



WINTER ■ 2005

## Growing Up Together: The 2005 Family Conference & Research Meeting

NICOLE CLEARY, MSS,  
is the Executive Director of IDEAS

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 materials within chromosome 15 (known as an interstitial duplication 15q) can have features similar to those with *idic(15)*.

BELIEVE

### EXCITEMENT IS BUILDING FOR THE 2005 IDEAS CONFERENCE!

**Growing Up Together**, our third international conference on Isodicentric 15 and related disorders, will be held June 23-25, 2005, in Schaumburg, Illinois (a suburb of Chicago) at the Hyatt Regency Woodfield. Families can find registration information on our website [www.idic15.org](http://www.idic15.org) and families on our mailing list will receive registration information in February.

We have invited several of our conference speakers to provide articles for this newsletter so that our families can learn a little bit about what the conference has to offer. These articles highlight the diversity of professional experts who will be presenting on topics ranging from medical and research issues, to education issues, to family life and futures planning. We are

pleased to be able to offer families such a wide range of highly qualified speakers.

We are also excited to inform families about an opportunity that may help interest many more researchers in studying *idic(15)* and *int dup(15)*. The Human Genetic Cell Repository at the Coriell Institute for Medical Research in New Jersey holds the world's largest collection of human cell lines for use in research, which includes about 2000 genetic disorders. **IDEAS** Professional Advisor Carolyn Schanen made a presentation at Coriell and talked with their staff about submitting the *idic(15)* cell lines from her study so that they are more widely available for research. Carolyn's article in this issue of the MIRROR provides more information about this exciting opportunity!

We look forward to seeing many of you in June!

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# Understanding Sensory Processing Disorders

**DEBRA J. DENNIGER OTR/L, BCP**

(Board Certified Pediatric Therapist) is co-founder and Director of Therapy Services (Physical, Occupational and Speech ) at The Rainbow Center, Inc in Illinois. With over 20 years experience as a pediatric occupational therapist and consultant, she specializes in the evaluation and treatment of children with sensory processing disorder.



**T**HERE IS MUCH CONFUSION among parents, teachers, and therapists alike who frequently use the term Sensory Integrative Dysfunction to refer to any child displaying symptoms in the area of sensory processing, sensory modulation, and sensory seeking behaviors. Children with sensory processing disorders often have an inability to modulate, discriminate, coordinate or organize sensation adaptively. Sensory processing disorders can be classified into two general categories, Disorders of Sensory Integration (DSI) and Sensory Modulation Disorders (SMD).

With **Disorders of Sensory Integration (DSI)**, Dyspraxia, or deficits in motor planning, is the primary characteristic symptom. Children with DSI appear normal, however, are somewhat clumsy and often do poorly in school. It is hypothesized that too much inhibition is taking place at the level of the brain stem (the brain stem is the portion of the brain that is responsible for filtering sensory information and determines what we respond, or do not, respond, too). When children with DSI are provided with intensive amounts of the needed sensory input, it is hypothesized that the neuro-

synapses began to fire and the presenting problem becomes essentially self-correcting. To summarize, children with DSI tend to be under-responsive to sensory stimulation and tend to need sensory stimulation of high intensity, long duration to maintain an appropriate level of central nervous system state of arousal needed for optimal attending, learning, and motor control.

Children with **Sensory Modulation Disorders (SMD)**, however, have a problem regulating and organizing the degree, intensity, and nature of response to sensory input in a graded and adaptive manner. SMD manifests itself by an over responsiveness or under responsiveness to sensory input, or fluctuations in response to sensory input, that is disproportional to that input.<sup>1</sup> Sensory modulation disorders do not necessarily take place at, or are a result of, dysfunction at the level of the brain stem.

Most of us are able to generate a response to sensory stimuli that is graded in relation to the importance of incoming sensations. Our highly sensitive central nervous systems easily balance what is important and not important to attend to. Persons

with sensory modulation disorders (SMD), however, often lack the ability to adapt or modulate their responses appropriately to environmental demands and either over-respond or under respond to the sensory stimuli present.

## **Sensory Defensiveness**

Individuals with sensory modulation disorders may have an inability to appropriately inhibit irrelevant sensory stimuli, displaying sensory hyper-sensitivity or Sensory Defensiveness. Sensory hyper-responsive behaviors involve either a quick or intense response to sensory stimuli that results in exaggerated responses (“fight or flight”) or a withdrawal from stimuli (“flight or freeze”) which most other persons perceive as benign.

## **Sensory Dormancy**

The opposite problem can occur where an individual becomes over-focused on an unimportant stimulus and is unable to divert his or her attention to important sensory stimuli. This is known as sensory hypo-sensitivity or Sensory Dormancy. In extreme cases of Sensory Dormancy, a child can become fixated, or stuck attending to insignificant details (such as a speck on the floor or a flying windows computer screensaver) and unable to attend to significant sensory stimuli (such as a person calling their name.)

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## Understanding Sensory Processing Disorders

DEBRA J. DENNIGER OTR/L, BCP

Persons with hypo-responsive behaviors respond slowly to sensory stimuli and require high intensity or increased duration of stimuli to invoke a behavioral response. Hypo-responsivity can take one of two forms. The child may have a diminished response to sensory input, making him seem lethargic. Alternatively, the child may seem very active, engaging in “sensory seeking” behaviors to satisfy a basic need or desire for additional sensory input to compensate for his or her under-responsiveness.

### Mixed Disorders

Most individuals with SMD have a combination of sensory

defensiveness and sensory dormancy and display symptoms of both, depending on the event, circumstance, type of sensory stimuli present, and familiarity of the environment. In either case, there is an inability within the Central Nervous System to adapt to changing environmental demands or situations quickly and efficiently. This affects the child's ability to attend and behave appropriately, and often interferes with learning.

Children with isodicentric and interstitial duplications of chromosome 15 who experience deficits in sensory processing tend to fall into the category of having

Sensory Modulation Disorders with symptoms of sensory dormancy, sensory defensiveness, or mixed disorders. Learning to identify your child’s sensory preferences and sensory needs, will enable you to adapt the environment to provide the “just right” challenge and provide the appropriate environment for optimal self regulation (self calming), attention, learning and motor control.

<sup>1</sup> Lane, Shelly J.; Hanft, Barbara, Toward a Consensus in Terminology in Sensory Integration theory and Practice: Part 2: Sensory Integration Patterns of Function and Dysfunction, AOTA Sensory Integration Special Interest Newsletter, June 2000

## A Vision of Hope

MARY ANNE EHLERT, CFP

*had a successful career in financial planning when she decided to act on her lifelong desire to specialize in serving the families of the disabled. The source of her inspiration was her younger sister, Marcia, who had cerebral palsy. Although their parents were naturally determined that Marcia should get the best possible care, they had also for years been understandably confused how best to plan and provide for her future, especially financially. Mary Anne is the president of Protected Tomorrows, Inc*

**A**S FAMILY MEMBERS of a person with a disability, we so often tend to view life in light of the challenges presented to us. A Vision of Hope looks at our lives in a whole new light, as Mary Anne Ehlert provides a passionate glimpse of her life with her sister Marcia. She will share with us her stories of not only the struggles but more importantly the wonders of life that Marcia taught her and all

those around her. Mary Anne believes that her sister changed the world in a way many of us never will, and that many of our family members with isodicentric or interstitial duplications of chromosome 15 may do the same for others. The presentation will be uplifting and entertaining, as well as provide us with a vision of what the future might hold as all of our lives are entwined in a special way.

In addition, she will provide some very practical advice in separate workshops entitled “Heart-to-Heart — Future Planning from other Family Members,” which will cover the following topics: Funding For the Future (Government benefits, other funding sources); Wills and Trusts (how to select, prepare for, and work with the attorney); Family Communication (what the family needs to know, documenting critical information, and expanding the circle of caregivers).

Finally, private consultations will be available upon request at the conference.

# What is Augmentative and Alternative Communication (AAC)?

**JILL E. SENNER, PHD, CCC-SLP**

is the owner/director of Technology and Language Center. In addition to her work at Technology and Language Center she is also a Post-doctoral Fellow at Northwestern University and an adjunct professor at Saint Xavier University (SXU) where she teaches graduate courses in augmentative and alternative communication (AAC).

## WHEN WE LOOK

at augmentative and alternative communication, it is helpful to consider the multiple modes of communication most of us rely on each day. We nod yes, smile to express pleasure, wave to a friend, ask directions when we are lost, or compliment someone who makes us a nice dinner. Many individuals with isodicentric or interstitial duplications of chromosome 15 have delays in language development along with impairments in one or more of these modes of communication. A subset of affected individuals have severe communication impairments, and are non verbal.

Augmentative and Alternative Communication (AAC) refers to an area of clinical, research, and educational practice for speech-language pathologists that attempts to compensate for the impairment and disability of individuals with severe expressive, and/or language comprehension disorders. At its most basic level, AAC is anything that helps a person communicate when traditional spoken or written forms of communication don't meet that person's needs. **Augmentative Communication** refers to an approach that is clearly an

addition to natural speech and/or handwriting. Some children can speak, but are unable to meet all of their communication needs using speech. Augmentative communication can be used to enhance or increase communication. One example is an approach called Total Communication in which sign language is paired with the spoken word or vocalizations to foster communication and increase understanding. **Alternative Communication**, on the other hand, refers to an approach that is clearly a substitute for verbal speech. This can range from light-technology options such as picture communication symbols to high technology computerized voice output communication devices.

One of the most common concerns parents raise is whether AAC will interfere with the development of speech. Research has shown that AAC does not inhibit the development of speech, and in fact may provide children who have developmental delays with an immediate means of communication, facilitate expressive and receptive language development, and serve as a bridge to future spoken language development.

## IDEAS

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BELIEVE

# Opportunity to Expand Research on Chromosome 15q Duplications

**N. CAROLYN SCHANEN, MD, PHD**  
*is the Head of Human Genetics Research at Nemours Biomedical Research in the Alfred I. duPont Hospital for Children. She is also a professional advisory board member for IDEAS.*

**I**N THE STUDY of human genetic disorders, samples from patients and their families are a critical resource for researchers, however it is often a major hurdle to identify families with specific chromosome abnormalities, like *idic(15)* and *int dup(15)*. Thus many researchers rely on tissue and cell “banks” for access to samples from patients with a specific diagnosis. These samples are often in the form of a “cell line,” which are derived from a blood sample that has been specifically treated to allow the cells to be grown in culture for extended periods of time. Our lab has established cell lines for most of the samples that we have obtained for our study of chromosome 15q duplications. We would like to submit them to the Human Genetic Cell

Repository at the Coriell Institute for Medical Research to make them widely available to other researchers who are interested in working on chromosome 15.

The Human Genetic Cell Repository at the Coriell Institute for Medical Research in Camden, New Jersey, holds the world's largest collection of human cell lines for use in research, which includes about 2000 genetic disorders. They maintain and distribute thousands of cell lines and DNA samples from individuals with diverse genetic disorders and make them available to researchers around the world for a nominal cost. Their collection is supported by grants from the National Institutes of Health and several private foundations with specific support by the National Institute of General Medical Sciences for the Human Genetic Cell Repository. To learn more about the Coriell cell repository, see their website: <http://coriell.umdj.edu/>

Coriell’s repository collects biological samples and relevant clinical information from donors. All personal identifying information is removed upon arrival to the Repository. In the catalog, basic information is provided to researchers ordering cell lines, including gender, race, the age of the individual when the sample was obtained, and if other family

members are in the Repository. However, all of the information is anonymized, meaning that there is no way for the researcher to know who the sample came from.

Families who are participating in our study can contact the Human Genetic Cell Repository genetic counselor, Tina Sellers, to authorize us to share your cells. Be sure to let her know if you are part of our study, because if we have samples that can be shared, we will send the cells to Coriell so that you do not need to have another sample of blood drawn. If families are not enrolled in our study, but would like to provide a sample for the cell repository, you can also participate in this opportunity to expand access to *idic(15)* and *int dup(15)* cell lines by contacting Tina. All interested families will need to sign the Coriell consent forms in order to have their samples in the repository. These forms are being generated and will be available from Tina Sellers.

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# Medical Options for Challenging Behaviors

**EDWIN H. COOK, JR, MD**

Professor, Departments of Psychiatry, Pediatrics, Human Genetics at the University of Chicago is a professional advisory board member for IDEAS

**A**FTER APPROPRIATE educational, behavioral and other therapeutic interventions have been optimized, many individuals with isodicentric and interstitial duplications of chromosome 15 have behavioral symptoms for which medication treatment may be considered. Although a systematic survey of which challenging behaviors occur at which frequency in idic(15) has not yet been conducted, there are clinicians experienced in treating children with idic(15) and related disorders. My presentation at the 2005 conference will focus on the kinds of behavioral problems I have seen in my patients. It is assumed that many children with idic(15) do not have these problems, particularly after educational, behavioral and other therapeutic interventions.

The most common presenting symptoms have been aggression (towards the self = self-injurious behavior [SIB] and/or towards others) and hyperactivity. Although both are common (and often occurring with epilepsy), the aggression is often the most

disturbing to the individual and those who care for them. A frequent cause of aggression in idic(15) is frustration related to obsessive-compulsive-like behaviors, often best treated with Prozac or similar medications. In other cases, unstable moods are present and respond to anticonvulsants that may stabilize mood. Frequently, such medications may need to be given to stabilize mood before trying medications like Prozac. Hyperactivity may be treated with stimulant medications such as Adderall XR or Concerta, but the response is probably not as reliable as it is for children with hyperactivity who do not have idic(15). Although not a first choice for long-term treatment, atypical antipsychotic treatment with medications such as Risperdal is often necessary for short-term management of aggression or for longer term treatment when other treatments fail or have more troubling side effects. Finally, approaches to monitoring response to treatment will be discussed.

## WORKSHOP

# On the Move: Strategies for Coping with High Activity Levels

**ANGELA SEARCY**

is a child development specialist for the Neuropsychology Diagnostic Center in Orland Park, Illinois, evaluating, and treating attention, perception sensory, memory, mood, and motor dysfunction; and discerning how these impairments correlate to specific brain functions

## IS YOUR CHILD ALWAYS ON THE MOVE or can't sit still?

Many children with isodicentric or interstitial duplications of chromosome 15 are affected by ADHD and high activity levels. Affected children may need structured help attending to and retaining information. Learn when high activity levels are age appropriate and when they are problematic. Learn practical strategies on how to increase short attention spans, hold your child's interest, and teach them how to complete adult directed activities.

This workshop will help participants better understand ADHD and how to cope with high activity levels from early childhood to adulthood.



# Working with Soma: Spencer's Story

<http://www.halo-soma.org/>



## SOMA MUKHOPADHYAY

is the founder of Rapid Prompting™ Method (RPM), an educational strategy for improving academic success and communication for individuals with autism. RPM is used to teach academics, and communication is also taught in the process. For more information on RPM, see the web site above. The 2005 IDEAS conference will include an RPM Instructional Workshop. Soma will provide brief 1:1 RPM sessions for children with *idic(15)* or *int dup(15)*, while a live video feed allows observers to watch the sessions.

**In this article Teri, mother of Spencer, shares Spencer's experience with RPM.**

## WE KNEW AFTER AN AMNIOCENTESIS

that Spencer had a chromosome anomaly on 15. The geneticist spoke of Prader Willi and Angelman but could not be very specific. We chose to continue with the pregnancy. Our beautiful baby boy was born on August 15, 1994, weighing 9lbs, 9oz. He was placed in ICU with a breathing tube and he had a problem sucking. Eventually I was able to breast-feed but it was a difficult start. When Spencer was 4 months old we had him tested at UCLA and at that time we received the diagnosis of Inverted Duplication 15, now called Isodicentric 15. We participated in the pilot study on children with isodicentric 15 when Spencer was 18 months old. (This is Dr. Carolyn Schanen's study).

Spencer met all the criteria for the diagnosis of autism on the Autism Diagnostic Interview and all but one criterion for diagnosis on the Autism Diagnostic Observation Schedule. The one domain on which Spencer's behavior did not meet the criteria was in terms of repetitive/stereotyped movement.

In 2002 when Spencer was 7 years old Soma came into his life as he was attending Carousel School. Soma was there to teach children with autism from a grant through Cure Autism Now, using the same method she had used to teach her son, Tito. In spite of Tito's severe autism, Soma was able to educate him and today he is able to communicate through typing and writing. At that time, Soma did not

know if she could teach other children using the same method, which she later called Rapid Prompting Method.

Soma started working with Spencer and 9 other children 1-on-1. She first started with choices. She started teaching pointing. She taught math, grammar, spelling, science, geography, and history. She would read a paragraph and asked a question with choices.

At this time Spencer's spoken language was emerging. The difficulty was that what he said and what he meant were two different things. We would ask him yes and no questions knowing the answer. For instance, we would ask him if he wanted some goldfish, which we knew he loved. We would give him a choice of yes and no. He would say no verbally but pick up the word yes. Soma taught him the multiplication tables. He would do the same thing: when given a choice he would say the wrong answer but pick up the correct answer. It was amazing what he really knew. We started treating Spencer more age appropriately.

Another thing we came to know is that Spencer is an auditory learner. It was so interesting to watch Soma teach Spencer as his eyes were looking at the ceiling and his head was cocked. You could tell he was listening to her very intently and when



she asked him to respond to a question he chose the correct answer by pointing at one of the choices that Soma had given him. His Dad and I observed her work with him 1-on-1 for two years. I would say his accuracy rate was about 90%.

Eventually she got him to a letterboard. When he was introduced to the letterboard he reacted quite negatively by not wanting to sit still, screaming, and using every avoidance technique he could conjure up. For quite a while Soma would introduce the letterboard a little at a time until eventually he was comfortable with it. It was so much fun watching Spencer communicate with Soma on the letter board. Sometimes she would think she knew what he was saying but

he was spelling out something else. He knew what he wanted to tell to her. Soma has now moved to Austin. Now it's our turn to work with him. We attempt to do his homework by giving him choices and we have a letter board that we use to ask him to spell words. He's still attending Carousel where they are teaching him the 4th grade curriculum. They use choices and they are working with him on the letter board. We miss Soma a lot and Spencer asks about her. She gave us a great foundation on which to build.

I've always said I wanted Spencer to be a productive person in society. Today, because of Soma, I've added an "educated" productive person in society. That's my goal for my son and I know the right people, places, and things will be presented to us so he can achieve this goal.

# Sound Therapy: What is It?

DORINNE S. DAVIS-KALUGIN, MA, CCC-A, FAAA

is the President and Founder of Davis Centers Inc. She is an Educational and Rehabilitative Audiologist with over 30 years experience.



**HAVE YOU EVER CONSIDERED** your body as a sound generator? Our bodies absorb sounds from our environment. What is less well known is that our bodies also create a complex frequency. The beat of our heart, the rhythm of our breath, and the movement of our bodies are all part of a frequency that each individual life emits. You could think about this frequency as a kind of sound generation. Optimum health requires a harmony between sound absorption and sound generation.

Dr. Alfred Tomatis, an ENT from France, discovered that this generation and absorption of sound had a direct impact on how well our bodies functioned. His ideas about the “voice-ear-brain connection” became known as “The Tomatis Effect”—3 laws that

simply say “the voice produces what the ear hears.” Based on this premise, he developed the Tomatis® Method. In my work, I have continued researching the “voice-ear-brain” connection and in 2003 added two additional laws to the Tomatis Effect known as the Davis Addendum™.

In addition to being a hearing mechanism, the ear is also the vestibular center for the body. Thus any vibration sensed by the ear may also affect the other senses.

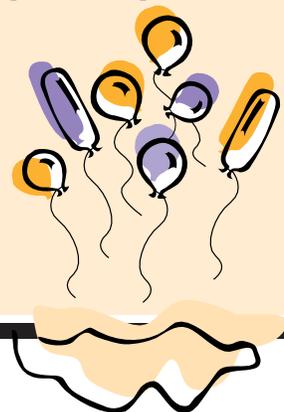
As the result of the vibrational impact of sound on the body and the ear in particular, changes can occur in:

- balance, coordination, and fine motor skills;
- receptive and expressive language;
- proprioception (body awareness in space);

- pragmatics of language (understanding the subtleties of connected words because of tonal rhythm, inflection, intonation, pitch);
- sensitivities to sound;
- attention, focus, and organization (better eye contact, better listening skills, better comprehension);
- reading skills;
- learning and development in general (desire to want to explore new skills, retention of skills learned, ability to learn at an easier pace);
- social skills (desire to want to communicate with others, ability to understand the subtle differences in tonal quality for comprehension, developing how to interact with others);
- auditory processing (listening with background noise, discrimination of sound

(continued)

## Happy Birthday to these special people:



• Khalid E	01/03/95	• Ryan T	02/07/02	• Allison G	03/01/97		
• Naomi G	01/05/71	• Nathan H	02/08/85	• Dylan M	03/01/94		
• Frederique D	01/08/92	• Matthias W	02/09/00	• Fabio C	03/01/93	• Marissa K	04/04/88
• Ethan L	01/08/01	• Emma D	02/09/99	• Lis R	03/06/98	• Chad T	04/08/94
• Christopher O	01/09/92	• Abby E	02/09/90	• Jackson R	03/08/94	• Jeffrey M	04/10/95
• Mason B	01/12/96	• Joshua B	02/09/76	• Samuel C	03/08/83	• Niklas H	04/11/99
• Pavel G	01/17/91	• Robin R	02/13/85	• Shawn K	03/09/93	• Jaime Lee J	04/12/93
• Genevieve M	01/17/91	• Thomas Q	02/15/00	• Benjamin R	03/13/98	• Marlana H	04/13/99
• Nathan L	01/18/00	• Noah H	02/16/99	• Kathryn B	03/14/00	• Bobby W	04/14/78
• Sarah B	01/24/94	• Tristan W	02/17/98	• Patience V	03/15/99	• Julie R	04/19/99
• Nicholas L	01/25/89	• Johanna C	02/17/82	• Jacob L	03/16/00	• Allora W	04/19/96
• Alexa V	01/25/87	• Connor L	02/22/94	• Michael H	03/17/80	• Cody L	04/19/93
• Kiam S	01/26/94	• Kathryn G	02/28/93	• Kathryn M	03/18/95	• Suzanne K	04/20/89
• Matthew B	01/26/89	• Payton F	02/29/00	• Jacob G	03/19/99	• Coleen S	04/23/93
• Katie B	01/27/98			• Christina M	03/20/85	• Alexis J	04/25/02
• Ryan M	01/27/86			• Joshua R	03/21/96	• Elisabeth A	04/27/95
				• Joseph G	03/21/88	• Robert M	04/28/94
				• Jason K	03/23/90	• Paige J	04/28/92
				• Katherine C	03/29/97	• Matthew V	04/29/88
				• Cody K	03/31/99	• Crystal O	04/30/87

# IDEAS Awareness Bracelets... Order Now!

IDEAS offers the opportunity to raise both *awareness* of isodentric and interstitial duplications of chromosome 15, and *much-needed funds* to support our upcoming conference and research roundtable!

Order silicone band bracelets—like the *LIVESTRONG* bands you may have seen—in royal blue that says **BELIEVE** and displays IDEAS's website.

We're asking a minimum \$5 donation, though some people are selling them for more.

Please consolidate orders as shipping costs add up quickly! Send your order—including *donation*, so we can ship to you—to:

Lori George  
18 Kings Road  
Canton, MA 02021

Note that the money received is a donation. We can not return donations, and therefore will be unable to issue refunds.

The plan is to start shipping the last week of January, so get your orders in!

Questions? Call...

Lori George  
781.575.0847

BELIEVE



(continued)

## Sound Therapy: What is It?

DORINNE S. DAVIS-KALUGIN, MA, CCC-A, FAAA

- differences, localization of sound, two-eared listening);
- emotional responses (feeling better about one's self, ability to better understand other people's emotional responses);
  - physical responses such as nutritional issues, biochemical imbalances, muscular/skeletal weakness, genetic disorders, toxins, pathogens, and more.

There are many sound therapies that address these changes. No one therapy is the panacea. However which therapy to choose has become an issue as more and more sound therapies have been developed. In my work as an educational and rehabilitative audiologist and teacher, I have trained and become certified in all of the major sound therapies, such as Auditory Integration Training, Tomatis®, FastForWord™, Samonas™, Interactive Metronome®, and BioAcoustics®. I have combined my understanding of sound, the ear, hearing, and education with the various therapies and developed the "Tree of Sound Enhancement Therapy," a developmental flow chart for the appropriate administration of the therapies available.

Based on my research, I have also created a diagnostic test

battery that can help determine if sound therapy is appropriate. This Diagnostic Evaluation for Therapy Protocol (DETP®) also provides a "foundational" order in which to achieve maximum positive change. This test battery takes away the "guessing" of which sound therapy will be effective and provides a defined protocol to follow. Once therapy is started, continued testing monitors change and refines the protocol continuum.

Sound can have a major impact on a person, and sound therapies can support positive change in a person. Determining which therapy can be effective and have desired outcomes has become easier with the Diagnostic Evaluation for Therapy Protocol (DETP®). For the person with any type of developmental, learning, or wellness challenge this assessment provides the steps for success.

### 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

Printing costs for this newsletter provided by Elwyn, Inc.

# Fabio

## Living with Fabio

**CHRISTINE,**

*Wife to Agostino, is also mom to Daniele, age 13 and Fabio, age 11 (idic 15). Christine and her family live in Italy*

**I**T IS DIFFICULT TO WRITE to you about this 12 years changing our lives so deeply, because surely you all know very well what happened to us. You are living in the same or in a mostly similar situation, also we are living in another continent and speaking another language (for the most of you) and many things of our daily life may be different.

We had Fabio as our second son, and because we—my husband and I—met so late, we weren't anymore much young, I had nearly 41 years and my husband nearly 48. We did not recognize at once that our baby had problems, although he had to stay suddenly after born a week in hospital, because someone saw something that could have been a seizure. They gave him back to me as a healthy child and I believed it. Mothers eyes sometimes are blind—his development since the first months was not normal, but I did not want to see it. Only when my pediatrician and also friends insisted I began to react, and the endless odyssey to the doctors began.

We tried to do all what we could do. With eight month he started with physiotherapy, he came early to the Kindergarten with a special person only for him, we had him have therapy with horses and music, we tried to learn about what he needs and how to understand him. We joked and laughed with him whenever we could, and we comforted him, when he was frustrated—mostly because we did not understand what were his needs. He never asked much, only the basic things, and grew up as a happy little boy.

Now he is frequenting a special experimental group where there are together



kids with different problems, mostly around autism, and where they with therapists and a psychologist live the day together, working on autonomy (eating, brushing teeth, clothing, washing...) and on social relationships between the kids and between kids and therapists. We are very happy to have found this school, and Fabio makes every day nearly 3 hours in car to stay there from 9 o'clock until 4 in the afternoon.

We had a very hard time when he was younger, because first of all you don't know what is happening to you and your son, you are feeling a responsibility on your shoulders that is bigger than you are, for so important decisions that seem to determine the conditions of his further life, and then, as you all know, it hurts, yes, I can't describe it different, it hurts so much, when they are so small and helpless.

While he grew up it was getting better. The pain became more sadness than desperation and there arrived other experiences, that helped to see our lives from other points of views and to give to the pain a right place among other, more positive sensations. I now know that the future of Fabio is not only my private responsibility. Sometimes it seems to me as if I had to give birth to Fabio another time, as if I had to learn to accept that he is a person of his own with his own life, that is not just a part of mine.

I learned to see that he is in a certain sense privileged, because he is born in a rich part of

this world where we are allowed to live in peace. How many children are dying for hunger, are maimed in one of the wars that continue to bother people, are losing their parents, are victims of sexual abuse. Fabio is a cute little boy, and he is most of the time happy. He loves his family, as we love him, and he is growing in the best way that is possible for us.

I have a special background in my personal history that is keeping alive in me these thoughts, because I was born in Germany, and my parents, the grandparents of Fabio, lived an important time of their lives during the nazi-fascism. Maybe not all of you know, that in these years not only Jewish people, communists, gays and gypsies have been deported and killed, but also a big number of special children like ours. They were brought together in special camps, sometimes telling their parents that they were cured there, and then, after some months, returned a letter that the child died for natural causes. In reality they were divided in two groups: who could say his name, had a possibility to survive; who could not say it, went to the gas.

Fabio does not speak at all.

Surely, it is not our fault, that this world is not a place where special persons are very welcome. And we will not change it, not alone.

But what we can do is let people know how much our children are giving to us and to this world. That life does not finish, when you have a special child, but it continues, only in another way. You will find helping persons around you, and you will get stronger. You will learn, that nothing in life is granted, and you will clear up your mind about superfluous and empty things, for to make place for important experiences, that make you grow.

Fabio gives all this to me, and I'm thankful that I have the opportunity to learn and grow, living with him.

## Family Portraits

# THANK YOU to our 2004 donors!!

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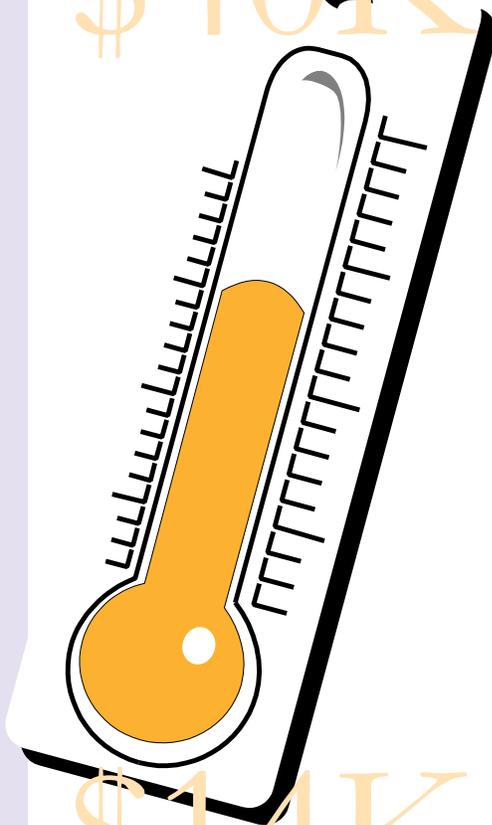
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Conference  
Fund Raising  
Goal:

Target = \$40,000

\$40K



\$14K

Funds Raised  
= \$14,000

# IDEAS

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 & Related Disorders

**DATE:** June 23 - 25, 2005

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

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