



AUTUMN ■ 2004

Family Support: The Cornerstone of our Mission

NICOLE CLEARY, MSS, Executive Director

IF YOU LOOK AT THE MISSION STATEMENT OF **IDEAS**, you will see that the first line reads: **IDEAS** provides information, education, and support to families with individuals affected by Isodicentric 15 and related disorders. How does **IDEAS** provide support to families? That is the focus of this issue of the **MIRROR**.

The support starts when new families contact us. Our co-founder, Donna Bennett has been sending an introductory packet of information to new families that contact her for over 10 years. Donna can be reached at

GBenn17364@aol.com

Sometimes new families find us through our website www.idic15.org which provides much needed information for a newly diagnosed family. We even have families who start their relationship with **IDEAS** through our listserv

Inverted-Dup15@yahoogroups.com

This listserv is a tremendous source of support, providing families with the opportunity to connect with other families who are raising children with a duplication of 15q11 - q13.

The **MIRROR** is published three times per year to educate families about duplications of chromosome 15, share family stories, and provide information about treatment options and current research.

Our families value the opportunity to meet each other, and **IDEAS** helps bring families together in two ways. **IDEAS** organizes and supports regional gatherings for families to come together for an afternoon or a weekend. The second way **IDEAS** helps bring families together is through our International Conferences. Held every two years, these conferences provide families with an unparalleled opportunity to meet other families, researchers, professionals and learn about the latest scientific and treatment advances.

We are thrilled to announce an

Isodicentric 15, abbreviated idic(15), is a genetic disorder in which a child is born with extra genetic material from chromosome 15. In people with idic(15), the extra chromosome is made up of a piece of chromosome 15 which has been duplicated end-to-end like a mirror image. It is the presence of this extra genetic material that accounts for the symptoms seen in some people with idic(15). People born without an extra chromosome but who have a segment of duplicated material within chromosome 15 (known as an interstitial duplication 15q) can have features similar to those with idic(15).

exciting new program to provide families with support. Beginning in October, 2004, **IDEAS** will have its own **PARENT MATCH PROGRAM**. **IDEAS** will match parents seeking support with experienced parent mentors who can provide emotional support during new diagnosis, transitions, or other difficult situations. This program will provide families with a means to gain support from someone who knows first hand what it is like to raise a child with a duplication of chromosome 15.

To learn more about how **IDEAS** works to provide support to families, read on!

INSIDE THIS ISSUE...

- **IDEAS Regional Gatherings in the Northeast, Northwest & Europe**
- **Announcing the IDEAS Parent Match Program**
- **2005 Conference Preview**
- **Conference Fundraising Targets**
- **Family Portraits: Jack and Pavel**

2004 Labor Day Regional Family Meetings

PAULA DAVIS

Mom to Emma (idic15), coordinator of the Northeast Gathering

NICOLE CLEARY

Mom to Corrina (idic15), coordinator of the Northwest Gathering

CHRISTIAN REITER

Dad to Lis (idic15), coordinator of the Northern Germany Family Gathering

NORTHEAST FAMILY GATHERING

On Saturday, September 4, 2004 Paula and Ben Davis hosted an Idic(15) BBQ for families in the Northeast U.S. Those



who attended were Paula & Ben Davis, Ben, Matt and **Emma** (age 5); Kathy & John Wise, and **Julia** (age 8); Joanne & Len Poore, Michael and **Lisa** (age 13); Kathy & Donald Marino, Derek, Daniel and **Douglas** (age 1); Lori & Pat George, **Will** (age 5) and Alex; and Paul & Dawn Rivard, **Megan** (age 8), Brooke & Kyle. It was a fantastic way to end the summer. Families were able to meet new families and reconnect with families they met a few years ago in Rhode Island. It was wonderful to sit and talk about so many issues that we are all juggling . . . meds, seizures, summer school programs, regular school programs, where to buy clothes, minor and major

milestones and eating issues, just to name some. Having this

opportunity to visit for a few hours with other families who are so open and willing to share was a gift, and the experience was awesome.

This was the first time that 16 year old Michael, had met other children that have some of the same issues as his sister Lisa. For one of his summer projects, Michael had to write a short story about a heroic person in his life and after attending this BBQ, he decided that the heroic person was his sister Lisa. The siblings all seemed to get along extremely well. They did a lot of good old fashion playing outside. The backyard hammock was a big hit for **Julia** and **Emma** and Kyle. A very special thanks to Paula and Ben Davis for hosting us, and to

everyone who attended and made it a very special day for all of us. Perhaps this can become an annual event. Kathy Wise has already volunteered to host us next summer!

NORTHWEST FAMILY GATHERING

While the Northeast families were enjoying a barbecue at Paula's house, eight IDEAS families from the Northwest came together at Maryhill State Park in the Columbia River Gorge. Tim & Nicole Cleary, **Corrina** (age 7), Sierra & Jasmine were joined by Brian & Susan Gazewood, **Jacob** (age 5) and Jacklyn; Greg and Carol Keller, Geoffrey, **Andrew** (age 2), and Grandma Lila; Tom



and Sheila Steffen, Levi, Hannah, **Abby** (age 6), Eleah, and Rebekah; Colleen and Jeff Lowell, Katie, Megan, and **Grace** (age 1); Kevin and Pam Jeffery, and **Charlotte** (age 1); Wendy Harris, Ryan, James, and **Warren** (age 7); and Bruce and Deb Lindgren, and **Chad** (age 28). This was a really wonderful gathering, with five of the families attending their very first IDEAS family gathering. Families of younger children

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2004 Labor Day Regional Family Meetings

PAULA DAVIS, NICOLE CLEARY, CHRISTIAN REITER

enjoyed visiting with the older children and were able to ask a lot of questions about everything from feeding and chewing to seizures to early intervention services to recreation and play. It was nice for the siblings to meet other kids who are growing up with a sister or brother with a disability. Parents felt that instant connection that is so common when meeting another family raising a child with idic(15) or int dup(15) — we all share this journey and it is a journey that is easier when shared with others. Meeting at a state park was a wonderful way for us to spend some relaxed time getting to know each other, eating together, chasing our kids together (especially **Jacob** and **Corrina**), and enjoying the beauty of the Columbia River Gorge.

EUROPEAN FAMILY GATHERING

September 4th also found 8 families spending the day together at Christian Reiter's Kindergarten in Bersenbrück, Germany. We had 8 caregivers that were taking care of the children while we parents heard some speeches, including Mrs. Dr. Kaiser-Höhne (child's



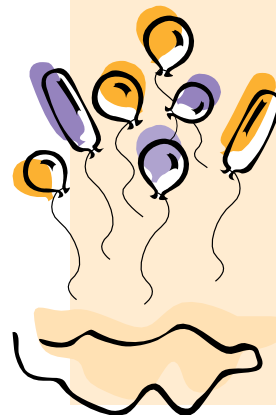
doctor) who made a speech about the development and her experiences with our daughter Lis. That was a very personal view from her side. Mrs. Dr. Exeler (human genetics; University of Münster) talked about genetics, how idic(15) is diagnosed and how it happens. She is involved in research in the field of chromosome 15 and is very interested in further contact with the families to know more about phenotype and genotype of idic(15). Mrs. Andrea Doerr made a presentation of speech development with idic(15)-kids. We had lunch in the kindergarten. Afterward, we discussed how we want to organize ourselves as a European group. In the evening we had a dinner at our house. We were more than 30 people eating, and playing in the garden. Everyone had a great time and we will surely repeat these meetings in the future. We found many friends and since the meeting our idic(15)-eu-yahoo-groups is exploding in its activity!

Happy Birthday to these special kids:

- Sarah D 10/02/96
- Adam R 10/02/91
- Sem K 10/05/99
- Joshua K 10/10/01
- George L 10/17/81
- Renate DJ 10/22/92
- Jarod W 10/30/89
- Shay P 10/31/92

- Anna B 11/03/99
- Richard M 11/04/86
- Corrina C 11/05/96
- Carrie J 11/07/83
- Hayley P 11/08/99
- Will G 11/11/98
- William C 11/14/94
- Stephen L 11/15/93
- Lindsay K 11/15/90
- Chandler G 11/20/98
- Melanie P 11/22/86
- Chad L 11/27/75
- Lisa P 11/30/90

- Jared L 12/04/02
- Naomi H 12/07/97
- Abigail S 12/09/97
- Ellie S 12/12/96
- Chase W 12/13/00
- Cody C 12/14/95
- Corey C 12/14/95
- Sven D 12/16/98
- Olivia T 12/16/94
- Nicholas B 12/18/87
- Austin B 12/22/95
- Megan R 12/22/95
- Caroline W. 12/22/00
- Justin O 12/23/97
- Chandler R 12/27/96
- Ada E 12/29/99
- Teddy S 12/29/90
- Kevin C 12/30/95



Announcing: *IDEAS Parent Match*

KADI LUCHSINGER

Coordinator of IDEAS Parent Match Program is a Physical Therapist and mother to Ethan, age 3, interstitial duplication of chromosome 15

THIS IS AN EXCITING TIME FOR **IDEAS**, as we are able to offer an incredible new service to our families. Think back to the time your child was diagnosed with a duplication of chromosome 15. Or think of a challenging time in your child's life, such as the onset of seizures. Would you have liked to talk to another parent of a child with your child's exact same diagnosis? What if you could get matched with a mentor who not only understood your child's diagnosis first hand, but also had a lot of experience raising a child with this disability? Someone who was willing to listen to your grief, fears, hopes, and questions, and share their experience with you? This is now an option for our **IDEAS** families.

The **IDEAS Parent Match** program was developed as a way to reach out and support our families during new diagnosis, transitions or any other difficult situation that may require emotional support. We hope to decrease family stress and feelings of isolation by providing this service to our

families. This program is available to any **IDEAS** family and is strictly confidential.

Families can call or email me, since I am the coordinator of the program. When we have a chance to talk I will ask you some questions and fill out an intake form that will help me find an appropriate match in our database of mentors. The mentors are parents of a child with a duplication of chromosome 15, who have participated in the **IDEAS** mentor orientation and have met all of the mentor requirements. Again, all requests and information are kept confidential.

Once a potential match has been identified, the family can expect a phone call from a mentor parent within 48 hours. If the match is not a good fit, then the family or mentor can relay this information to me and I will find an alternate mentor. It is our hope, based on extensive background information on the mentors, that an appropriate match will be made from the start. Our main goal is to provide a supportive service to the family in need, and we will

do what we can to meet that goal.

We all know what it is like to feel isolated and distraught during tough times, and we hope to help families during these times. Whether you are a new family, having trouble with school, need support during a hard transition, or just someone to talk to about the experience of raising a child with a duplication of chromosome 15, this is the program for you. The other nice thing about the **IDEAS Parent Match** is that families who do not have access to the Internet and cannot join the listserv can find support through this new program. Nothing is better than having close personal contact from someone who understands what you are going through.

If you are interested in participating in this program, either as a mentor or as a family seeking a mentor, or have further questions about the program, please feel free to contact me anytime. Finally, I want to thank all of the parent mentors who have volunteered to be a part of this program.

Kadi Luchsinger
7895 East Genesee Street
Fayetteville, NY 13066
315.637.4191

kadi@twcny.rr.com

2005 Conference Preview

JANE TRUE

Chair of the Growing Up Together Conference Committee is mother to Clare, 24 years old, idic(15)



GROWING UP TOGETHER, Our Third International Conference on Isodentric 15 and related disorders, is taking shape as a not-to-be-missed event! It will be held June 23 - 25, 2005, in Schaumburg, Illinois (a suburb of Chicago) at the Hyatt Regency Woodfield. This is a great location close to O'Hare International Airport and across the street from the Woodfield Mall. See this hotel's many amenities at

www.woodfield.hyatt.com

Thursday, June 23, 2005

New families (those who have never attended one of our conferences before) are invited to attend an orientation session Thursday morning at 10:00. This will be a time to gain information about the basic genetics of idic(15), get an orientation and tips about how to get the most out of your time at the conference, and pair up with an experienced parent if you wish.

The conference will open for everyone at 12:30 and you will want to be there for this special ceremony! Rick Guidotti, Program Director of Positive Exposure, will open our conference. His organization challenges the stigma associated with difference and celebrates the richness of genetic variation with positive images and powerful life stories.

It is a wonderful presentation and to better understand it check out at

www.positiveexposure.org

Rick will be available to photograph our children at the conference on Thursday and Friday.

Thursday afternoon will be devoted primarily to medical issues. Our Professional Advisory Board will provide an update on current research. Other sessions include Medical Options for Challenging Behaviors, Gastro-Intestinal Issues, and Seizure Recognition and Management. Thursday evening we will have a Taste of Chicago dinner party for everyone registered for the conference. We will ask you to wear something representative of your hometown to this party, so start thinking!

Friday, June 24, 2005

Friday's conference focus will be educational issues. Soma Mukhopadhyay, founder of the Rapid Prompting Method, will be with us for the entire day. She will give presentations in the morning and demonstrate her method by working with a few of our children in afternoon sessions. For more information about her work see

www.halo-soma.org

We also will have Dorinne S. Davis, MA, CCC-A, FAAA, with

us to present how sound-based therapies can help children with idic(15) and related disorders. More information on this topic can be found at

www.thedaviscenter.com

In addition we will have sessions on Educational Approaches for Autistic Spectrum Disorder, Connecting and Engaging Emotionally with Your Child with idic(15), and Sensory Integration Issues. Friday afternoon we will have a bus available to take the children and their care givers to the zoo, with the parents joining us at the zoo in the evening for dinner and some social time. Watch the next issue for details.

Saturday, June 25, 2004

A very special day for all families in attendance will be our family life day. Protected Tomorrows will be with us all day to discuss futures planning, a model of hope, estate planning and how to prepare for the day when the school bus stops coming. Learn more at

www.protectedtomorrows.com

Saturday will also highlight Dr. Jill Senner, who will present on augmentative communication and engineering your environment to promote communication. Saturday will include workshops for siblings, breakout sessions for men only

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2005 Conference Preview

JANE TRUE

and for women only, a parent panel on toilet training, and a conference closing with future directions for **IDEAS**. We will wrap up by 4:00 after a very full day.

Registration Information

We have negotiated a discounted rate of \$109/night plus tax with the hotel. You must identify yourself as someone attending the **IDEAS** conference to get this reduced rate. Conference fees will be \$150 for the first adult, \$125 for the second and all other adults, \$75 for children under 18, and no charge for individuals with **idic(15)/int dup(15)**. We will offer a single-day attendance fee of \$100 for anyone wishing to attend a single day of the conference. Conference fees include breakfast and lunch on Friday and Saturday, and dinner on Thursday night. We are unable to offer child care, but there will be a respite room and we are planning activities for the children. Families may be able to access funding sources in their community to help with conference expenses. Families should look into funding options early in the new year. We all look forward to meeting you and sharing our experiences at **GROWING UP TOGETHER** in June 2005!

jtrue@kc.rr.com

Finding Help with Conference Expenses

WHITNEY WOLANSKI
Mother to Chase, **idic(15)**

THE **IDEAS** CONFERENCE planning committee wants to provide families with helpful options for getting to our 2005 conference. While it is easy to say that we're looking forward to seeing each and every one of you, we recognize that the expense of taking time off from work and traveling costs money. **IDEAS** hopes to be able to provide scholarships as we have for our past conferences, but we are encouraging families to look for conference support first in your local communities and states.

You may find it helpful to write an introductory letter regarding your family and briefly explain what **idic(15)** is, and how it has impacted the members of your family. You should emphasize your interest in learning new therapies, and programs that will help your affected child be successful. This letter can be submitted to a number of agencies who may have resources to support parents of children with disabilities in attending conferences related to their child's disorder. These funds are sometimes referred to as parent training grants. We recommend you make your requests in January 2005 for the best chance of getting help with conference expenses. Some sources of information about parent training grants include:



Easter Seals

www.easterseals.com

Just as your loved one has unique needs (physical assistance, medical services, financial aid, legal guidance, emotional support and more), you also may benefit from resources that provide support to help you provide the best care possible. Please contact Easter Seals to learn more about resources available to meet your needs.

The ARC Family Resource Guides

www.thearc.org/familyguide

A guide to benefits supports & services for families raising children with cognitive disabilities and related developmental disabilities.

Parent Training & Information Centers and Community Parent Resource Centers

taalliance.org/centers

Each state is home to at least one parent center. Parent centers serve families of children and young adults from birth to age 22 with all disabilities: physical, cognitive, emotional, and learning. They help families obtain appropriate education and services for their children with disabilities; train and inform parents and professionals on a variety of topics; and connect children with disabilities to community resources that address their needs.

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IDEAS Sets Conference Fundraising Goal



RON BRUCE

Chair of the IDEAS Fundraising Committee is the father of Anna, 4 years old with idic(15)

WITH THE 2005 conference less than 9 months away, it is time for **IDEAS** to shift into high gear for fundraising! The 2005 conference budget is approximately \$40,000. As the chair of the Fundraising Committee, I am energetic about reaching this goal by June, 2005. However, in order to reach that goal and beyond, we will need help from everyone!

This is a chance for every family who feels that IDEAS has been a valuable resource to help support our organization. As you all know, **IDEAS** does not require a membership fee, so we don't have guaranteed money each year. **IDEAS** is a registered non-profit, tax exempt corporation. We are the only organization in the world dedicated to supporting families and fostering research into Isodicentric and Interstitial duplications of chromosome 15. We depend on contributions from individuals, businesses and philanthropic foundations to support our work. Every tax deductible contribution makes a difference!

Don't be afraid to get creative! The fundraising committee is currently working on a list of easy fundraising activities for families. If you would like to hold a fundraiser but need help with ideas or preparations, please feel free to email me at

rhbruce@att.net

A fundraiser can be whatever you make it; just do what feels comfortable. Prior to Anna's diagnosis, Heather & I did not have any experience with fundraising. We have since held 3 fundraisers and have 2 in the works! Fundraisers can actually be quite simple—or more complex, if you have the time and energy! Please let me know when you're planning a fundraiser. We are keeping a calendar of upcoming fundraisers.

We are now looking for families who would like to participate in our annual Holiday Card fundraiser. **IDEAS** will supply families with a beautiful fundraising insert that can be added to holiday cards. These inserts will be customized with your child's picture, a description of **IDEAS** and our 2005 conference. The card will contain a request, as well as instructions for donations. Please consider participating in this fundraiser. To get a set of customized inserts for your holiday card, you can contact Paul Rivard at 603.647.6497 or

privard97@comcast.net

We are also asking families to consider making a personal donation. I realize that many of us do not have a lot of extra money with the expenses of raising a special needs child, but no amount is too small! All donations are tax deductible. Please send donations

to the following address:

IDEAS c/o Paul Rivard
P.O. Box 4616
Manchester, NH 03108

The Fundraising Committee has room to grow! If you are interested in joining, please send me an email.

We can make *GROWING UP TOGETHER* an outstanding conference for our families.

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Finding Help with Conference Expenses

WHITNEY WOLANSKI

State Office of Mental Retardation & Developmental Disabilities

Your state office of developmental disabilities should be able to provide information about parent training grants available in your state and how to apply for them.

Parent to Parent Organizations

Some state parent to parent programs provide support for families to attend conferences related to their child's disability.

If you need help in identifying resources in your state, please contact Heather Bruce at

rhbruce@att.net

Jack

SARAH RASMUSSEN

Mother of Kyle and 2 year old Jack (idic15)

AS THE MOTHER OF A NEWLY diagnosed child with Isodicentric 15 (idic 15), one book continually comes to my mind as I deal with the day-to-day process of raising a disabled child, **The Places You Go** by Dr. Seuss. This book is often given to college graduates as they embark on the “rest of their life,” but it is so fitting for a parent of a newly diagnosed child with idic(15), or any child with a disability. The places our son Jack has taken our family is unbelievable, and he is only two years old! The people you meet and the places you will go when you have a child with idic(15) is such a pleasant surprise.

Jack Peter Rasmussen was born on June 7, 2002. Jack began his life by not wanting to eat anything for the first 6 weeks. We all took turns force feeding him a bottle and setting the alarm clock at night to make sure he ate every three hours. I asked the doctor if we might be blessed with a quiet, sleep-through-the-night kid, but he said “not likely,” so we continued to set alarm clocks! Jack is our second child, so at the time I kept hoping this was just going to be a “phase” that Jack went through. I thought once we were able to get him eating all would be fine. Unfortunately, all



was not fine. Jack did eventually start to eat on his own. We got him off bottles and onto breast-feeding in about a week, the first of many signs not to give up on anything. But, we started to realize that Jack was far behind in reaching all of his milestones. At his six-month check-up, the pediatrician agreed with our “something just doesn't seem right” call and he sent Jack for further evaluations. While the evaluations were started, we had Jack get involved with the Early Intervention program in our county, and we also took him to Boston to a pediatric ophthalmologist to evaluate his crossed eyes. At eight months, we had him fitted for glasses to try and correct the crossed eyes. He is now on his third pair of glasses, and they seem to be helping.

So the evaluations began. All of the neurologists and developmental pediatricians agreed Jack had global delays but no one was sure why. First came the MRI with abnormal findings. Ultimately his MRI turned out to be normal (we had it re-read at Children's Hospital Boston). Then we moved onto more neurological testing in Boston.

Nothing was found, and so it was decided to initiate genetic testing. I knew when the neurologist called on a Friday afternoon of Labor Day weekend that this was not going to be good news. We were told Jack had an extra marker from the 15th chromosome and we would need to go and meet a geneticist to learn what this meant for Jack. Even though I have a brother and sister, both in the medical field, who re-explained to me what the doctors said, I was confused and very scared as to what this would mean for Jack. One of Jack's aunts, a pediatric nurse practitioner, flew in from CA to attend the two initial genetics meetings. Even with her by our side to help us sift through all of the information being given to us, the appointments were surreal with no definitive answers. I listened intently, asked all of my researched questions, but felt like I was talking about someone else's child the whole time. None of the doctors had any hard concrete answers for us as idic(15) is still a newly identified genetic disorder, and as we all know, every kid is affected differently. Like the birth of my two children, I will never forget that day we were given Jack's formal diagnosis of Isodicentric 15—it was October 31st. Following the appointment, we went out trick or treating and tried to smile and be happy with the kids, especially for the 4-year-old who was just trying to be the coolest Power Ranger anyone has seen. It's funny how

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Jack

SARAH RASMUSSEN

people remember the little details of sad days.

At this point, I did not know what to think or feel. I was trying to grasp what we were being told and at the same time denying any of it was true. Inside my head all I could think was Jack was not going to fit into any of the categories I saw on the idic(15) website, even though he was already fitting into many of them. I was pretty sure the genetic testing was fool proof, but not 100% sure. Maybe the doctors had

this whole thing wrong. I was hoping at the follow-up appointment that they were going to tell me this was a mistake (like the incorrectly-read MRI) and that they were still trying to figure out what was causing his delays. Unfortunately this was all wishful thinking. It was just going to take time to comprehend his diagnosis and start to accept it as another part of Jack.

It has been 10 months since his diagnosis and we are slowly accepting it and learning to

appreciate Jack for who he is, not who he is not. Our family is trying to get Jack as many services as possible, so that he has the optimal chance of succeeding in life. We have him working with specialists in Physical Therapy, Occupational Therapy, Speech and Language Therapy, Vision Therapy, and he has a Personal Care Attendant who helps us work on all of his therapy goals. The biggest lesson we have learned from Jack in the past 2 years is that all good things come to those who wait. Jack is on his own timeline for reaching milestones, but once he reaches them (at the cheers of everyone) he never looks back. We have all learned to be patient, give Jack a little (sometimes a lot) more time to learn something and when we are at the end of our rope, Jack decides he is ready to do the skill. He did this with feeding (force feed until 6 weeks), crawling (not until 14 months and lots of encouragement), signing (started to sign "eat" after 3 months of showing him), and walking (not until 22 months).

Each day is a new adventure and a new "place to go" with Jack. But Early Intervention, therapy and testing are not going to define our son. We leave that up to his smile, hardy belly laughs, surfer blond hair hanging down in front of his eyes (actually in front of his glasses) and the joy he brings to his favorite big brother, mother, father, his therapists and our family and friends.

Pavel

DOREEN & TOM GLADIS

Adopted their son Pavel in 1992. Doreen shares their experience as an adoptive family raising a child with interstitial duplication(15)



IT WAS JULY 31ST, 1992, the day after my birthday, and our long awaited son Pavel was to arrive from Moscow that evening. The back-ground checks, credit checks, meeting with social workers, home studies, immigration correspondence and MAPP training to prepare us for the challenges of adopting a child were complete. Now Tom and I could take our son home and live the life of a "normal" family. No more paperwork, no more sharing intimate details of our personal life.

We agreed to adopt a special needs child. Pavel was born with a

bilateral cleft lip and palate and several developmental diagnoses. We were so happy to meet Pavel and become a family. We were apprehensive and yet hopeful of what lay ahead. Certainly, a loving family who wanted so much to have a child, some good food, plastic surgery, a little speech therapy and early intervention would make up for 18 months Pavel lost in a public hospital and orphanage. With the surgery completed, he would begin to talk; he would attend regular classes, maybe get a little speech

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Pavel

DOREEN & TOM GLADIS



therapy, be an average student, graduate, find a job, start a family and have a happy and fulfilling life.

Within 6 months, Pavel was doing well. He seemed to be adjusting to his new home, cleft palate surgery was completed, he gained 10 lbs, began walking and was enrolled in early intervention, but there were also concerns. We took him to a geneticist, who explained the implications of a cleft and how it would affect his children. They didn't see any reason to do any genetic screening as they didn't believe he had a "syndrome." We were advised to continue therapies and bring him back if he seemed to reach a plateau. At 2-1/2 Pavel was diagnosed with PDD, at 3-1/2 Autism and cognitive impairments, at 6 verbal apraxia, at 6-1/2 Interstitial duplication on chromosome 15 and ADHD. Just recently he was diagnosed with Bi-Polar disorder.

I have found that the need for support as well as the type of support has changed over time. I have always had the support of my loving husband, Tom, as well as support from our extended families. They have shared Pavel's accomplishments, listened to our hopes and fears, sent their prayers and opened their hearts to us when we were in need.

When Pavel was diagnosed with PDD we realized that we were going to need a lot more support and that we must not only accept it,

but search it out. We have received support from government programs, including a Katie Beckett waiver, college students, therapists, school teachers, tutors, church, and advocacy groups.

When Pavel was diagnosed with interstitial duplication of chromosome 15, our geneticist gave us a pamphlet from **IDEAS**, which opened up a whole new world of support. Finally, a group of people whose children shared a common genetic diagnosis. I remember first talking to Donna Bennett, who shared the story of her son Josh. Later we became members of the listserve and met other families either in person or through the list. These families became an important source of emotional support, sharing their hopes and dreams as well as practical ways of dealing with important issues, therapies and sage advice. It was comforting to know I was not the only one dealing with a particular problem. I later attended the two **IDEAS** conferences. It was nice to finally meet some of the people whose stories I had read on the list.

In spite of Pavel's early deprivation and disabilities he has progressed. I am so proud of him! His self help and daily living skills are his strength and are improving daily. He can swim laps. He's learned to read, spell some words, type on the computer, do some simple math and tell digital time.

His speech and language has improved, but his intelligibility is still poor. He's not conversational, has few interests, and his social skills need work. We will continue, with the help of our support system to build on his strengths and hopefully alleviate the weaknesses.

Pavel is 13.6 now and adolescence has taken its toll on us and him. He's becoming his own person and his behavior is changing. We have seen regression in toileting skills. We are searching out new avenues of support to deal with the challenges of this milestone.

My hopes and expectations have changed since that July day 12 years ago, but in some ways have remained the same. I hope Pavel will have a happy life. I hope he can live in a small group setting and have one good friend. I hope that he can have a job that gives him pride and find leisure activities that give him joy. I hope that he is always surrounded by people who love him, who can see beyond his disability and accept him in spite of his limitations. We have been blessed to have this little boy (soon to be young man) in our lives. I am thankful for all the support we have received. As I look ahead, I know we will continue to need support through each milestone. Looking even further ahead Pavel will need his own circle of support as he enters adulthood. That will be our biggest challenge.



Calling All Shutterbugs!

IDEAS

CORPORATE OFFICERS & BOARD MEMBERS

NICOLE CLEARY,
EXECUTIVE DIRECTOR

LORI GEORGE,
CORPORATE SECRETARY

PAUL RIVARD,
FINANCE OFFICER

DONNA BENNETT,
CO-FOUNDER/BOARD ALTERNATE

RUTH KROSS,
BOARD MEMBER

KADI LUCHSINGER,
BOARD ALTERNATE

JODI MILLER,
BOARD ALTERNATE

VICKI MILLER,
BOARD MEMBER

JANE TRUE,
BOARD MEMBER

AS PART OF OUR THIRD INTERNATIONAL CONFERENCE, we are creating a collage of electronic pictures of our children "Growing Up Together." We need pictures of your favorite people with idic(15) or int dup(15) being themselves . . . being cute, being silly, accomplishing new things, and just being their joyful selves. We plan to make this collage available on CD for families, fundraisers, and raising awareness of our children's disorder. Please send up to 3 pictures of your child to one of the following people:

If you have electronic pictures, they can be sent to Ruth Kross at

ruthkross1@aol.com

If you have a photograph that we can scan, mail them to:

Deb Case
21 Wilshire Blvd.
Machesney Park, IL 61115

Please provide a stamped return envelope.

We will need a publicity release in order to include your child's picture in this collage. Simply cut out the following form and send it with photographs to Deb Case, or send an email granting **IDEAS** permission to use the photographs when you send your electronic pictures to Ruth Kross.

We can't wait to share all those beautiful smiles with everyone at the conference!!!

PUBLICITY RELEASE

Child's Name: _____ Date of Birth: ___|___|___

I give permission for **IDEAS** to use photographs of my child in brochures, publications, medical journals, presentations, and the **IDEAS** Internet website. My child's identity will not be revealed. I understand that publicity may also include the print and broadcast news media as they describe **IDEAS** activities. I understand that photos used in publications and on the website are open to view by the general population. **IDEAS** will not be held responsible for any unauthorized use of published photos in the public domain.

I have been informed that at any time, I may stop further use of my photos on the website and in as yet un-printed publications by contacting **IDEAS** at 503.253.2872.

Signature of Parent or Guardian: _____

Date: ___|___|___

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 Jane True, MIRROR Editor at:

JTRUE@kc.rr.com

or to IDEAS
PO Box 4616
Manchester, NH 03108.

Jane True, Editor

Lin Neighbors, Design & Layout

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I D E A S

is a non profit organization dedicated to providing information, education and support to families with individuals affected by isodicentric and interstitial duplications of chromosome 15. **IDEAS** unites families, researchers, and professionals; and promotes research, awareness and understanding of Isodicentric 15 and related disorders.

Third International Conference on Isodicentric 15

DATE: June 23 - 25, 2005

PLACE: Hyatt Regency Woodfield
1800 East Golf Road
Schaumburg, IL

CONTACT: Jane True
816.453.4862

jtrue@kc.rr.com