

THE MIRROR

The Newsletter of IDEAS - IsoDicentric 15 Exchange, Advocacy and Support

2003 IDEAS Conference

The *Second International Conference for Parents and Professionals on IsoDicentric 15* is really taking shape! This conference promises to be an ideal combination of professionals and parents sharing information and experience about idic(15). The full conference agenda will be posted on the IDEAS website (www.idic15.org) in late January, 2003.

Conference Dates: Thursday, June 19 - Saturday, June 21, 2003. Registration opens at noon on Thursday and the first presentation is at 2 p.m. The conference officially ends at 3 p.m. on Saturday.

Conference Location: Airport Marriott Hotel, Philadelphia, PA (USA)

Conference Room Rate: Approximately \$99/night.

Conference Registration Fee: \$175.00 for professionals, \$150.00 for first parent, \$100.00 for 2nd parent and other adults 16 and over. There is no charge for anyone with idic(15) and for children under 16. The fee includes meals from Thursday dinner through Saturday lunch.

Conference Agenda: The conference agenda will address the following topics:

- Concepts in genetics for the person with idic(15)
- Idic(15) research update
- Smile stories from our kids
- Effective teaching strategies for children with idic(15)
- Verbal behavior training for the child with idic(15)
- Sensory integration: lifelong strategies
- Family life with your idic(15) child
- Sexuality in the child with idic(15)
- Alternative therapies: vitamins and nutritional supplements
- Education issues: labels, IEP's and placements
- Vocational training/transition to adulthood
- Taking care of the caregivers
- Seizure recognition and management
- Occupational therapy for the child with idic(15)
- Genetic counseling issues and idic(15)
- Mapping idic(15): A technical discussion of gene mapping

Isodicentric 15 idic(15), formerly known as Inverted Duplication 15, is a disorder in which a child is born with extra genetic material from chromosome 15. Symptoms may include: poor muscle tone, developmental disability, seizures, and autism. Although the exact prevalence is not known, Isodicentric 15 one of the most common causes of autism.

WANTED ...SMILE STORIES

As you may have read recently on the listserve, the conference committee has come up with a wonderful idea of putting together a smile stories booklet for our upcoming conference.

A mailing has been sent out detailing this effort. If you did not receive the mailing, contact Kathy Wise at jawise@compuserve.com or call her at 603-635-9077. She will get the information out to you as soon as possible.

We would love to see pictures of your beautiful children and hear any "smile stories" that you would like to share. Please start thinking about contributing to this booklet! It will be so inspiring for all of us! The deadline for submitting stories is 2/10/03.

--Smile Stories Team
Donna Bennett, Brenda Finucane, Kathy Wise

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CONFERENCE cont'd from previous page

Social Events:

Thursday Evening: All conference buffet dinner and DJ entertainment.

Friday Evening: Elwyn BBQ Dinner

Saturday Evening: Group outing to restaurant for dinner for families staying over.

Childcare/Family Visiting Room: Childcare will not be available during this conference. However, we are reserving a "family room" which will be available throughout the conference and will have comfortable couches and a TV/VCR for families to relax and visit together. The Airport Marriott also has a small pool which several of the children enjoyed during the 2001 conference. The Airport Marriott is located within walking distance of the John Heinz Nature Reserve which has several nice walking paths that families could take advantage of during the conference.

Conference Rate and Scholarship Information:

This information will be available on the IDEAS website in late January, 2003.

We are really looking forward to re-connecting with old friends and making new ones at the conference. Hope to see you there!

*-- The IDEAS Conference
Planning Committee:
Vicki Miller, Chair,
Donna Bennett, Heather Bruce,
Nicole Cleary, Brenda Finucane,
Patti Rubel, Jane True*



IDEAS: Where We Have Been & Where We Are Going

The IDEAS Board would like to share some history and invite you to look to the future, as we continue to evolve as a support organization.

IDEAS was established in 1994 by Donna Bennett, a parent whose son Joshua is affected by idic(15) and Brenda Finucane, M.S., a genetics counselor at Elwyn, Inc. Genetic screening was not available when Joshua was young, so Donna and her family struggled with not knowing the cause of Joshua's disability until he was 11 years old. Even after they received the diagnosis of idic(15), the family did not have much information about the condition. At the time, there wasn't much information about how to best address Joshua's needs or what kind of therapies might help. Donna wrote a letter to a disability magazine and was contacted by three other families raising idic(15) children. IDEAS was launched as a group of four families seeking information and support for their children. Eight years later, we have over 200 members from around the world and we are growing.

As more families get appropriate genetic screening for their children experiencing the constellation of symptoms associated with idic(15), the need for IDEAS will grow. IDEAS provides these fami-

lies vital information about what the diagnosis may mean for their child, types of interventions and their effectiveness and how to get involved with current research. Most importantly, IDEAS is a life-long source of support for families as we raise our special children.

We've come a long way as a support organization. In 2001 we held our first conference and established a Board of Directors. The board has established bylaws and committees to do the day to day work of our organization. In 2002 we matured even further by establishing a formal fiscal sponsorship arrangement with Elwyn, Inc. This relationship opens the door for us to raise funds for IDEAS using Elwyn's non-profit status. We have formed a fundraising committee that has embarked on a fundraising campaign. A conference planning committee was formed and is now hard at work planning a second international conference for June, 2003.

In 2002, a Microsoft Access database was established for IDEAS families and we resumed production of our newsletter, *The Mirror*. A flyer on IsoDicentric 15 was created by an IDEAS member and features pictures of many of the IDEAS children. It was distributed to families and shared with many people working with our kids. The board has created relationships with other genetic support groups so we can benefit from the lessons learned by others. And best of all, our listserv now has 175 members providing an immediate resource for expert advice on issues related to raising an idic(15) child.

In 2003, the Board is looking forward to involving more members

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IDEAS continued from previous page

to help IDEAS grow. In the spring, we will be holding open elections for the IDEAS board. We have a seven member board which serves a three year term providing leadership and guidance for our organization. We are also inviting members to participate in our committees: Education & Outreach, Fundraising, Conference Planning, Research, and Membership. For information about how to get involved with the committees, contact Nicole Cleary at niseli@aol.com or 503-253-2872.

One of the issues the new board will consider is whether IDEAS should become its own nonprofit organization and when this might occur. The new board will also be responsible for prioritizing new initiatives and the possibilities are exciting! These initiatives include creating outreach and educational materials, strengthening our linkages with researchers, identifying "best practices" for educational and therapeutic interventions, helping families advocate for excellence in special education services, identifying options in adulthood, and fostering a sense of community within IDEAS so that we can all continue to benefit from, and support each other in the shared experience of raising our children. IDEAS will continue to grow as we combine our energies and enthusiasm as stated in our mission statement: To serve our membership by uniting families, researchers, and professionals, and promoting awareness and understanding of idic(15)/chromosome 15 abnormalities.

**--Nicole Cleary
Chair, IDEAS Board of Directors**

IDEAS Fundraising: A Grassroots Effort

One of our most significant accomplishments in 2002 was entering into a fiscal sponsorship arrangement with Elwyn, Inc. This arrangement allows IDEAS to start raising money using Elwyn's nonprofit status, since IDEAS is not yet set up as a nonprofit organization. The IDEAS fundraising committee has geared up to meet our first big fundraising challenge - the 2003 IDEAS Conference.

Our last conference cost approximately \$20,000 and was sponsored by Elwyn, Inc. with the support of several corporate donors (Boeing Company, Nathan Speare Foundation, Mid-Atlantic Regional Human Genetics Network, Craftech Computer Solutions, Sunoco, Inc., Walmart, Sandvik Special Metals Corporation and Frito-Lay Corporation). Many of these corporate donors were approached by IDEAS families and made donations after learning about the conference and being asked to support it. The remainder of the funding came from the conference registration fees.

The 2003 conference budget is estimated to be a little more than \$30,000. Part of the increase in this conference budget comes from our desire to double the number of scholarships available for families. We are also including costs for a one-day meeting of researchers, currently conducting research on

idic(15), and members of the IDEAS board. The additional increase comes from the rising cost of hotel facilities and our associated "hard costs".

The fundraising committee has two projects underway to raise funds. First, we are again approaching potential corporate donors to provide some large conference grants. These potential donors include Novartis Pharmaceuticals, Pfizer, and Cephalon. The fundraising committee is working to identify additional potential corporate donors. If you know of any corporations who might be willing to help support IDEAS, please contact Jane True via email at (jtrue@kc.rr.com).

Our second activity is our IDEAS members fundraising campaign. This is where you come in! The fundraising committee is asking all IDEAS families to consider helping in our efforts to raise money for the 2003 conference. This may be an opportunity for you to talk to family, friends, neighbors, and employers about your child with idic(15) and the exciting conference in the works for families who are raising children with this disorder. Additional donations are needed for the "general conference fund" and are best **not** to be earmarked for specific conference expenses at this time.

Donations should be made out to Elwyn/IDEAS and can be sent to IDEAS, c/o Paul Rivard, PO Box 4616, Manchester, NH 03108.

We are excited about our upcoming conference and are hoping that many of you can join us by helping raise the money we need to make this conference a success.

**--Paul Rivard, Fundraising
Committee Chair**

Family Portraits

Corrina's Happy Saturday

Corrina always seems cold, probably because at 6 years old, she only weighs 37 pounds dripping wet. She seeks warm surfaces to lay on at every opportunity. These include heater vents, our backyard slide on a sunny day and of course Mom and Dad's bed in the morning. This is a sweet time for us if it doesn't come too early. Corrina is usually a good sleeper, but we try to draw the line if she gets up before 6 AM. Especially on Saturday. Regardless of when our day starts, Corrina likes to be held tight with her head buried in our hair (preferably Nicole's) covered with blankets. She can be very giggly at these times and likes simple contact games like "Eskimo Kisses" (touching noses), tickling and the nearly lost art of individual toe pinching to the rhythm of ABC. It's really a nice way to launch the weekend.

Once she gets bored with that, or we have to get going on the day, she will lead us into the play room off our bedroom, and point out a video of either "Teletubbies" or "Bear in the Big Blue House". We make her take it out of the box and put it in herself which is about the

limit on her fine motor skills, but she is highly motivated. Once the video starts she will clap, do her funny little jump, and wave her hands in excitement. She may not talk but she can certainly communicate. Her goal is to be one with the TV. Her preferred viewing distance can be determined by the lick marks on the screen. This does have the small side advantage of greatly discouraging her younger sister Sierra from any morning TV viewing since it is mostly a view of Corrina's back side.

Sierra is one of Corrina's sisters and at age 4 she is quite certain that she is the oldest. Since baby Jasmine was born 7 months ago, her status has been confirmed. Sierra is also the boss, of course as all 4 year olds are. Sierra knows that Corrina can't talk but probably doesn't really know that she is "different" because when you are 4, everyone is different. Some are big, some are small, some are loud and some are noisy. She can be amazingly sweet and often acts like Corrina's interpreter. "Corrina wants the toy" she will say, or "Corrina doesn't like any more pasta". Sierra will likely ask us some day about being different and we think from time to time about how to explain it. The girls benefit from each other more than either realizes. I guess that is how it is in most families.

Breakfast on Saturday is one of our favorite times with Corrina. As much as we like to catch up with her

after a week at work, you can tell that she feels the same way. Corrina is non-verbal but does know how to communicate and understand simple commands. You can't just yell, "breakfast is ready" and expect a response but if you guide her to within site of the table and say "sit in your chair" she will do so. She uses a combination of PECS pictures that we have scattered throughout the house, and a couple of simple signs and gestures. For example her sign for "dear little sister Sierra, please stop bugging me" is an open palm moving up and down, bonking the top of Sierra's head. Sierra understands these signs as well, although she does not always respond in the desired fashion.

Corrina is not a big eater and we have always had trouble getting her to have enough nutrition. We still give her Carnation Instant Breakfast drink both in the morning and the evening as a supplement. She sometimes will still "cheek" food but this has gotten better over time. She eats better if she has a stim toy or if we sing but we try to keep this to a minimum unless it's been a particularly bad day. She does have some favorite foods that act as rewards. These include bacon, hot dogs, potato chips, and french fries. Makes us wonder how she could be skinny at all. Generally, salty things, very rarely anything sweet.

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She also loves ketchup and will eat many things under its influence. Bacon in particular is a word that she recognizes and she will seek out bites from us at every opportunity. Best not to put it within reach as she is a crafty thief and has little concern for whose plate she steals from. This has become a small concern for use at brunch restaurants.

We also give her fruit with powdered Super Nu Thera vitamin supplement every morning. She doesn't notice the vitamins in this form and we think they help her general awareness. Our trend has been to try out up to 2 or 3 different therapeutic approaches at any one time so as not to swamp her with too many things. We really want her to enjoy being a little girl as well as making as much progress as we possibly can. We favor non-chemical approaches but will evaluate anything that seems like it would help at least for a while. Fortunately, Corrina has not exhibited the seizures that seem common among idic(15) kids, at least so far. Things we have tried include horse riding therapy, vitamin supplements, music (Samonas), neurotherapeutic sensory integration, swimming therapy, ABA, speech therapy (definitely not her favorite), Ditropan for spastic bladder and of course rough housing with Daddy therapy which has shown clear improvement in her advanced giggling and hugging skills. Corrina started kindergarten this fall and for the first time we are giving her Ritalin to help with her attention span.

We try to get Corrina to eat by herself but she isn't quite there. She will guide a fork into her mouth but

hasn't yet mastered getting anything on it. There are many areas like this where she is making progress but it's slow and at her own pace. She still wears pull-ups but will sit on the potty when asked and generally produce a result. She sometimes has accidents in her pants but is getting better about using the potty mostly



Corrina

due to the consistent hourly potty trip routine that we keep her in. She can't brush her teeth but she will hold the brush under the faucet and then suck the water off it. She can't wash herself but she will obligingly take a wash cloth and rub it around her tummy. She can't walk all through the zoo but can make the 5 blocks to the nearby park. She can't tell us that she loves us but she can melt our hearts with one special look so that her love is seared into our souls.

When you look at Corrina's test scores during the yearly assessments you can see that she is operating at the 12 - 18 month level for most things. Every year the gap between Corrina and a typical child gets big-

ger. Every year it is easier to see that she is disabled; mentally retarded, low functioning and autistic. We most often choose "autistic" to describe her. It helps people have some idea and opens a lot of doors for services. Looking at the orange juice cup at breakfast, we choose to see it as half full. Corrina does have a learning curve, it's just more gradual than most kids. Corrina has a special brand of magic and love that touches us and everyone who works with her. Most of her therapists thank us for the opportunity to work with Corrina.

Breakfast is finished when she makes the sign for all done. It's one of 3 traditional signs that she knows, the others being more and water. She also learned how to sign I love you by pointing to herself, her heart and the person to whom she is communicating. We un-strap her and tell her "cup in sink". She mostly knows how to do this unless she gets distracted in the 10 foot trip from chair to sink. Then it's time for a reward for all the hard work. "Kiss the Girl!" This is everyone's reward. We go over to the stereo and turn on the CD that has a permanent home in slot 5 and we all dance (pick up the girls and twirl around) to the Disney Little Mermaid song, "Kiss the Girl". This is the story of the mermaid princess who gave up her voice so she could be with her true love on land. She will only get it back if he kisses her.

"She don't got a lot to say but
there is something about her.
You don't know why but you want
to give it a try,
Go on and kiss the girl!"
So we do.

--Tim Cleary, Corrina's Daddy

THANKS TO THESE BUSINESSES FOR THEIR SUPPORT...

Teradyne, Inc., Hudson, NH

For underwriting the IDEAS Board conference calls and for profiling the Rivard family in *Teradyne World*, an international company newsletter.

Capitol Electric Corp., Boston, MA

For underwriting the cost of a mailing to all IDEAS members to kick off our grassroots fundraising campaign.

Stoops Freightliner, Indianapolis, IN

For providing free conference calling for the IDEAS fundraising committee.

We're grateful to these businesses for their generous support and to our members who asked their employers to support IDEAS.



Fundraising News IDEAS RECEIVES FIRST GRANT!!!

An anonymous donor has contributed \$3,000 to IDEAS. This contribution, made by a friend of an IDEAS family, is earmarked for family scholarships for the 2003 IDEAS Conference. Funds are needed for various conference costs, so please don't forget to speak with your family, friends, neighbors and employers about your idic(15) child and the need for raising conference funds. Many individuals from the IDEAS group are working on other fundraising opportunities as well. We need your help! The conference budget is \$30,000 and we have a long way to go! Additional donations are needed for the "general conference fund" and are best **not** to be earmarked for specific conference expenses at this time. Contact: Paul Rivard, Fundraising Committee Chair at his email address: privard97@attbi.com or by phone at: (603)647-6497.

Board's Corner

Your Next IDEAS Board

IDEAS is holding an election in Spring, 2003 for the next Board of Directors. The next board will serve a three year term from June, 2003 to May, 2006. IDEAS has a seven member board responsible for setting the priorities for IDEAS, establishing committees to carry out our work, providing adequate resources for our activities through active fund raising and developing and maintaining a communication link to IDEAS members. One of the biggest tasks of the next board is determining when IDEAS should pursue its own non-profit status.

Our current board spent time at our last meeting identifying characteristics that we'd like to have on the next board. They include:

- Time commitment of 20 - 30 hours/week shared among the members
- Background in nonprofit organizations
- Legal background/expertise
- Accounting or business background/experience
- Experience with outreach and building community
- Medical or research background
- Special education background
- Fundraising enthusiasm and experience

In March, 2003 open nominations for board membership will be held. Nominations will then be posted on the listserv at (<http://groups.yahoo.com/group/Inverted-Dup15>). In the event that only seven people self-nominate then no elections need be held. If more than seven people self-nominate, a poll will be facilitated by the board on the listserv so that IDEAS members can vote. The poll will begin the last week of March and conclude two weeks later.

If you are considering serving on the board at this time, you may want to consider joining one of our current committees. It's a great way to get involved in the day to day activities of IDEAS and to get to know each other. By joining a committee, we can each contribute something to IDEAS and make this organization a stronger source of support for our families and the families to come. If you are interested in joining a committee, contact the chairperson and they can help you get involved. A full list of committees and chairpersons can be found on the IDEAS website at <http://www.idic15.org>.

Husband and Wife Team Raise Money and Awareness for Daughter's Genetic Disorder

When Paul and Dawn Rivard aren't working at the Teradyne Connection Systems (TCS) Hudson, NH, facility, they can often be found working with IDEAS, an organization made up of parents and family members of children with a genetic disorder called Isodicentric 15.

Isodicentric 15 is a chromosome abnormality characterized by neurological, physical or behavioral problems, or some combination of these. One of the Rivards' three children, six year-old Megan, was diagnosed with the disorder about five years ago.

Paul and Dawn joined IDEAS (IsoDicentric 15 Exchange, Advocacy and Support) shortly after Megan was diagnosed with the disorder and have been heavily involved in spreading awareness and helping parents and families cope with the disorder.

"It's a great resource for advocacy and support for families," said Dawn, who has been a TCS customer service representative for more than six years.

"We're able to share our daughter's experiences and learn from other families whose children are affected with this rare disorder."

The mission of IDEAS is to unite families, researchers and professionals, and promote awareness of Isodicentric 15 abnormalities. The organization also raises money for research, and this year part of the money raised will help fund the second annual IDEAS Conference, which connects researchers and doctors with parents and families of children with the disorder. The conference will be held in 2003.

"I think the reason I'm so focused on this organization is because I remember what it was like when Megan was diagnosed and we didn't know where to turn for answers," said Paul, a TCS engineer. "We're continually expanding IDEAS to current members and new members around the world, so that they have an immediate outlet to find the answers and comfort they need."

Note: At the Rivards' request, Teradyne recently agreed to underwrite the cost of next year's IDEAS board of directors' monthly conference calls.

--This article appeared in Teradyne World, Teradyne's employee magazine. Paul Rivard works for Teradyne in Nashua, NH.

--Reprinted with permission from the editor of "Teradyne World".



January

Khalid E.	1/3/95
Fabio C.	1/3/93
Frederique D.	1/8/92
Christopher O.	1/9/92
Mason B.	1/12/96
Pavel G.	1/17/91
Genevieve M.	1/17/91
Nathan L.	1/18/00
Sarah Kate B.	1/24/94
Nicholas L.	1/25/89
Alexa V.	1/25/87
Kiam S.	1/26/94
Matthew B.	1/26/89
Katie B.	1/27/98
Ryan M.	1/27/86

February

Nathan H.	2/8/85
Matthias W.	2/9/00
Abby E.	2/9/90
Emma D.	2/9/99
Joshua B.	2/9/76
Robin R.	2/13/85
Thomas Q.	2/15/00
Noah H.	2/16/99
Johanna C.	2/17/82
Brandon J.	2/24/97
Connor L.	2/22/94
Kathryn G.	2/28/93

March

Allison G.	3/1/97
Dylan M.	3/1/94
Jackson R.	3/8/94
Samuel C-R.	3/8/83
Shawn K.	3/9/93
Benjamin R.	3/13/98
Delancy H.	3/14/97
Patience V.	3/15/90
Michael H.	3/17/80
Kathryn M.	3/18/95
Jacob G.	3/19/99
Christina M.	3/20/85
Joseph G.	3/21/88
Joshua R.	3/21/96
Jason K.	3/23/90
Katherine C.	3/29/97
Cody K.	3/31/99



IN MEMORIAM

Joshua has endured 8 years of medical challenges, always with a joy and exuberance for life that has touched and inspired all who knew him. Our sunshine boy, he has been our special gift from God, and we will miss him dearly. His weak, little heart just needed to rest, but the unending love he shared is still beating strong.

--Sophia and Robert Dentiste
brothers-Jacob(7) and Jonah(2)

Joshua Robert Dentiste
9-1-94 to 11-03-02

got news?



The Mirror welcomes the stories, insights, and ideas of all parents and professionals interested in idic(15). We'd also like to hear your suggestions for future articles. Send correspondence to Jodi Miller, Editor, c/o The Mirror, 300 N. Pine St., Mt. Prospect, IL 60056. Or email your newsletter items to j3smiller@aol.com

MIRROR

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