

WINTER ■ 2007

What is **IDEAS**?

FROM OUR EDITOR
 FROM OUR EDITOR

What is this group called IDEAS? How did it get started? What does it do that might help my child? Who can join this group? How do they pay for what they do, like this newsletter? What does IDEAS plan to do in the future? How might that improve my child's life? How can I plug into this group? How can I become more involved?

These are all valid questions, to which many of you reading this have some of the answers. But do you know the story of the founding of IDEAS? Do you know about the new web site and the new message board? Are you aware of the conference coming up in June? Have you read the long-term strategic plan which was recently developed?

The information in this "Focus on IDEAS" issue should be of interest to every family, as IDEAS prepares to take itself to the next level. Our commitment to increasing awareness of our condition starts with educating ourselves about our own group. Then we can go out in numbers and take our message to the world. So start your education right here!

Best Regards,
 Jane True, MIRROR Editor

A Road Less Lonely -

The History of IDEAS by Jane True

Parents who travel the road of raising a child with special needs know it is lonesome and worrisome.

The parent of such a child is often on their own to find strategies, solutions and emotional support.

This was the situation faced by Donna Bennett for the first 11 years of her son Josh's life. She dealt daily with global developmental delays. At age 6, seizures

were added to the challenges. She had no diagnosis or information to help her.

Then one day in 1987, Donna and Josh walked through the doors of Elwyn Institute in Elwyn, Pa., and met Brenda Finucane, a genetic counselor. Brenda told Donna, "I don't know what has caused this, but together we are going to find out."

Chromosome 15q duplication syndrome (dup15q) is a clinically identifiable syndrome which results from duplications of chromosome 15q11-13. These duplications most commonly occur in one of two forms. These include an extra isodicentric 15 chromosome, abbreviated idic(15), which results in an individual having 47 or more chromosomes instead of the typical 46. Individuals with an interstitial duplication 15 are born with the typical 46 chromosomes but have a segment of duplicated material within their 15th chromosome.

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Donna and Brenda became a powerful team. In 1992, Josh was diagnosed with an inverted duplication of his 15th chromosome (today referred to as isodicentric 15 syndrome or idic(15)). But what did this mean? Both women knew Josh's symptoms well—the developmental delay, hypotonia of muscles, impaired cognition and speech, and seizures. There was no literature about this condition. They did not know of any other people who had the same or a similar diagnosis.

One day Brenda noticed a letter from a parent in a 1990 issue of *Exceptional Parent Magazine*. The mother wrote, "Our daughter...has a disorder of the 15th chromosome...The disorder seems to have affected all areas of her development...we have never been able to find any documentation on this exact disorder. We would like very much to find someone with 15q+." Brenda recognized the description was similar to Josh. She encouraged Donna to respond.

Donna's letter appeared a few months later: "Our 15-year-old son was diagnosed...with a rare chromosome disorder called tetrasomy 15p and partial tetrasomy 15q. We know very little about this disorder...Any information would be greatly appreciated." Three families responded to Donna's inquiry. One mother wrote, "I can't tell you how thrilled I was to see your letter, just to know that there are other parents out there dealing with this problem...Our

biggest frustration is trying to figure out how we can help our daughter live in this world."

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 for years. During this time Elwyn underwrote the cost of newsletters and two conferences. MUMS (Mothers United for Moral Support) National Parent-to-Parent Network and the Alliance of Genetic Support (now the Genetic Alliance) were contacted and soon IDEAS had 15 additional families.

By 1995, IDEAS was serving 45 families. Donna obtained a grant from Gladfelter Insurance Group (her local insurance agency) to print idic(15) brochures. Brenda wrote a grant proposal to publish newsletters and to mail brochures to all genetic counselors in the USA to raise awareness of IDEAS. By 1998 IDEAS had grown to 114 families.

In 1999, an internet listserv was established. Families and professionals shared information, photos, ideas, and stories involving idic(15). They made friends and provided support to each other. A website was launched. Families and professionals worldwide now had access to idic(15) information.

Today, over 300 families affected by dup 15q syndrome -- idic(15) and interstitial duplications of chromosome 15 -- benefit from IDEAS and the road traveled by Donna Bennett and Brenda Finucane.

Jane True,
MIRROR Editor serves on the
IDEAS Board, and lives with her
husband Jim in Kansas City, Missouri.

jtrue@kc.rr.com

Why I Go to the IDEAS Conference

By Sarah Rasmussen,
mother to Kyle (7) and Jack (4),
idic(15).

The 2005 conference in Chicago was the first IDEAS conference I had ever attended. I left the kids and husband at home and asked my sister to join me. I wasn't sure what I expected, but knew that I wanted answers to a thousand questions. Not only did I receive the answers to my questions. I also gained lots of new friends.

The lectures and seminars are outstanding and 100% geared to our kids, but you can see that from the registration form. Attending this conference will allow you and your family the opportunity to casually meet other families over a bagel at breakfast, or riding in the elevator to your hotel room, or sharing a laugh while swimming in the hotel pool. Through these casual meetings you will learn so much more than even conference sessions can offer. It is where you share your tried and true family secrets to handling your kids at family gatherings and outings. It is where you learn how to better communicate to your community what your family and child needs. It is where you learn how to handle IEP meetings from a veteran parent or most importantly, just how to succeed in making your family life work when you have a kid with idic(15). There is nothing like human, one on one contact to make you better understand what someone is trying to tell you or share with you.



I could never have received this type of information solely through the phone or via the list serve. It took the warm smile from another mom

to give me the courage to ask a question I never thought I could put on the list serve or bring up at our son's next IEP meeting. It took the casual dinner chit-chat to make me realize other families want the same things for their kids with idic(15), no matter how old they were or where they live in the world.

So, I hope we will see and meet you at the conference in Boston this June, as I will be there with my entire family and looking forward to all of the casual, easy going talk that makes our conference such a worthwhile journey for me and my family.

IDEAS CHEERS!

OUR VOLUNTEERS

SARA AND ERIK RASMUSSEN

One of the more comforting things in our life is knowing that we have another "family" to turn to help us with our son who has idic(15). The IDEAS family has been a huge source of help and support – the Parent Match, the list serve, the website and the conference we attended in Chicago. We know these services cost money and my husband I wanted to find a way to support IDEAS. In the past, we had asked for donations from our family and friends, but now that our son is older, we were looking for a way to raise money and awareness of IDEAS in a long-term format.

Being an athlete, I thought about doing a race as a fundraiser. What started as chitchat with some friends on a girls' night out turned into one of the most fun and exciting days we had in 2006. Thanks to all of my Knitting Night ladies, the businesses within our community, Jack's school and all of our family and friends we raised over \$8,300 at the 1st annual Killington Vermont 5K Run/Walk for IDIC 15.

Not only did we raise money for IDEAS, I felt like we helped create an event that brought together families and friends from our community for a positive, fun, athletic, affordable event. Any family considering hosting something like this in

your community, my advice is to go for it! It is work but it is not hard. Start small, set a goal you are comfortable with and then just do it. If anyone has any questions, please feel free to e-mail me at home – serasmussen@comcast.net. We will also be publishing step-by-step instructions on how to run a race on the IDEAS website.



IDEAS

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FOLLOW THE CHILD

by Nicholas Martin (Future Horizons, 2004)

One valuable service IDEAS provides to families is connecting them with various professionals both through articles in the Mirror and through presentations at conferences. Author Nick Martin is a conflict resolution consultant who provides training for parents raising children with special needs. He will be a featured presenter at the 4th International Conference on Chromosome 15q Duplication Syndrome June 28-30 in Boston. The following article has been adapted with permission from "Strengthening Relationships When Our Children Have Special Needs".

One of the most striking things I have learned from parents raising children with disabilities is that there is at least one fundamental difference between raising "normal" children and raising those who are not. Our society and culture, our institutions and conveniences – all the things we are surrounded by – are geared towards normalcy. And our society has a fairly standardized and accepted approach to parenting (whether good or bad) in which children are expected to follow the pathways set out by their parents. These expectations may be set directly, according to what the parents say or do, or they may be set indirectly, through the governments, school administrators, and other officials that parents elect. But when children are atypical, the parents must follow the child! **The less the child conforms to standard patterns, the more challenging it may be for the parents, because each child is unique and will often require "learning as we go."**

Thus we hear stories such as "Thomas the Tank Engine" becoming the focus of the family, if only because it is the one thing that captures Danny's imagination and draws him out into joyous expression and contact with the outside world. We hear of a couple that never had a full night's rest until they started running a fan in Tony's room, which almost magically helped him sleep through the night for the very first time. For another, it was dancing with their baby to "The Teddy Bear's Picnic" that quieted the midnight tantrums that otherwise seemed to have no end.



One mother shared these thoughts with me: "My older son, who is 10, takes a considerable interest in Disney movies, especially *Toy Story*". I can remember one time in particular; he was lying in the middle of the mall kicking, screaming, crying - the whole nine yards - just because he could not get something he wanted. So, just out of the blue I said, "Let's go to Pizza Planet," a saying that Andy used with his mom in the *Toy Story* movie. It was lunch time anyway, and that's what I was trying to do - get him to come with me to get some lunch. He stopped immediately, and replied, "To infinity and beyond! Pizza Planet, here we come!!!"

It is so true that you can't use the same techniques on normal kids as you can with kids with disabilities. To a disabled kid, if they can't find a par-

ticular toy, trust me, the whole world STOPS until it is found!!! Your normal kid would just make another choice.

In so many categories of disabilities, the parents will be placed in a similar position of having to learn from the child. They won't have the luxury of being able to just raise their children the way they were raised, nor to expect their children to simply do as we do, listen to what we say, and be like everyone else. Instead, they will have to be inventive, resourceful, and creative, and let the child be their guide and teacher. One parent phrased it this way: "I think most of us who have children with disabilities are constantly trying to find ways for our children to fit into what society says they should be". But for me, when I quit trying to mold Brandon into what I thought society expected of him and what I wanted him to be, well, it was amazing how easy parenting became.



Make your reservations today to see Nicholas Martin at the 4th International IDEAS Conference "SHARING THE JOURNEY" June 28 – 30, 2007 at the Seaport Hotel in Boston, MA Registration materials available at www.idic15.org

IDEAS Provides New Message Board Forum

Have you tried out the new message board feature on the IDEAS website? The message board link is at the top of the page at www.idic15.org. The message boards were created in response to IDEAS families concerns about the open nature of the yahoogroups forum. The message board is for members only, password protected, and members must be authorized before they are allowed to have access to our conversations. Security is a priority.

■ Message Board conversations are easier to follow

The new message boards are organized by topics so the conversations are easy to read and follow. Our members can see “at a glance” what discussions are taking place, and it is easier and more efficient to contribute to conversations. The message board allows users to follow a conversational flow without scrolling through multiple duplications of messages.

■ Members can quickly view new messages

Members can easily sort the message boards to only show new messages since the last time they posted by using the “View Posts Since Your Last Visit” link at the upper right side of the page. Whether you visit once a month, or are on line all day, you will be able to still see at a glance what conversations have transpired.

■ Message boards provide private messaging opportunities

The message board has an e-mail-like private messaging system which allows members to have private conversations without leaving the message board environment. Very convenient!

■ Members can be notified when someone responds to their posts

If they prefer, members can choose an option to be notified by e-mail when someone has responded to their questions or conversations. This feature only sends the notification- you have to follow the link to the boards to read the full response.

■ Members can receive email alerts for topics of interest

If they prefer, members can subscribe to particular topics (for example, if your interest is seizures you can be notified whenever a message occurs in the “Seizure” topic).

■ Members can create on line profiles

Members of the message board can create an online profile that can be viewed by other community members. Members can use photos of their children as “signatures” of their posts. (This feature is not only fun but brings members closer together by celebrating the beauty of our children!).

■ Message Boards allow for fun customizing of messages

For fun, members can experiment with different fonts and colors, and post emoticons (smilies) in their messages.

■ Moderators are available for technical help.

If you need help getting started, send an email to Michelle Young, michelle@yoyostudios.com.

We look forward to talking with you on the boards!



Please Help Support IDEAS

IDEAS is a completely volunteer run non-profit organization dedicated to providing family support, raising awareness, and fostering research into chromosome 15q duplication syndrome. IDEAS relies on the involvement of families to help us raise money to accomplish our mission.

... RESEARCH UPDATE:

Researching Interstitial Duplications of Chromosome 15q

IDEAS families play a critical role in increasing the understanding of chromosome 15q duplications through their participation in research studies. IDEAS provides families with information about current studies for their consideration. These studies have been reviewed by the IDEAS board and professional advisors to ensure that the proposed research is safe, confidential and directly addresses an important aspect of chromosome 15q duplication syndrome. In this issue of the MIRROR we highlight a new study of interstitial duplications of chromosome 15q.

Phenotypic analysis of interstitial duplication 15q11-q13 patients

Larry Reiter, Principal Investigator

University of Tennessee Health Science Center

My lab studies a protein called UBE3A and its role in autism spectrum disorders. The primary role of UBE3A is to target other proteins for degradation by the ubiquitin proteasome system. It has been known for some time now that maternally inherited mutations in UBE3A or deletions encompassing UBE3A can cause the developmental disability called Angelman syndrome. More recently several groups have shown that individuals with interstitial duplication 15q preferentially inherit this duplication from their mothers. We believe that this maternal preference is a clear indication that duplication of the UBE3A gene is responsible for at least some aspects of the autism phenotype in these individuals. In a recent publication Dr. Carolyn Schanen has shown that at least some 15q duplication patients have elevated levels of UBE3A protein in their lymphocytes. Our hypothesis is that the proteins regulated by UBE3A are detrimentally affected by this elevation in UBE3A levels resulting in an autism phenotype.

What is the purpose of this study?

The focus of this study is to do an in depth analysis of individuals with interstitial duplication 15q in order to gain insights into which characteristics of this type of autism may be the result of UBE3A mis-regulation. The study will involve three days of tests that include a neurological exam, a blood draw, an EEG, language, and neuropsychiatric evaluations. It may be necessary to sedate patients for part or all of the EEG, but this would be the only type of medication given during the study. We hope that by analyzing individuals with this

small 15q duplication, we will be able to better understand which characteristics of autism are related directly to the up regulation of UBE3A levels.

Who do we want to recruit for this study?

Our goal is to recruit 20 individuals with interstitial duplication 15q11-q13 for this study. Since our focus is primarily on the phenotypic effects of the UBE3A gene, we are not recruiting patients with the larger isodicentric 15q duplication as the additional genes in this duplication will complicate the phenotypic analysis. Also, since this particular duplication is rare, the study is open to patients of all age groups. We will also be recruiting 20-40 non-15q duplication autism controls for the study. This pilot study is currently being funded through the Shainberg Neuroscience Fund from Le Bonheur Children's Hospital. Although we do have some travel funds available, we can only provide these on a case by case basis due to funding limitations.

Whom do I contact?

Families who wish to learn more about this study please contact Dr. Lawrence T. Reiter in the Department of Neurology at the University of Tennessee Health Science Center, Memphis, TN.
E-mail: lreiter@utm.edu. Phone: 901-448-2635.

IDEAS MOVING INTO THE FUTURE

Nicole Cleary is the chair of the IDEAS Board. She lives with her husband Tim and daughters Corrina (idic(15)), Sierra and Jasmine in Portland, Oregon.

It seems like a long time ago, but in reality it has been only three years since IDEAS was incorporated as a nonprofit organization. The organization's focus in the years following incorporation was to fully implement our mission through the development of our programs:

Providing Information, Education and Support to Families Through...

- ***Quarterly MIRROR Newsletter***
- ***Parent Match Program***
- ***International Conferences***
- ***Regional Family Gatherings***
- ***Informative Website***
- ***Interactive Message Boards***

Promoting Research and Hope for Effective Treatments Through...

- ***Bi-Annual Scientific Meetings***
- ***Collaboration with Researchers***
- ***Promoting Human Tissue & Cell Line Repositories***

With our program areas fully established, the IDEAS board spent a considerable amount of time in 2006 creating a strategic plan to guide IDEAS into the future. The development of this plan was grounded in our mission and enriched with input from IDEAS families, professional advisors, therapists, teachers and medical personnel. The input received from these sources was invaluable. My heartfelt thanks goes to the entire IDEAS board, especially Danielle Wagner who provided outstanding leadership for the strategic planning process.

IDEAS is a completely voluntary grassroots organization. As such, IDEAS provides an opportunity for anyone interested in making positive change for families affected by chromosome 15q duplication syndrome to contribute their time, energy, creativity, skills, or financial resources. Together we will improve the lives of individuals and families affected by this syndrome.

IDEAS Mission

IDEAS provides family support and promotes awareness, research and targeted treatments for chromosome 15q duplication syndrome.

Strategic Goals

This strategic plan was developed to guide the growth of IDEAS from 2006 - 2009, identify how IDEAS will meet its goals and provide a framework for evaluation and modification of the plan as necessary. IDEAS strategic goals include the following:

1. IDEAS will raise awareness of the link between dup15q syndrome and autism.
2. IDEAS will help establish research priorities in dup15q syndrome.
3. IDEAS will establish and promote family involvement in the IDEAS registry.
4. IDEAS will identify educational best practices for individuals affected by dup15q.
5. IDEAS will develop and implement fundraising activities that allow IDEAS to exceed its annual operating budget by at least 5%.
6. IDEAS will hire an employee to provide administrative support for the purpose of advancing the goals of the group.

The IDEAS Board recognizes that monitoring and evaluating the status of strategic plan implementation is as important as identifying strategic issues and goals. IDEAS corporate officers report on the status of these goals to the full board each month. The board evaluates progress on the strategic goals at each monthly meeting and will make modifications as necessary.

We will be sharing our progress on this plan with our families through updates published on the IDEAS website. IDEAS began with the passion of an exceptional parent and genetic counselor. We have grown into a strong, effective organization that is leaning forward into the future. The IDEAS Board looks forward to the continued partnership with our families as we further develop, refine and, grow this organization. If you would like to get more involved with IDEAS, please contact me at nicleary503@comcast.net.

REMEMBERING CLARE

The “True” Meaning of Life

— A compilation by Jodi Miller with stories and thoughts submitted from many IDEAS families.

It was a privilege and an honor to have known Clare True and to have her in our lives. She was and always will be an inspiration to everyone she touched. Some things will never be the same...like when someone tucks a tag in on the back of my shirt, or picks a piece of lint off me. Yellow jackets with zippers and white crisp gloves take on a whole new meaning. Let me explain.

Clare had a way of making friends with everyone. If she didn't befriend you, then you probably weren't worth befriending. She had a magic touch. Once when we were planning the last IDEAS conference, she saw a group of men in the lobby of the hotel. The men were in full ornate dress including fancy white gloves. She mentioned to one of the men in her “Clare” type of way that she liked his gloves. The man didn't seem to take much notice, but later when we were going out for dinner, Clare was wearing the gloves. You see, this man was taken with Clare and later he happened upon Clare's Dad Jim in the lobby and said “please give these gloves to your daughter”. This type of thing happened often and Clare often attained items like this including yellow jackets, key chains and anything to do with Cookie Monster. She was a people magnet and people loved her.

Everyone she touched will truly miss Clare, and she will never be forgotten. She was an inspiration to her friends and family and especially to her extended IDEAS family. Many of us have mentioned that Clare was something we all aspired our children to be like. This doesn't have to change. Clare embraced the “True” meaning of life. She never let things get her down. She sang beautifully, skied, read books, loved, laughed and enjoyed every minute of her life. This is a huge credit to her family, Jane, Jim, Toby and Tyler. They encouraged Clare every step of the way to be all that she could be. It is the spirit with which we will remember Clare and she will live on in our lives through her family and through the many fond memories we have of her.



Clare with her two brothers, Toby and Tyler



Clare

--by Sarah Miller

Caring person who accepted everyone and everything that crossed her path

Loving, tender and funny

Awesome woman who was an inspiration to everyone she met

Rambunctious, fun-loving good ol' buddy ol' pal

Excellent, exciting and extravagant person whom we will always remember with love!

Thank You

We would like to thank our IDEAS Family for their many acts of kindness and support during the loss of Clare. We are grateful for those families who made the huge effort to travel and be with us for her services, and really appreciate all the many stories and memories you have sent to us.

To those who have so generously contributed to the Clare True Research Fund, we would like to reaffirm our commitment to see that this fund makes a difference in the quality of life for our children. It is our intent to support research into the seizure aspect of idic(15) and we plan to remain actively involved in making this happen.

The True Family

Reflections
Reflections

We are looking for siblings who would like to share their thoughts in a future issue of the Mirror.

If you are interested, please contact the editor at jtrue@kc.rr.com

Reflections
Reflections

This part of the REFLECTIONS

column shares perspectives

from a sibling.

REFLECTIONS FROM A SIBLING

by Matt Davis, brother of 8-year-old Emma (idic(15))

My name is Matt. I'm almost 11 years old and in 5th grade. My brother Ben is almost 12, and my sister Emma is turning 8 this month. Emma has IDIC 15. Because of her, my life is very different from most of my friends. In some ways it's good, and in some ways it's bad. But mostly, I love my sister and we get along great.

In my life my sister makes a lot of good changes. She makes me feel special and different and not boring like some other kids I know. Sometimes it's hard

to make friends when Emma's around because some people think she is weird. But after people get to know Emma, they get along great and they actually think she's pretty cool. It's just a matter of getting them to understand her. Sometimes my friends ask me, "Why does your 8 year old sister act so much younger?" I say she has idic(15), then I have to explain what that is. I tell them it takes her



Left to right: Ben, Matt and Emma

longer to learn things, and it's harder for her muscles to do things.

Although it's hard sometimes, I love my sister a lot. Every night I help put Emma to bed. She can't go to sleep until I kiss her goodnight. I usually read her bedtime stories too. Every morning I hug her before I leave for school. We give great hugs to each other.

Once in school, our question of the week was, "Who is your favorite person in your family?" I answered, "My sister." The other kids wanted to know why. I said because she has special needs and I have to help take care of her. Sometimes I have to act like her Mom. Her being special makes me feel important and special in my own way too.

There are a lot of bad things about having a sister like Emma too. You can't do some fun things like spending time with your family at a really nice restaurant or going on a fancy vacation. We also can't all go skiing as a family; either Mom or Dad has to stay behind with Emma. Emma also gets into all my stuff and often breaks or loses it. I have a safe in my room where I put all my important things.

I love Emma and I can't imagine my life without her in it.

<http://www.idic15.org>

We are an Italian family who lives in Rome, Italy. I'm Camilla, 31 years old; my husband is Alessandro, 33 years old. We have two children, Leonardo, 7 years old, and Fiamma, 2 years old with idic(15). What follows is her history.



Fiamma was born by a normal childbirth. But she was not able to attach herself to the breast, so I did not nurse her as I had done with her brother. When she was only three months, I realized that something was not right.

Bambina Polce Fiamma

Fiamma was growing all right; however, she was not moving, she was not holding her head up as she was expected to, she was not looking at anything and she was not interested in the world around her! So when Fiamma was five months old we decided to take her to one of the best Italian children's hospitals, "Bambino Gesù". There they did not realize that there was a genetic disorder. They suspected there were metabolic problems and carried out relevant tests. Of course, none was positive.

We went through several months in doubt, without knowing what was wrong with our baby. She still was not moving, she still was not interested in anything, not even in us! At last the physicians resolved to carry out some genetic tests. When Fiamma was ten months, we finally had the diagnosis.

Meanwhile, as Fiamma's hypotonicity was really serious, when she was seven months she started a rehabilitation program three days a week. I believe that was her good luck! In fact, in a little time, she started to keep things and toys. When her interest of the world around her increased, she began to move, to go where she wanted and keep what she wished for. In a few months she started to sit and to crawl on all fours. Now she goes always to the same places: in the bathroom as she loves water, in the terrace because she loves plants, in front of television when it is alight. When she arrives where she wants, she stands up and tries to walk! Standing up was a great accomplishment, but the best one is about the relationship with us and her brother. Now she turns always when we call her and she wants physical contact, hugs and caresses. Even if she doesn't speak, she communicates her state of mind: she smiles when she's happy and she gets angry when she is not able to do something. Fiamma is an obstinate child and this helps her in life challenges. She is also developing a sense of danger and this makes us a bit more relaxed.

When we received the diagnosis, the physicians didn't explain

exactly what such a diagnosis meant and its importance and seriousness. So we started looking for information on our own and experienced the frustration of discovering that there was nothing published in Italian and that also the physicians were not competent about this syndrome.

After several months, we found on the internet some scientific articles by Dr. Agatino Battaglia that explained exhaustively this syndrome, so now we are in touch with him and at last have had the answers. We have finally

realized all the problems that Fiamma will have to face. It has been a very painful moment. However, the realization has stopped the fight against the "unknown" and this has allowed us to share our experience with other families. During these months, in fact, we found the IDEAS website, and through this organization we got in touch with other families in

Every day Fiamma teaches us that the differences don't always mean unhappiness! Her smile is wonderful because it comes from her heart, it lights the world, like her name means...



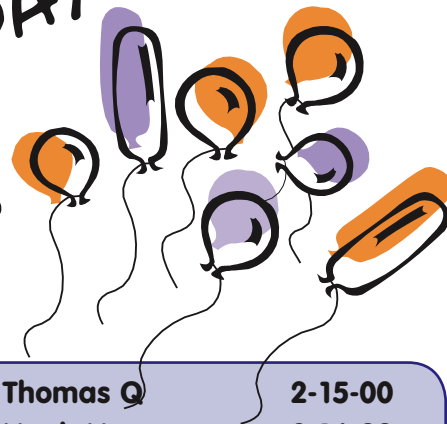
Italy and Europe. It was been very important for us, as it allowed us to feel no more alone! We hope to stay up to date about current research and treatment options because in Italy, unfortunately, there is very little about it.

Family Portrait continued from page 10

Now Fiamma is continuing the rehabilitation program three days a week and she loves her therapist, Laura. When she attains a new aim (as a vocal sound or a new movement) she repeats it only with Laura, like a gift! And just after a lot of time she does it with us.

This November Fiamma is attending school with a support teacher, but here there aren't any kind of special programs at school for such little children. Obviously, for parents it is very hard to accept that something is seriously wrong with their child. Our pain concerns her disabilities. Now she's not able to play, to eat, to walk, to communicate... like a "normal" child. I don't know if she will speak one day or go to the bathroom alone, if she will play with other children. I don't know where and what she will achieve. But I'm sure that she'll be happy all the same. Every day Fiamma teaches us that the differences don't always mean unhappiness! Her smile is wonderful because it comes from her heart, it lights the world, like her name means. Fiamma in Italian means "flame"; she smiles not only by her mouth but also by her dark and expressive eyes, by herself. Her smile is spontaneous, genuine. She constantly gives us the happiness of having her next to us.

**HAPPY BIRTHDAY
TO YOU!**



Joseph B	1-2-84	Thomas Q	2-15-00
Khalid E	1-3-95	Noah H	2-16-99
Naomi H	1-5-71	Tristan W	2-17-98
Shane R	1-7-00	Johanna C	2-17-82
Ethan L	1-8-01	Ben I	2-20-85
Frederique D	1-8-92	Connor L	2-22-94
Christopher O	1-9-92	Aiden L	2-23-04
Sarah G	1-9-90	Stuart H	2-25-99
Mason B	1-12-96	Kathryn G	2-28-93
Angela B	1-13-94	Payton F	2-29-00
Pavel G	1-17-91	Allison G	3-1-97
Genevieve	1-17-91	Dylan M	3-1-94
Nathan L	1-18-00	Fabio C	3-1-93
Sarah B-	1-24-94	Kameron R	3-2-00
Nicholas L	1-25-89	Jacob C	3-3-03
Alexa V	1-25-87	Liz R	3-6-98
Kian S	1-26-94	Samuel C	3-8-83
Matthew B	1-26-89	Shawn K	3-9-93
Kate B	1-27-98	Benjamin R	3-13-98
Ryan M	1-27-86	Kathryn B	3-14-00
Avery J	1-31-04	Patience V	3-15-90
Jacob PT	2-3-95	Jacob L	3-16-00
Ryan T	2-7-02	Michael H	3-17-80
Nathan H	2-8-85	Jacob G	3-19-99
Graham R	2-9-00	Christina M	3-20-85
Mathias W	2-9-00	Joshua R	3-21-96
Emma D	2-9-99	Joseph G	3-21-88
Abby E	2-9-90	Jason K	3-23-90
Joshua B	2-9-76	Katherine C	3-29-97
Robin R	2-13-85	Cody K	3-31-99
Nicholas D	2-14-05		

IDEAS

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Ideas is a non profit organization that provides family support and promotes awareness, research and targeted treatments for chromosome 15q duplication syndrome. Ideas offers help and hope for chromosome 15q duplications.

Hope to see you at...



The 4th International IDEAS Conference

“SHARING THE JOURNEY”

is coming up on June 28 — 30, 2007
at the Seaport Hotel in Boston, MA.

Registration materials available at
www.idic15.org



“Phantom” Tea Party

IDEAS is holding the first annual Phantom Tea Party on May 15th. We'll help you invite your family and friends to a phantom tea party to support IDEAS. We provide a lovely note card that you mail to your family and friends asking for a donation to IDEAS. The people receiving your card can enjoy a cup of tea (we provide the tea bag!) at their leisure while they write out a check to support the work of IDEAS.

Contact Kadi Luchsinger for more information at 315-637-4191 or kadi@twcny.rr.com.