

THE MIRROR

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

Winter
1999-2000

HAPPY NEW YEAR!

The long-awaited new millennium is finally here, and with it comes hope for new breakthroughs in the understanding and treatment of developmental disabilities, including isodicentric 15 syndrome. In this issue of The Mirror, look for an update on secretin research as well as information about the therapeutic role of music for people with autism. This was a hot topic of discussion recently on the isodicentric 15 e-mail listserve. Haven't signed up for the listserve yet? Find out how you can access this terrific resource for idic15 parents.



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RESULTS OF RECENT STUDIES ON SECRETIN THERAPY FOR THE TREATMENT OF AUTISTIC SYMPTOMS

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As many of you are aware, there has recently been a flurry of interest in a hormone called secretin as a treatment for autistic symptoms (see The Mirror, Summer 1999). Due to this interest, several double blind, placebo controlled studies have been initiated. Up until now, stories about the success of secretin have been anecdotal, meaning that they're based solely on reports of people's personal experiences without being studied in a controlled, scientific way. A double blind placebo controlled study includes the following components:

- 1) *Placebo Group*: individuals receive a substance or treatment that is known to have no effect on the behavior of interest.
- 2) *Double Blind Methodology*: Neither the experimenter nor the individual receiving the treatment knows which treatment is being given until after the study concludes; participants in the study are randomly given either the experimental treatment (in this case secretin) or a placebo (in this case, saline (salt water)).

For a study measuring the effect of a medication on behavior, it is important to include these two components because of the large effects that other, unrelated aspects of the

study may have on the results. For example, aspects such as increased attention to the child, special treatment, etc. may influence the behavior in question and the change may not be due to the drug under study. Likewise, if the individual, his or her family, or the experimenter is aware of who is receiving the experimental drug, they may treat or evaluate that individual differently than they would a person receiving the placebo.

The results of the first two double blind placebo controlled studies have recently been published. Unfortunately, both studies failed to show a significant effect of secretin for the treatment of autistic symptoms. The first study was published by the world wide web-based online journal called *Medscape* (www.medscape.com). To view the full text of this article, you must register at this site and access the October 6, 1999 General Medicine issue (Owley, et al., 1999). To summarize, twenty children (age range = 3.4 to 9.2 years) meeting a criteria of IQ > 20 and an age equivalent of at least 24 months on a standardized measure of adaptive behavior participated in this study. All children met diagnostic criteria for Autistic Disorder according to the DSM-IV as assessed by several standardized measures and by a licensed psychiatrist. This investigation was a double blind placebo controlled crossover study. Standardized measures of Autism, receptive language, fine motor skills, and adaptive behavior were administered to each child at the start of the study and at 4 week and 8 week intervals. Each child was initially given either an infusion of pig-derived secretin or clear saline. The saline was visually indistinguishable from the secretin. Children were randomly assigned to either group. Participants, parents, and all members of the assessment team were unaware of whether a child received secretin or saline. At the four week interval, those children who were given secretin were given saline and those who were given saline were given secretin. Across all measures, no benefit was observed for the children who received secretin as compared to saline. This was the case for the children who received secretin first or second. At week 4, there was some increase reported in social skills for children in both groups. This is assumed to be the result of an "expectancy effect" (parents / experimenters reporting what they hope to find). Since the small increase in social skills was present even for the children taking placebo, it was clearly not due to secretin. At week 8, the social skills measure returned to near baseline.

The second recent study appeared in the December 9 issue of the New England Journal of Medicine (Sandler, et al., 1999). This study randomly assigned 60 children, aged 3 to 14 years of age with either Autism or Pervasive Developmental Disorder, to an experimental or

control group. The experimental group of children received an infusion of synthetic human secretin, the control group received a placebo of saline. Standardized ratings of autism were used to assess autistic symptoms before infusion and at 4 weeks post infusion. All participants and raters were unaware whether a child received secretin or saline. Secretin treatment was not associated with improvement on any outcome measures at the 4 week assessment. Both groups improved over baseline. This again was felt to be due to an expectancy effect. In this same issue of the *New England Journal of Medicine*, Volkmar (1999) discusses the negative results of this research and the use of the news media in publicizing tentative research findings. Limitations of these recent studies are the small numbers of children involved and that only a single treatment of secretin was given. As more research is reported on the use of secretin for autism, I will continue to keep people up to date through IDEAS. If any parents of children with idic(15) have used secretin I would be interested in hearing from you. (Elliott Simon, Ph.D., Elwyn, Inc., 111 Elwyn Road, Elwyn, PA 19063; phone: 610-891-2422; email:elliotts@elwyn.org)

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- Owley, T., Steele, E., Corsello, C., Risi, S., McKaig, K., Lord, C., Leventhal, B., & Cook, E. H. (1999). *A double-blind placebo controlled trial of secretin for the treatment of Autistic Disorder*. **Medscape**: General Medicine, October 6, www.medscape.com.
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Family Portraits

Life With Cheyenne

by Ellen Doxtator

Newmarket, Ontario, Canada

Just recently, I was watching T.V. with my four year old son Samuel. At the end of the program they advertised the Kids Helpline. Samuel looked at me and said "We should call that number, Mommy." I asked him why and he said, "so we can get help for Cheyenne" (his 6-year old sister with Idic15). Curiously, I asked him how he thought they would help Cheyenne. Without hesitation he said, "Well they could help her learn to talk properly, color without scribbling, look at people when they talk to her, and walk so her legs don't turn in like this", and he demonstrated how Cheyenne walks. I was amazed at the accuracy of his observation skills and how such a little guy could be more perceptive than some of the doctors we have encountered. How I wish it could be as easy as just calling the Kids Helpline to get help for Cheyenne - a sort of one-stop-shopping network for kids with special needs.



Cheyenne graduates from kindergarten



Cheyenne and her best friend, brother Samuel

Life with Cheyenne just hasn't been that simple or easy. But, like Samuel, I have found that focusing on what Cheyenne needs has helped us to surpass the medical profession's expectations of Cheyenne. I guess we are in fact Cheyenne's personal helpline. Of course, when Cheyenne was born we had no idea of the multiple problems she would face. She was such a beautiful looking baby with a head full of black hair, rosy lips and a natural tan. She looked just like how I imagined a Cheyenne would look. She was a perfect baby girl who never cried and slept all the time. Looking back this was our first indication that something was wrong. She had no ability to suck and no hunger instinct. She had loose hips and was placed in the special nursery because her heartbeat was slow and her temperature was low. She spent her first 3 days there. We were so relieved when she finally came out. Feeding was still a huge issue, and Cheyenne still couldn't feed when she was released from hospital at four days old.

When we got her home, I tried everything - breast-feeding, tube feeding, etc. with little success. We finally took her to the emergency room but had to wait until the next day before we saw a pediatrician. Our pediatrician monitored Cheyenne daily, and we did everything just to keep Cheyenne awake. I fed her every hour and a half, twenty four hours a day. Because of the feeding problems, we discovered other things. Cheyenne was slow to sit up, crawl, or roll over. She was incredibly floppy, just like a rag doll. But of course, to everyone else she was a perfect baby, sleeping lots, rarely crying and loving to be held. Other people did not realize some of the difficulties we faced, like Cheyenne's inability to feel pain or her constant screaming and crying throughout the night for the first four years of her life. I always felt like just when we were starting to deal with one diagnosis, something else would be discovered. We still didn't have a diagnosis for Cheyenne. In fact we didn't get one until she was 3. But she always demonstrated her will to succeed. One of her favorite songs is

"Zippity do dah". Cheyenne has changed the words and it is how she approaches life. She sings "Zippity do da, Zippity day, My oh my what a wonderful day, plenty of sunshine, get out of my way, Zippity do da, Zippity day!

At eighteen months we were just starting to realize the severity of what we were dealing with when I became pregnant with Cheyenne's brother Samuel. Samuel turned out to be a motivating force in Cheyenne's life. For Samuel, every skill Cheyenne struggled with came easy. And that made his sister mad. Samuel helped his sister do things like walk and talk faster. Even though at times Cheyenne was quite jealous of him, pulling his hair and hitting him because she couldn't express herself yet. Of course they have a typical sibling relationship. Sometimes having fun together and sometimes fighting over silly things. And of course, always sharing illnesses. Samuel just recently broke out in chicken pox so we are awaiting Cheyenne's spots. When I told her I didn't see any spots yet, she said "And no rectangles or squares either".

Two of the most difficult things about dealing with a child with special needs are the never ending trail of paperwork and dealing with all the professionals. When I think back, some of the professionals have been excellent and able to provide us with the support and information we needed. Others have not. Some focus on all the negatives: Cheyenne won't be able to walk, talk or see. At first, as parents, we believed everything that the professionals told us. But as time passed, we learned to ignore their predictions and expect the same of Cheyenne as we did from her brother. She may take longer to learn a particular skill but she showed us never to underestimate her stubbornness and determination. I remember one visit to a doctor's office where the doctor was challenging Cheyenne to do something she didn't want to do. Without hesitation, Cheyenne got up, walked to the door to leave, turned around and said "I am NOT coming back here again. GOODBYE!" During another visit to a hospital where Cheyenne had a test to measure her nerve responses, Cheyenne fought us (2 doctors, 2 nurses, and myself) like crazy. The doctor said "She sure is strong" and I said "That's kind of a contradiction considering she has such low muscle tone". The nurse said Cheyenne's stubbornness and determination would take her far in life. So far it has. She continues to surpass everyone's expectations of her, and we hope she won't lose her spirit along the way.

We never know ourselves what to expect. At home she chatters non-stop from the time she gets up until she goes to bed. At school, she barely talks at all and tries to convince them of how little she knows. Yesterday we got a note home from the school saying Cheyenne often misinterprets what adults are saying or the tone they are using and will put her hand over her mouth and close up. I have never seen her do this but the teacher noted, once she closes up, it is very difficult to get her to talk. I couldn't help but laugh, that is part of dealing with living with Cheyenne. At home she sometimes says things that I would never expect. Like the other night when at 10:00 p.m. she got out of bed and I told her to go back

to bed. She said "Who cares, Mommy? Who cares?" When I said "I care because you need your sleep", she replied "Well that's your business Mommy".

Cheyenne continues to make progress in all areas. She walks independently (with supervision), her speech and vocabulary continue to improve and her comprehension and understanding are developing. Physically, she finds any academic work using her fine motor skills difficult, although she has great flexibility -like last night when she was playing pat-a-cake with her feet! She still tends to prefer interacting with adults rather than her peers but does engage in some parallel play. She has a great sense of humor and loves listening to music and watching Arthur. She and Samuel are typical siblings, playing, fighting, and arguing together. I credit a lot of her progress to the home therapy program she is involved with. Although it takes lots of time and effort from our family and the caregivers who come into our home, it has been worth it. As long as Cheyenne continues to progress and have fun, we will continue to do everything we can to help her succeed.

To the outside world, Cheyenne's life will always be filled with can'ts and won'ts. Recently we were told within 5 minutes of a professional meeting that Cheyenne won't be able to use a computer. Yet Cheyenne is using a computer at school every day and quite enjoys it. If we focused on these can'ts and won'ts, we would never expect anything of Cheyenne. Somehow we have to keep our eyes and hearts open to expect that we can receive help for Cheyenne. Just like Cheyenne's brother did. I hope that as Samuel grows older, he will still have the same love and concern for his sister as he did when he suggested we call the Kids Helpline. I hope he grows to appreciate the strength of character it takes to be Cheyenne. And maybe someday there will be a Kids Helpline where families could get the support they need. And maybe there would be someone on the other end who could appreciate a kid like Cheyenne, and just maybe they would take the time to listen.

[Click here to read a poem by Ellen Doxtator](#)

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MUSIC FOUND TO IMPROVE ACQUISITION OF LANGUAGE ON CHILDREN WITH AUTISM

Recent discussion among parents on the isodicentric15 listserv focused on the use of music / song to communicate and motivate their children. With this in mind, the following article is reprinted with the permission of Autism Research Review International, San Diego, California (website: www.autism.com/ari)

A common method of teaching autistic children to communicate is “simultaneous communication,” in which the therapist signs and speaks to the child at the same time. Noting that autistic children recognize and enjoy musical patterns and are often musically gifted, Evelyn Buday set up an experiment to test whether children with autism would learn more words or signs if the simultaneous communication technique was combined with music. Buday worked with 10 autistic children, teaching them a total of 14 signed and spoken words. Seven of the words were incorporated in a musical verse, and the other 7 were part of a rhythmic verse which was not set to music. While the music or non-musical verse was played on a cassette player, the therapist would speak and sign only the targeted words. (For instance, if the verse was “three bears out for a walk one day,” the therapist would say the word “bears” along with the singer or narrator on the tape.) In addition, as each word was approaching on the tape, the experimenter would show a picture of the item the word represented.

“Results indicated a significant difference in the number of signs correctly imitated,” Buday notes, “with more signs imitated during music condition training than rhythm condition training.” Buday also found that students imitated more spoken words during the sessions, and recalled more spoken words the next day, if they had learned the words during the sessions involving music. There was no significant difference in the number of signs recalled.

Buday suggests that music reduces boredom, thus allowing autistic children to focus more intently on the words being taught. She notes, “I observed less hand (flapping) and head movements during the music conditions as well as less incoherent babbling.” She adds that the children appeared to enjoy the music sessions much more than the non-music sessions, saying that “many of my subjects would sing or speak many (in some cases all) of

the words in the music verse in addition to the tested key words.” In contrast, she says, “it was evident that the children who spoke frequently during music testing would often stop talking altogether during (non-music) rhythm testing, or their voices would become dramatically softer.”

REFERENCE: "The effects of signed words taught with music on sign learning by children with autism", Evelyn M. Buday, Masters' thesis, University of Illinois at Chicago Circle, 1995.

**For more information about the benefits of music therapy,
as well as how to find a music therapist in your area, contact:**

American Music Therapy Association, Inc.

8455 Colesville Road, Ste. 1000

Silver Spring, Maryland 20910

Phone: (301) 589-3300

Fax: (301) 589-5175

E-mail: info@musictherapy.org

website: www.musictherapy.org

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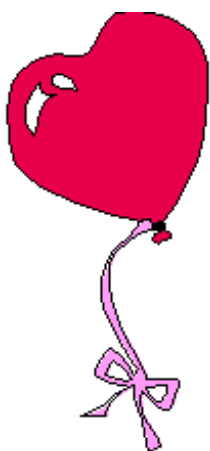
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Happy Birthday!



Adam 10/02/91	Naomi 12/07/90	Sarah Kate 01/24/94
George 10/17/81	Nicholas 12/18/87	Nicholas 01/25/89
Jarod 10/30/89	Austin 12/22/95	Alexa 01/25/87
Shay 10/31/92	Megan 12/22/95	Kiam 01/26/94
Richard 11/04/86	Justin 12/23/97	Matthew 01/26/89
Corrina 11/05/96	Chandler 12/27/96	Ryan 01/27/86
William 11/14/94	Teddy 12/29/90	Abby 02/09/90
Stephen 11/15/93	Kevin 12/30/95	Joshua 02/09/76
Lindsay 11/15/90	Khalid 01/03/95	Robin 02/13/85
Chandler 11/20/98	Frederique 01/08/92	Johanna 02/17/82
Laura 11/20/97	Christopher 01/09/92	Connor 02/22/94
Melaine 11/22/86	Mason 01/12/96	Kathryn 02/28/93
Chad 11/27/75	Pavel 01/17/91	
Lisa 11/30/90	Genevieve 01/17/91	

GREAT MINDS THINK ALIKE!

In the last issue of *The Mirror*, we announced the creation of an email list through eGroups, not realizing that a few months earlier, one had already been set up on ONElist by parents Erica Jackson and Paul Rivard. Once we realized this, we posted a message at eGroups redirecting interested families to the ONElist, where the real action is! The bottom line? There really is only one active email list for isodicentric 15 (see below).



Computer Listserve is a Great Resource for idic15 Families

At last count, 39 families and professionals from around the world have signed onto the email listserv dedicated to isodicentric 15 (a.k.a. Inverted Dup15). It has turned out to be a powerful source of information and support for all, and it's absolutely free of charge! If you have a computer, don't miss out on this valuable resource. Once you register, messages about idic15 from other members will appear on your email as they are posted. Never used a listserv? Don't worry - this listserv is free, easy to use, and a great way for families to connect.

To register, please visit the website at www.onelist.com and select **NEW MEMBER**. Once you are registered, you will be able to sign up for the Inverted-Dup15 list as well as any other list you choose. Our list name is Inverted-Dup15 (no spaces and case sensitive letters). You can then sign up in either of the following ways:

1. Via email, send a blank email to:

Inverted-Dup15-subscribe@onelist.com

<http://www.idic15.org/wint00mirrornews.html> (1 of 2) 9/21/05 8:32 PM

case sensitive letter 'y'. You can then sign up in one of the following ways:

1. **Via email**, send a blank email to:
Inverted-Dup15-subscribe@onelist.com
2. **Or Via the ONElist website**, using the URL to subscribe:
<http://www.onelist.com/subscribe.cgi/Inverted-Dup15>

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In addition to the internet email list, the inverted-dup15 onelist also allows members to view and post photos and other documents. Over the past few months, a beautiful gallery of photos of people with idic15 and their families has blossomed there, thanks in large part to the efforts of parent Paul Rivard.

- To access the idic15 files, first register with onelist (free of charge) at www.onelist.com.
- Next, enter into your Inverted-dup15 list.
- On the left side is a list of options, one of them being "Files".
- Click on "Files" and a list of current files will be posted in front of you. Clicking on any one of these will enable you to view them.

Here's how you can post a picture:

- Once you have scanned the picture, try to save it as "jpg" file. This is generally good for file size and viewing.
- Follow the directions above and click on the "Files" button.
- To post a picture, click the Upload icon just below the current list of pictures.
- Once in the next screen, it will ask you for the file name. There is a "Browse" button next to that line. Click on the browse button, find your file that you have saved on your system, give it a title that we will all see, and then select "Upload". It generally takes a little while depending on how fast your computer is. But within a few minutes it should then appear as a viewable entity for all.



Three year old Megan's photo is one of many on the Onelist Inverted-dup15 file

WISH-GRANTING RESOURCE



Check out the Internet website
below for descriptions of and links to a
variety of wish-granting
organizations for special children:

www.familyvillage.wisc.edu/general/wish-grant-orgs.html

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