed a letter from a parent in the "Letters and Search" column of a 1990 issue of *Exceptional Parent* magazine. From the description, she recognized a child who was very similar to Josh. She encouraged Donna to write to the magazine, and Donna's letter was published in the April/May 1992 issue. Soon, three families responded to Donna's inquiry. When Brenda learned that there were four families who had found each other, she encouraged Donna to start a support group. This was the birth of IDEAS.

Brenda and Donna nursed the fledgling group out of Brenda's office at the Elwyn Institute for years. During this time, the institute underwrote the cost of the group's newsletters and the first two IDEAS conferences. Acting on a lead given by one of the families who wrote to *Exceptional Parent*, Donna contacted MUMS (Mothers United for Moral Support) National Parent-to-Parent Network. This organization connected her with 14 more families. Then, at Brenda's suggestion, Donna connected with the Alliance of Genetic

Support Group (now the Genetic Alliance) in Washington, D.C. IDEAS gained 11 more families. The *Exceptional Parent* exposure also continued to grow the group. When asked in the early years how they found IDEAS, 26 families said they found the group through the magazine or its Resource Guide. By 1995, IDEAS was serving 45 families.

That January, Donna obtained a grant from Gladfelter Insurance Group (her insurance agency) to print brochures describing children with dup15q syndrome. The next year, Brenda wrote a grant proposal for money to produce newsletters and a direct mailing of brochures to all genetic counselors in the United States to make families aware of IDEAS. As a result of these efforts, by 1998 the group had grown to 114 families.

In April 1999, a Listserv was established. This Internet forum allowed families and professionals to share information, ideas, and stories, make friends, and support each other. The listserv allowed IDEAS families to post documents to a shared files section and create a gallery of photos of individuals affected by dup15q. Also, a website was established to facilitate people seeking information.

In 2001, the first International Conference on Isodicentric 15 and Related Disorders was held with the support of Elwyn, Inc. At that conference, a group of interested parents formed a board of directors fueled by Nicole Cleary and began discussions to build an independent support and advocacy organization. Elwyn assisted IDEAS again in 2003 to host its second international meeting. In 2004, IDEAS was formally incorporated in the state of Oregon with the help of Todd Luchsinger, CPA. At this point, we were officially on our own.

Growing Up Together, our third international conference, was held in Shaumburg, Ill. *Continued on page 4...*



This year, the IDEAS board created a strategic plan to guide the organization through 2013. Here are the goals from the plan. (To see the full document, visit [www.dup15q.org/strategicplan.html](http://www.dup15q.org/strategicplan.html).)

**IDEAS** will assess and implement an organizational restructuring and strategic succession plan for the purpose of strengthening and maintaining continuity in organizational operations by June 2010.

**IDEAS** will help establish research priorities in dup15q syndrome and will host annual scientific meetings to build multi-disciplinary collaborative efforts to promote research into dup15q.

**IDEAS** will establish and promote family involvement in an IDEAS research registry.

**IDEAS** will seek the involvement of a graduate student(s) to develop a "family guide to dup15q" that will assist families in understanding best practices for supporting children with dup15q from birth into adulthood.

**IDEAS** will establish a targeted awareness campaign with a focus on pediatricians, neurologists, geneticists, parents of children with autism or epilepsy disorders, and early childhood intervention programs.

**IDEAS** will develop, communicate, and provide quarterly status updates to families on a three-year budget that supports the goals in the strategic plan.

**IDEAS** will encourage and support families in holding fundraising events to help IDEAS exceed each annual operating budget and support continued growth for the organization.



## IDEAS Committees & Services

IDEAS is always looking for volunteers. Following is information about the many ways IDEAS helps our families.

### FUNDRAISING COMMITTEE

This committee meets quarterly via conference call to discuss fundraising ideas. It develops plans to help IDEAS reach its financial goal. The IDEAS store is also part of this committee. We are looking for people to help with a grant writing subcommittee as well. The Fundraising Committee is always seeking fresh ideas and new energy, so if you are interested please e-mail [info@dup15q.org](mailto:info@dup15q.org)

### SUNSHINE COMMITTEE

This committee sends birthday cards to all of the children and adults with dup15q on their special day. Karen Sales is the coordinator of the Sunshine Committee. She distributes the birthday list to our fantastic volunteers, and they send out the cards. If you are interested in helping, please contact Karen at [ksales76@msn.com](mailto:ksales76@msn.com).

### CONFERENCE PLANNING COMMITTEE

Cindy Johnson chairs this committee. The committee is now working hard to plan the 2011 conference, which will take place June 23-25 in Philadelphia. This committee helps with T-shirts, totes, registration, finding and securing speakers, planning the menu, and the other many details that go into making each conference fantastic.



The fifth annual Idic 15 5k/15k run was held in Killington, Vt. The event, chaired by Sarah Rasmussen, raised more than \$17,000 for IDEAS. Thank you! Families pictured are: the Doucettes, the Bopps, the Poores, the Trues, the Rivards, and the Luchsingers.

### The Mirror

*The Mirror* is published quarterly. We welcome articles about IDEAS events and stories of children and adults who have dup15q syndrome and their families. Each issue includes a Family Portrait and Reflections from a Sibling. If you enjoy writing or photography and would like to share with other IDEAS families through *The Mirror*, please e-mail [jean@editorhouse.com](mailto:jean@editorhouse.com).

### PARENT MATCH

This is a service that IDEAS offers to our families. Families can call or e-mail if they want to connect with another family for support. Volunteer mentors contact these families in need as well as make phone calls to welcome new families to IDEAS. We can always use volunteers for this committee; we ask that you have had your child's diagnosis for at least two years before providing support to other families.

### RESEARCH COMMITTEE

This is the committee that interacts directly with our scientific advisors to propel research about dup15q syndrome. This committee is also involved in the development of a medical registry.

### PUBLIC RELATIONS COMMITTEE

This is an emerging committee, to be formed soon. IDEAS hopes to launch a public awareness campaign and will need a committee to assist with this. If you are interested, please contact [info@dup15q.org](mailto:info@dup15q.org).

### WEBSITE

IDEAS is looking for people to assist with monitoring and updating the website. Please e-mail [info@dup15q.org](mailto:info@dup15q.org) for more details.

## Please Vote in the Pepsi Refresh Project

We are in! And we need your help! IDEAS is in the running for a \$50,000 grant to support our international conference (June 23-25, 2011). This grant would fund our research meeting and significantly reduce the costs for our families to attend the conference. We need you to vote **THREE** ways every day and ask your friends and family to do the same! Here are the **THREE** ways to vote daily:

1. [www.refresheverything.com/dup15q](http://www.refresheverything.com/dup15q)
2. Text 103709 to Pepsi (73774)
3. Facebook using the Pepsi Refresh link

Spread the word. Ask friends and family to sign up at [www.dup15q.org](http://www.dup15q.org) to get daily reminders to vote. We can do this!

If you have questions, please call (877) IDEAS-15 or e-mail [info@dup15q.org](mailto:info@dup15q.org). Voting ends November 30, but if we don't get the grant this month and are in the top 100 IDEAS will be qualified for December, so please vote!

### JOIN BIG TENT TODAY!

**BIG TENT IS OUR ONLINE FORUM WHERE FAMILIES CAN CONNECT, ASK QUESTIONS, LEARN FROM EACH OTHER AND, LAST BUT NOT LEAST, SUPPORT EACH OTHER. VISIT [WWW.DUP15Q.ORG](http://WWW.DUP15Q.ORG) FOR THE LINK TO BIG TENT. IDEAS HAS A RESTRICTED GROUP. THE GENERAL PUBLIC CANNOT JOIN. YOU MUST BE A REGISTERED FAMILY WITHIN IDEAS TO READ AND POST TO THE FORUM. THIS RESTRICTION IS IMPORTANT TO MAKE THE FORUM A SAFE AND SECURE SITE FOR OUR FAMILIES. IT IS IMPERATIVE FOR YOU TO SIGN UP, AS BIG TENT IS OUR MEANS OF TRANSMITTING IMPORTANT INFORMATION QUICKLY TO OUR MEMBERS. DON'T DELAY. SIGN UP TODAY!**



### BIG TENT TIP

SOME IDEAS MEMBERS HAVE SAID THAT THEY DO NOT HAVE THE TIME TO READ ALL OF THE E-MAILS FROM BIG TENT. YOU CAN ADJUST YOUR SETTINGS TO RECEIVE THE E-MAILS IN A SUMMARY FORMAT. THIS WAY YOU CAN SCAN THROUGH THE CHATTER AND SEE WHAT IS OF IMPORTANCE TO YOU. IF YOU NEED HELP WITH YOUR SETTINGS, PLEASE E-MAIL [INFO@DUP15Q.ORG](mailto:info@dup15q.org).

## Financial Report: What About the Dollars & Cents



by Tom Doyle, Vice President of Finance

As we near the end of the third quarter in our fiscal year, we currently have \$278,795 in our bank accounts. We have established strong review procedures for our budget and finances. The largest sources of income during the first three quarters of the year have been from the IDEAS Golf Tournament in Illinois (netting more than \$13,000 so far) and more than \$20,000 in gifts and memorials. We anticipate significant sums coming in soon from the Fun Run in Vermont.

Our major expenditures up to this point in the year have been the costs to send members to a research meeting in Philadelphia and the purchase of donor software to help better track and serve our donor base. According to the annual budget, to date we have brought in \$7,000 more than budgeted and spent nearly \$11,000 less than budgeted. We are attempting to be good stewards of IDEAS funds so that we can provide great information, conferences, research, and support for our families. Should you have any questions about the budget, please feel free to contact me at [tkdoyle@speakeasy.net](mailto:tkdoyle@speakeasy.net).

## Celebrating 20 Years of the ADA Introducing the IDEAS Assistive Device Tag

by Rachel Doucette, Vice President of Communications

**T**wenty years ago, the Americans with Disabilities Act (ADA) was signed, extending civil rights protection to people with disabilities. The ADA defines those covered by the law as follows:

***To be protected by the ADA, one must have a disability or have a relationship or association with an individual with a disability. An individual with a disability is defined by the ADA as a person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment. The ADA does not specifically name all of the impairments that are covered.***

Discrimination may occur intentionally or unintentionally, from ignorance or prejudice, and may occur from an individual or from a company or organization (including employers or schools). Many components of the law protect those with disabilities. These components include employment, public transportation, telephone service, accessibility, education, healthcare, labor, housing, parks and recreation, and agriculture. The corresponding federal agencies with ADA responsibilities include the Equal Employment Opportunity Commission, Department of Transportation, Federal Communication Commission, Access Board, Department of Education, Health and Human Services, Department of Labor, Housing and Urban Development, Department of the Interior, and Department of Agriculture.

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*History of IDEAS from page 2...*

This was the first conference that IDEAS conducted independently, with Jodi Miller and Jane True serving as the chairs.

By 2006, more than 300 families affected by dup15q syndrome (the current umbrella term for idic(15) and interstitial duplications of chromosome 15) were registered with IDEAS. That was the year IDEAS completed its first strategic planning process, with a nine-member board. The year 2007 brought our fourth international conference, Sharing the Journey, to Boston and a few changes to IDEAS. Nicole Cleary stepped from the executive director position into the role of board chair, and I became the executive director.

The past two years have been very busy. In 2009, Heather Bruce chaired our sixth international conference, Full Steam Ahead, and the IDEAS board grew to 12 members. In May 2010, IDEAS held its first scientific meeting in conjunction with the International Meeting for Autism Research (IMFAR) in Philadelphia, Pa. (visit [www.dup15q.org/spring-summer-2010\\_web.pdf](http://www.dup15q.org/spring-summer-2010_web.pdf) and refer to the spring/summer 2010 issue of *The Mirror* for all of the details). IDEAS decided that we will continue to hold annual scientific meetings in addition to the conferences, which are held every other year. Also in 2010, the IDEAS board once again embarked on a strategic planning process to guide the growth of the organization over the next three years. (The full strategic plan can be found on the IDEAS website; the goals set for 2010-2013 are in the sidebar, "Strategic Planning" on page 2.)

To date, more than 600 families benefit in many ways from their association with IDEAS. Advances within IDEAS and in genetic testing have fueled the organization's growth. In the past 15 years, we have added more than 550 families, with our largest growth in the past few years. Families can communicate with one another and with the IDEAS leadership in a variety of ways. The organization has an extensive and easy-to-navigate official website ([www.dup15q.org](http://www.dup15q.org) or [www.idic15.org](http://www.idic15.org)), as well as an active message board ([www.bigtent.com](http://www.bigtent.com)). IDEAS publishes a quarterly newsletter, *The Mirror*, which is available through the U.S. mail or via e-mail (archived issues are available on the official website). A Parent Match program provides individual matches upon request, so newer families can turn to more experienced families for information and support. Currently, a registry database is in the development process. IDEAS offers regional gatherings for families as well as the biannual international conference.

In addition to encouraging communication and education for families, IDEAS also supports and facilitates research into dup15q syndrome. Fundraising efforts are always ongoing so IDEAS can fund these many projects and services. I am extremely proud of the growth of IDEAS and equally excited to see the goals in our strategic plan fulfilled.



## Corporate Officers and Board Members



**BOARD CHAIR LEN POORE** lives in Tewksbury, Mass., with Joanne, his wife of 33 years, and their two children. Their son is a graduate student at UMASS Lowell and their daughter, diagnosed with dup15q syndrome, attends the LEAP program at the local high school. The LEAP program is a transition program providing life skills training and on-the-job work experience. For more than 35 years, Len has been employed by MetLife, where he is a senior business systems consultant. His business background includes various management positions with responsibilities for both budgeting and project resource management. He was elected to the IDEAS board in September 2007, was elected board chair in June 2010, and has served on the Fundraising Committee since 2008.

**EXECUTIVE DIRECTOR KADI LUCHSINGER** joined the board in 2004 and became executive director in 2007. Kadi helped to start the Parent Match program, which is a mentoring program to connect families. She has been involved in the Conference Planning Committee since 2004, as well as the Fundraising Committee. Her favorite activity within IDEAS is talking with new families. She is extremely proud of the growth in IDEAS and is looking forward to getting the registry up and running. She lives in New York with her husband, Todd, and their three children.

**VICE PRESIDENT OF COMMUNICATIONS RACHEL DOUCETTE** is the mother of a child with dup15q syndrome and has a background in nutrition. This is her second year serving on the IDEAS board; she is currently serving as the vice president of communications. While serving on the board, Rachel hopes to increase awareness of dup15q and IDEAS within the medical and educational systems; facilitate a nutrition component within the IDEAS population; help identify and secure significant funding sources; assist in communication among members, to the public, and within the board; and support families, caregivers, therapists, teachers, and physicians in relation to dup15q syndrome.

**VICE PRESIDENT OF FINANCE TOM DOYLE** is the grandfather of Grace Lowell (age 7, daughter of Jeff and Colleen). A retired high school teacher and athletic director, Tom lives in Bellevue, Wash. He became a board member in 2009, prior to the Indianapolis conference, and has taken over the financial officer/treasurer duties. As a grandparent, Tom has the time and energy (as long as it lasts each day) to be involved with this wonderful organization. He also is attempting to be involved in the extended family message board on Big Tent and hopes to encourage other grandparents and family members to be actively involved with IDEAS, to learn more about the organization and our children.

**CORPORATE SECRETARY KAREN SALES**, the mother of William, 7, has been involved with IDEAS since her son's diagnosis in 2004. Besides attending all three conferences since then, she has been involved with the Sunshine Committee, Fundraising Committee, and Conference Planning Committee, and is now the corporate secretary. IDEAS has definitely been her family for the last six years and she wants to give as much as she gets! Karen works as an economist for the U.S. Department of Labor in Ankeny, Iowa. She has discovered that one of her passions in life is to raise awareness and understanding of disabilities.

**BOARD MEMBER PATTI RUBEL'S** son, Adam, was diagnosed with dup15q syndrome at two years of age. He is 19 years old now. Patti joined IDEAS  
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# IDEAS

## CORPORATE OFFICERS & BOARD MEMBERS

LEN POORE Tewksbury, MA	Board Chair
KADI LUCHSINGER Fayetteville, NY	Executive Director
RACHEL DOUCETTE Georgetown, MA	Vice President of Communications
TOM DOYLE Bellevue, WA	Vice President of Finance
KAREN SALES Ankeny, IA	Corporate Secretary
PATTI RUBEL Fairfax, VA	Board Member
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CINDY JOHNSON Wrightstown, NJ	Board Member
LISA LIGHTNER Avondale, PA	Board Member
LINDA MEAGHER Sugar Land, TX	Board Member
DONNA BENNETT Thomasville, PA	Co-Founder & Lifetime Board Member

## PROFESSIONAL ADVISORS

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

# The IDIC 15 International Conference in Italy: Hope and Answers for Families

by Patti Rubel



Recently, I had the pleasure of attending the IDIC 15 International Conference in Italy. The conference was held September 8-11 at an old monastery outside of Florence in a city called Prato. Cristina Cannugi, who coordinated the conference, asked me to come speak to the families about my experiences with my son Adam over the years.

I flew out of Washington, D.C., on Wednesday evening and landed in Florence around 4 p.m. on Thursday. Eventually, I made it to my hotel, which was located on the Arno River within walking distance of downtown Florence. I planned to spend the next day sightseeing, and Florence did not disappoint. Its art galleries and beautiful churches were breathtaking.

Early Saturday morning, I checked out of my hotel and (after a number of mishaps) got to Prato mid-afternoon. I sat in on the presentation by Dr. Mario Beghi, who is head of the Italian National Association for Epilepsy and leader of a research team in Milan at the Italian Research Institute. The families had many questions for him, and it was obvious that what he had to say was very helpful. After Dr. Beghi's presentation, I spoke to the group, mainly about the treatments and therapies that we've tried over the years with Adam. I had put together a slide show with pictures of Adam from an early age, doing all

sorts of things like riding a bike, riding horses, skiing, and enjoying amusement parks, just to name a few.

The families were particularly interested in hearing about the U.S. education system. I noted some significant differences between not just our education systems, but also our health services and access to private therapies. The United

*“The best part of the conference for me was meeting the families and spending time with the children. They were warm and loving people who made me feel very welcome.”*

States seems to be much more advanced in all three areas, although it appears that Italy is trying hard to catch up.

On Saturday evening, a wonderful group came to the monastery to entertain the children. The troupe sang, danced, and put on funny skits. The performance took place in a beautiful courtyard with gorgeous gardens reminiscent of Versailles. It looked like something straight out of a Hollywood movie! In true Italian fashion, dinner began at 8 p.m. I am not

sure how the children lasted until then, but I suppose that is what they're accustomed to.

There was a great presentation about Applied Behavioral Analysis (ABA). I learned that this therapy is only just now getting a foothold in Italy. ABA is not being used in classrooms yet; rather, it is offered as a private therapy in a few places (mainly in northern Italy). After the ABA presentation, a gentleman spoke to the group about the benefits of exercise for our kids. He owns a gymnasium and works with children who have gross motor deficits. The families were able to see how this intensive therapy can help our kids learn to walk and navigate their daily environments. The final presenter explained to the families (many of whom are new to IDEAS and have small children) how to use Big Tent. The Italian families also have their own website about dup15q syndrome, [www.idic15.it](http://www.idic15.it).

The best part of the conference for me was meeting the families and spending time with the children. They were warm and loving people who made me feel very welcome. I intend to stay in touch to help them keep current about the latest treatments and therapies, so their children can be the best they can be.



In this issue of *The Mirror*, we are introducing the “Family Favorites” feature. This quarter, we asked IDEAS families to share **WEBSITES, SOFTWARE AND PHONE APPS** that their kids benefit from, use, and enjoy.

- [www.starfall.com](http://www.starfall.com): Practice reading with phonics
- [www.jumpstart.com](http://www.jumpstart.com): Adventure-based play teaches math, reading, and critical thinking
- [www.zacbrowser.com](http://www.zacbrowser.com): A browser specifically for children with autism spectrum disorders
- [www.intellitools.com](http://www.intellitools.com): Classroom tools for students who face learning challenges
- [www.funschool.com](http://www.funschool.com): Games and activities for preschool-6th-grade level
- [www.kindergarten.com](http://www.kindergarten.com): Products and apps based on Advanced Behavioral Analysis (ABA)
- Words Around Me: Software helps students with special needs to learn common words
- Millie's Math House: Software includes fun math activities
- IBooks: Various children's books

*Officers and Board Members from page 5...*  
around 1994, before there was a formal group. Soon she joined other parents to formally set up the organization we now call IDEAS. Patti served on the board for a couple of terms and enjoyed it very much, as it was exciting to see our small, informal group of parents grow and change into a very productive organization whose main goal is to help families. Patti and her husband, John, have another son, Matthew, who is 14 years old. They live in Fairfax, Va., just outside of Washington, D.C. John works for Accenture, and Patti homeschools Matt and oversees Adam's school program, in addition to serving on local disability boards. Patti is thrilled to be back on the IDEAS board and hopes to make a strong contribution to IDEAS over the next couple of years.

**BOARD MEMBER MIKE PORATH** lives just outside of Los Angeles with his wife, Sarah, and their two children, Annabel, 4 (dup15q), and Isaac, 1. Mike spent the last 12 years in New York and Washington, D.C., working as a journalist for ABC News, NBC News, *The New York Times*, and AOL. Last summer, the family moved to L.A., where Mike manages a network of pop culture websites as a senior vice president of BuzzMedia. Mike joined the IDEAS Fundraising Committee in 2009 and was elected to the board in 2010.

**BOARD MEMBER RYLIE MCHAM** is the mother of Jimmy, who is 5 ½ years old. Her family moved to Columbus, Ohio, from Colorado a little over one year ago. Rylie grew up in Columbus, where her family still lives. She says it has been really great to have the resources that Columbus offers, as well as the support of family; now Jimmy is surrounded by his cousins. Rylie is a social worker and recently returned to work. She does individual counseling and some conflict resolution services for people with disabilities. She recently joined the IDEAS board and is excited to be involved. She feels she has benefited so much from IDEAS knowledge and support, and she is thrilled to be able to participate and give back to such a wonderful organization.

**BOARD MEMBER CINDY JOHNSON** lives in New Jersey with her husband, Andy, and their three daughters. They have been members of IDEAS since 2003 after receiving a dup15q diagnosis for their youngest daughter, Alexis. Cindy and Andy retired from the U.S. Air Force in 2007 after 20 years of service.

They remain in New Jersey because of the outstanding services they receive for Alexis. Cindy is currently enrolled in a masters of arts program in elementary and special education. She will graduate this December. This graduate program is providing her knowledge to better care for Alexis and to become a stronger advocate for her and other children who have special needs. Cindy and her family have hosted four annual summer reunions for IDEAS families in the Northeast. Also, she served on the 2009 Conference Planning Committee and is the conference chair for the 2011 IDEAS conference being held in Philadelphia, Pa.

**BOARD MEMBER LISA LIGHTNER's** family consists of her husband, Dan, their son Kevin, who is 4 and has dup15q, and their other son, Brian, who turned 1 in March. The Lightners also have three greater Swiss mountain dogs: one old girl who is almost 12 and two young puppies less than a year old. Lisa did animal-assisted therapy with the older dog, who is now retired, and one of the puppies is in training to carry on the tradition. The Lightners live in southeastern Pennsylvania, near Philadelphia and Wilmington, Del. Lisa recently took on the role of fundraising co-chairperson, so most IDEAS members will hear from her as the committee ramps up fundraising efforts for next year. Lisa is looking forward to meeting many of you at the 2011 conference in Philly!

**BOARD MEMBER LINDA MEAGHER** is a former western New Yorker transplanted to Texas. She is wife to Mike and mom to Jessica, 12 (dup15q), and Madison, 10. Linda has been a member of IDEAS since the very first conference. When she and her husband walked into the Philly airport for their first conference and started meeting other parents, they knew they had found friends for life. Once their girls were a little older, Linda started helping out on the IDEAS Conference Planning Committee and the Sunshine Committee, and as a parent match for new families in Texas. The more she got involved, the more she could see the tremendous amount of work it takes behind the scenes to keep this wonderful organization moving forward to help families. Linda is honored to have been accepted to the board and is looking forward to assisting with the IDEAS public awareness campaign and helping develop a parent information book.

**LIFETIME BOARD MEMBER DONNA BENNETT** is the co-founder of IDEAS. Donna worked as a secretary for 16 years full time and 8 years part time. For 39 years, she has been married to Gary, who was a draftsman. Their children are Joshua, 34, who was diagnosed with dup15q syndrome and lives in a group home near his family, and Elizabeth, 32, who is a woodworker. Donna and Gary are now enjoying retired life. To learn more about Donna, please see the article "The History of IDEAS" in this issue.



The first annual Golf Outing was held in Chicago August 6. Ember Burke and Shannon Rozovics co-chaired the event, which included a wonderful day of golf, a silent auction, and dinner. More than \$14,000 was raised for IDEAS. Thank you! Pictured are: the Millers, the Boyds, the Horaths, the Krosses, Paul Karch, the Burkes, the Rozovics, the Quinlans, and Kadi Luchsinger.

## A Place at the Table

by Eileen Flood O'Connor

I am watching the movie “Home Alone” with our four kids and as an elderly character explains to the movie’s protagonist the inevitable complexities of family life, I am struck by the timing of this insight. Only seconds earlier our son Will, 7, had been yelling at our daughter Erin, 8, to “stop making so much noise and stop blocking the TV!” And, as is our routine, I had been imploring Will to please be quiet and let me correct Erin, because I am the mother.



Erin, who has a mosaic form of dup15q syndrome, prefers to stand as close to the screen as possible while reading aloud from a book in a voice several decibels above the television volume. This might be annoying to anyone trying to follow a program storyline, but it incites a particularly intense rage in Will, who (though 17 months younger than Erin) fancies himself the oldest and, therefore, enforcer of all house rules and regulations—especially those related to the TV.

But as the old man expounds on his own complicated relationship with his family, Erin retreats to the sofa, and we all grow quiet and listen. As he explains how love sometimes gets mixed up with other feelings and how sometimes you regret things that you do and say and how you treat each other even though you never stop loving, I look around the room and wonder if the message strikes a chord.

I know that Will and his younger brothers, ages 5 and 3, love Erin. When she spends a night at my parents’ house, her absence is palpable. With her seat at the dinner table empty, one of them inevitably laments, “I miss Erin.” (I bite my tongue and refrain from asking what exactly they miss because so often I spend dinner reminding Erin to stay in her chair or to stop banging her spoon, or repeating that she cannot bring eight books to the table or feed Mr. Rabbit her macaroni. Is it possible they don’t hear this commotion, or that they’re not as bothered by it as I imagine?) When my mother and I took Erin to Florida for a “girl’s trip,” her brothers greeted her with unabashed hugs and kisses upon our return. And Erin, in turn, spoke of “the brothers,” as she refers to them, constantly throughout the trip: “The brothers will meet us for dinner?”; “The brothers will go to the beach with us?” No, Erin, they are back in New York, remember? “But they will come with us,” she replied hopefully every time. She missed them; she loves them implicitly and shows her love in a way all her own.

A few weeks after Will was born in December 2002, we sent out a Christmas card with a picture of Erin happily holding her two-week-old brother on her lap. On the back of the card, we pasted another photo, taken seconds later: Will’s face scrunched up, mouth wide open in mid-scream, Erin’s arm across his body having just squeezed his forehead a little too affectionately. We thought it was funny—and so very typical—a love touch from a doting older sibling.



That Christmas we had yet to receive a diagnosis for Erin, then 17 months old. Motor delays aside, she otherwise appeared to be developing “typically.” We were living in London at the time and had recently been told by a respected neurologist that “there is a wide range of normal” and Erin just happened to be on one end of that spectrum (a verdict we

were more than happy to receive). It was just a few short months later, after we moved back to New York City, that a geneticist delivered the news that in fact we would be dealing with a very different type of spectrum. And that Christmas card would be the first snapshot of a very complicated sibling relationship in which “love touches” can easily be misconstrued as something a little less than love—something that is, frankly, more painful.

The geneticist who delivered the news to us was not all that familiar with dup15q syndrome but knew the life of challenges that lay ahead for Erin. And although much of that appointment remains a blur, I will never forget the advice he offered after we riddled him with questions: Where do we go? What do we do? How do we help her? Largely, he was stumped, but after reviewing the obvious course of therapies—OT, Speech, PT—he paused and added, “and I would suggest having more children. In these kinds of situations, siblings can offer a lot of support for her now and in the future, when you are gone.” While I wasn’t ready to wrap my mind around that last bit, I felt we could get on board with the siblings. My husband and I had both grown up in large families and had always hoped to surround ourselves with a similarly busy and boisterous crew. And while most days in the midst of our household chaos it’s hard to imagine “the brothers” providing Erin with anything more than a source of disruption from her favored activities, slowly they seem to be moving in the right direction, displaying definite glimpses of light and levity along the way.

While the boys have grown accustomed to Erin’s very singular approach (know-

*EILEEN FLOOD O’CONNOR AND HER HUSBAND, BILL, LIVE IN RYE, N.Y., WITH THEIR FOUR CHILDREN, ERIN, WILL, PATRICK, AND JAY. EILEEN, A FREELANCE WRITER, IS CURRENTLY WORKING ON A SERIES OF ESSAYS ABOUT THE CHALLENGES AND JOYS FACING PARENTS AND SIBLINGS OF CHILDREN WITH SPECIAL NEEDS.*

## “How you feel about your family is a complicated thing.”

—Old man in the John Hughes film, “Home Alone”

ing that a hug can quickly turn into a full nelson, that if they get between her and a favorite book or toy they may as well brace for the worst, and that sometimes there’s just no explaining a completely unprovoked scratch or pinch) they have also each come to share and delight in Erin’s very joyful spirit and creative take on the world. The younger two revel in her ability to engage with them in imaginative play for hours (cooking and caring for a host of stuffed animals), and they look forward each week to singing and dancing alongside her in music therapy. They know well and seek out the particulars that make her happy (yellow rubber ducks, strawberry ice cream, and Hannah Montana), and they serve as willing participants in the group nursery rhyme readings Erin orchestrates, smiling as she hands them each a book, instructs them to turn to the appropriate page, and commands “One, two, three: Read.” And even Will, our pragmatic police officer and toughest sell, appreciates the prism through which she views the world: how she eats her pizza backwards (crust first) and explains that on rainy days “the sun is hiding” and when the wind blows “the trees are dancing.”

About a year ago, Will learned that there is a word that can explain why his sister has difficulty with things that come easily to him and why she sometimes acts differently than other kids their age. His growing understanding and use of the word “autism” have given him a sense of control and a means

of explaining often inexplicable and embarrassing behaviors to his friends. I remember his prepping a classmate who was visiting our home for the first time that his sister has autism and “she may yell for no reason, or throw her book on the floor, or she might even scratch you.” I am sure the boy did not know what to expect, and he appeared entirely relieved when Erin bounded into the house after getting off her school bus with nothing more than a request for raisin toast and some time alone with her books.

It probably goes without saying that there were no in-depth discussions on the complexities of family life after our “Home Alone” viewing. Although I did note that while the kids were captivated by the young protagonist’s ingenious means of keeping robbers at bay while he was home alone, they were equally enthralled by his family’s reunion at the end. They were visibly thrilled when finally the boy was no longer alone. And while I was left to contemplate the nuances of our family’s dynamics, I realized that, regardless of what they each bring to the table, at the end of every day what matters most to them is that they each have a seat. However many times Erin pops up to add to her book stack or retrieve a missing stuffed animal, what matters is that she returns to her seat alongside them. And while I may grow distracted by banging utensils and flying food, for them that’s all it takes for order to be restored and the family to be complete.





# Cheers

to our Volunteers

by Tyler True

**Jane True** feels it was an honor to serve as editor of IDEAS' newsletter, *The Mirror*, for seven years. The Mirror is "the basic vehicle of communication" for the group, according to Jane. "It is the go-to document for the newly diagnosed to find out what life might have in store for them. It's really the only written record of our history as a group, of the support

we give one another." Even when they don't have time or energy for anything else, people around the world can participate in IDEAS by reading *The Mirror*.

Jane has always had a hand in volunteering for civic organizations, such as the Women's Symphony Alliance, Alvin Ailey dance troupe, Junior Tennis League, Kansas City String Quartet Program, and Easter Seals' "Kids on the Block" puppeteers; for public schools as an art appreciation teacher and as treasurer of the county Developmental Disabilities Board; and for other groups, including IDEAS.

After her daughter, Clare, was finally diagnosed with dup15q syndrome, Jane and her family looked for support. They attended the Williams Syndrome Association conference in 2000. (Williams Syndrome is a genetic disorder of the seventh chromosome.) Soon afterward, Jane's sister discovered IDEAS online.

Carrying on the work of Donna Bennett, Jodi Miller, Paul Rivard, Charlie Brady, Nicole Cleary, and other IDEAS members, Jane began contributing to *The Mirror* and edited the newsletter from spring 2004 until summer 2010.

She also served as a board member for a number of years.

Jane located a printer who helped the group by offering a significant discount. Her neighbor, professional graphic designer Peggy Durban, worked tirelessly for *The Mirror* at a fraction of her normal rate. As editor, Jane was also responsible for locating business leaders, physicians, and other professionals to contribute to each issue along with friends and families of IDEAS. She assembled and edited these articles, verified information, coordinated with the layout and graphic designer, and oversaw the printing.

Each quarter, Jane and the IDEAS board chose a theme for *The Mirror*, a key issue to focus on. Jane is particularly proud of "Facing Our Fears" (Spring 2008), which handled a difficult topic delicately yet realistically. Peggy Durban's graphics were critical in making the issue work. Many IDEAS families appreciated the tips for travelling with children with dup15q syndrome in "Travel" (Spring 2007). "Caring for the Caregiver" (Winter 2006) was an important issue," Jane says, "because it often gets overlooked."

Jane mentioned that one of the things she was most impressed with was the "Family Portrait," especially those columns written by the fathers. "Their stories were truly inspiring to other families, especially those new to IDEAS," Jane says.

For the benefit of the IDEAS community and for herself, Jane has passed along the responsibility of editing *The Mirror*. In the future, she plans to continue supporting IDEAS' families and events. With her free time, she is finishing her novel, *My Skiing Sister*, based on Clare and her family's life with dup15q.

Congratulations to Jane, IDEAS' Volunteer of the Quarter!

### Twenty Years of the ADA from page 4...

As parents, extended family members, caregivers, and friends of individuals with dup15q syndrome, we struggle daily with the many things we must do for the people we support; it can become overwhelming and frustrating when we encounter discrimination. Although the ADA exists, many advocates do not understand how this law applies to the individuals it is meant to protect. Learning the fundamental rights accorded to disabled individuals will empower you to not only face those experiences confidently, but to successfully achieve the most beneficial outcome when supporting the one you strive to protect. When advocates can articulate the disabled individual's

rights to anyone who may discriminate (whether intentionally or unintentionally), people affected by dup15q syndrome will be permitted access to all the activities and places to which they are entitled.

### ASSISTIVE DEVICE TAG

An assistive device is a tool, product, or type of equipment that helps a person perform an activity. For instance, these devices may help one move, see, communicate, or eat. They may be high-tech or very basic. Even another person could be considered a "device" that is necessary to achieve a task to aid a disabled person who otherwise would not be able to achieve the task without assistance. If this assistive device is

necessary for his or her disability, the device is subject to the disabled individual's rights as defined by the ADA.

IDEAS families have voiced concern about being prevented from using strollers to assist their disabled children in accessing environments. For example, a younger child with dup15q syndrome is in a stroller waiting with her family to enter a restaurant. The hostess informs the family that strollers are not permitted in the restaurant and the stroller parking area is located at the entrance. This may seem to be a reasonable request



Continued on page 11...

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# Reflections from a Sibling

by Kasaria J. Mackling



May, 25, 2007, was the day my little sister, Kaylor Jade, was born. At first, I didn't know what to think. All I knew was that I had a little sister. As Kaylor grew, she was soon diagnosed with dup15q syndrome. When my mom first told me, I remember feeling confused and somewhat scared. But now that Kaylor's grown up a bit, she's been doing all the things that the doctor said she'd never do. She's walking and talking. She makes eye contact and smiles.

Kaylor always amazes us, whether it comes to singing "Rain, Rain" or giving mom a kiss and saying "I yuv yu." She is very smart and loving. At times, I wonder what our life would be like if she didn't have special needs, but I'm always thankful that she's here with us.

Like all kids, Kaylor is scared of some things. She gets scared when our baby brother, Kole, chases her or when a loud noise comes by (she's getting more used to that now, though). The doctor says she has sensory processing disorder. When I

first heard of it, I thought it meant that it takes her a while to see things clearly—like when you're still half-asleep and you get up to go to the bathroom. But she can't tune out things like we can. She can hear a distant dog bark while we play at the playground. She can hear the cars rush by when our windows are open, and she can hear people eating at restaurants. Sometimes I wonder if she ever hears God's voice in the distance or angels singing. Isn't God always telling us things, but we are too distracted to hear? What if Kaylor hears?

Kaylor loves giving hugs and kisses. To be honest, sometimes it gets a little annoying. She'll follow you around the house, and when you turn around, she will open her arms wide and stand on her tippy-toes. Then she'll give you a big slobbery kiss and say "mwah!" A big smile will land on her face, and she will give you another big, slobbery kiss. "Mwah!" At times, she'll say "I yuvvvv yu!"

Kaylor is very smart. She's learned how to open the door. It's not a very good thing to learn, because we live in an apartment. The stairs are just a few turns from our door, so we have to lock it.

A lot of times I wonder, "What if Kaylor didn't have special needs?" But I just can't imagine her without her disability.

It makes her who she is, like a peanut butter and jelly sandwich. The peanut butter is nothing without the jelly. Kaylor is Kaylor, and I wouldn't change a thing.

Mom says Kaylor will never be able to live on her own. She says that Kaylor doesn't have a sense of danger. (I believe that because Kaylor will stand up and jump on the couch if she gets a chance.) So Kaylor will live with Mom and Dad for the rest of her life. It upsets me sometimes because I have trouble understanding that. I'm not sure why; I just can't.

Kaylor is always learning new things. Even if it's just a new word, we cheer for her and say "Yay, Kaylor! Good job!" Then she will be so happy that she will dance around the room and say, "Yay, yay, yay!" Now that Kaylor is in our lives, we view things differently. We are more thankful, for instance about being able to understand things and do the activities we could do so easily before. Before, if you had asked us if we were grateful, we'd say "Yeah, sure." But ever since Kaylor was born, we are more thankful and grateful to God for giving us these gifts. And most of all, for giving us Kaylor, our very special little girl.

*KASARIA, 13, IS THE OLDEST OF THREE CHILDREN. HER SISTER, KAYLOR, IS 3, AND HER BROTHER KOLE IS 15 MONTHS OLD.*

## Assistive Device Tag from page 10...

initially because the child may appear to be simply a young child in a stroller. The family informs the hostess that the stroller is required for their child because she is disabled. The hostess insists that the stroller will not be permitted in the restaurant. This is discrimination against that child, as the stroller is being used as an assistive device due to the disability. What should the family do? They should ask to speak to the manager. If the manager supports the message that the hostess communicated, the family should explain that this device and child are protected under the ADA. If



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the restaurant staff continues to discriminate, the family has options: They could request to involve the police or leave and not to patronize the establishment. If the establishment was simply unaware and makes accommodations without issue, then filing a complaint is probably not warranted. If the authorities become involved and/or the family chooses to leave due to discrimination, filing a complaint is probably reasonable.

In an effort to assist communication and facilitate access for those affected by dup15q syndrome, IDEAS has created an Assistive Device Tag, which can be used on any assistive device. The tag is a 2-by-3-inch, flexible, long-lasting vinyl luggage tag with a plastic strap that allows it to be attached

to any device. Printed on one side is the universal symbol for accessibility and the words "assistive device." The IDEAS logo is on the reverse. Tags can be purchased for \$5 from the IDEAS store at [www.dup15q.org](http://www.dup15q.org).

### FOR MORE INFORMATION, VISIT THESE SITES:

- ◆ ADA website: [www.ada.gov](http://www.ada.gov)
- ◆ ADA Guide to Disability Rights: [www.ada.gov/publicat.htm#Anchor-14210](http://www.ada.gov/publicat.htm#Anchor-14210)
- ◆ ADA Regulations & Technical Assistance Materials: [www.ada.gov/publicat.htm](http://www.ada.gov/publicat.htm)
- ◆ Disability.gov (users can also access individual state information on this website): [www.disability.gov](http://www.disability.gov)
- ◆ IDEA (Individuals with Disabilities Education Act): [idea.ed.gov](http://idea.ed.gov)

*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 duplication.*

### Save the Date:



June 23rd, 24th, 25th 2011

#### Crowne Plaza Hotel

Philadelphia Downtown  
Philadelphia, PA 19103

[www.crowneplaza.com/philadelphia-centercity](http://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](mailto:cynthiaj100@verizon.net).

#### It's Time for Direct Ask

Please do not forget to send in your end-of-year direct asks. 2011 will be a big year—with a conference, a research meeting, and a registry. Contributions of any amount are most appreciated.

Thanks in advance for your help!

#### Care to Go Paperless?

If you would like to receive your copy of *The Mirror* via e-mail rather than your friendly postal delivery person, please visit [www.dup15q.org/Mirror.html](http://www.dup15q.org/Mirror.html) to sign up for the newsletter online.

Or, if you prefer, you can send an e-mail to [ideasadministration@gmail.com](mailto:ideasadministration@gmail.com).

<http://www.dup15q.org>

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