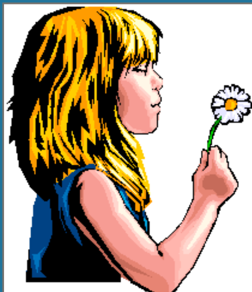
THE MIRROR
The Newsletter of IDEAS - IsoDicentric 15 Exchange, Advocacy and Support

SUMMER 1999



THE MIRROR is back on track!

It has been a while since the last IDEAS newsletter came out, and we thank you for your patience. We know how much parents value information about isodicentric 15, since there is relatively little out there. In this issue, we address the hot topic of secretin therapy, a controversial treatment for autism. We also bring you tips on record-keeping, and of course, a family portrait. And for those of you who use the Internet, look for an important message on page 5 about our newly-established email listserv.

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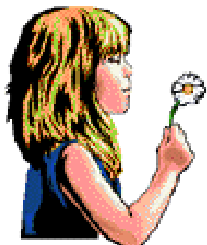

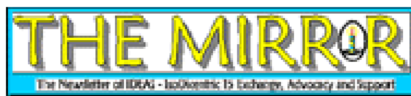

SUMMER 1999 NEWSLETTERS HOME

COULD SECRETIN HOLD THE SECRET TO AUTISM?

Recent television news programs such as Dateline and 20/20 have focused on the use of a hormone called secretin for the treatment of autistic symptoms. While the broadcasts emphasized the dramatic results seen in some children, many questions remain. Because our office has received many inquiries about secretin, we have reprinted below (with permission) a recent letter from well-known autism researcher Dr. Bernard Rimland. For further information, contact Dr. Rimland at the Autism Research Institute, 4182 Adams Avenue, San Diego, California 92116, or check out their web site at www.autism.com/ari/secretin2.html

September 1, 1998
To: Those inquiring about the use of secretin in autism
From: B. Rimland, Ph.D.

For more than three decades, the Autism Research Institute (ARI) has served as an interface between the families of autistic children and the autism research community. Our primary role is to identify promising approaches to treatment and to accelerate the process of evaluating and implementing the best of these approaches. The use of secretin appears to be the most promising treatment yet discovered for the treatment of autism. ARI has set itself the task of obtaining, as quickly as possible, at least tentative answers to the questions of greatest interest to parents and clinicians, and to researchers embarking on clinical trials.

Our Secretin Outcomes Survey (SOS) is a single-page questionnaire designed to elicit maximum useful information, with minimum effort, from the parents. The SOS has been distributed to parents of children undergoing secretin treatment through a variety of means: Directly to parents, by mail or fax, via physicians, in Victoria Beck's book, and via the Internet. To date just over 200 forms have been submitted to ARI, and more arrive daily. Many are incomplete or illegible (faxes don't like No. 3 pencils!), but most are useful and provide valuable data. Here is what we have learned thus far. Obviously, these findings must be regarded as preliminary and tentative.

Who is the best candidate for treatment with secretin?
We don't know. We expected to find that certain categories of autistic persons would be more likely to show benefits than others; for example: low-functioning vs. high-functioning, those with diarrhea vs. those with normal bowel function, early onset vs. late onset, boys vs. girls, younger vs. older. So far none of these anticipated predictors has proven valid, although there is a slight tendency for those with diarrhea to respond better behaviorally to secretin, but negligibly so. Judging from what we hear from physicians who have infused many cases (not from our SOS data) at least 75% (!) of their patients on the autistic spectrum show benefits from secretin, but we cannot yet identify a subgroup that does notably better or worse than the total group. Laboratory tests, such as blood secretin or blood ammonia levels, may prove predictive.

What is the best dosage?
We don't know. The Ferring Company suggests 1.0 to 2.0 Clinical Units of secretin per kg of body weight (for diagnosing digestive disorders - not treating autism), and that is what many have been given. However, our data include dosages ranging from 0.5 to 7.3 CU per kg. If we consider only those between 2.0 CU/kg and 5.2 CU/kg, disregarding the few cases at the extremes, there is no perceptible advantage to giving the larger amounts. There are slightly more negative reactions (e.g., hyperactivity) among those given the large doses. From present data, we would guess that a few years hence, when we know more, the optimal dose will be found to be between 2.0 and 3.5 CU/kg, on average, though some will need less and others more. (Some do well on 1.0 CU/kg.)

What benefits are seen?
Many, and they are benefits that are important in autism--eye contact, awareness, sociability, speech, and so forth. An unexpected benefit, better sleep, was a write-in, mentioned by many parents but not included among the choices we provided on the SOS form. Several children began sleeping the night through on the night of the infusion.

What about adverse effects?
About one third of the children showed negative responses, mostly hyperactivity, and some aggressiveness, for a few days to a few weeks after the infusion. In only a few cases were the problems severe. However, many autistic children have periods of disruptive behavior from time to time without secretin. In the absence of a matched control group of untreated autistic children, we have no way of knowing whether the problems actually were, in any or all cases, caused by secretin. There is speculation that behavior problems are more likely to be seen in the children on drugs, especially seizure drugs, but we have too little data to confirm or refute this, and other possibilities.

What is the optimal schedule of administration?
We don't know--too few data as of yet. Some say 5 to 6 weeks, but we don't really know. Our data do tell us, however, that the benefits, when they occur, can start quite quickly, and seem to peak in terms of percentage of children who respond, at about the end of the second week. Thus, we have been telling clinical researchers that the optimal delay between infusion and evaluative testing is about two weeks.

Other questions: While the dim outlines of the answers to some of our questions are beginning to emerge, we need much more data in order to come up with needed information. Among the outstanding questions:

- ***Age:*** How well do adolescents and adults respond to secretin? It is too early to be sure, but it is beginning to appear that teenagers and adults improve as well as the children.
- ***Repeat infusions:*** If the first and/or second infusions do not show significant benefit, is it worthwhile to try again?
- ***Relapses:*** How long until relapse if secretin is discontinued, and do some improvements relapse faster than others? While, as mentioned above, five weeks is sometimes mentioned, we really don't have a good answer to these questions.
- ***Adverse effects:*** What causes adverse effects? Do drugs, diets, infections, and other factors influence outcome? We don't know. Parents and physicians are urged to help our data collection efforts. We will share what we learn.

March, 1999

Six months have passed since the secretin story was first made public at our Defeat Autism Now! conference in New Jersey. The media coverage, in the U.S. and overseas, has been extensive. Just a few weeks ago the autism/secretin connection was a front page story in the Wall Street Journal (March 10, 1999). Media interest shows no sign of abating, judging from the phone calls and faxes which arrive daily.

Where are we now?

The news still looks good, which is news in itself. Our best estimate is that somewhere around 2,500 to 3,000 autistic children (mostly children--a few adults) have been given secretin by perhaps 200 to 250 physicians around the U.S. The vast majority have received the secretin by infusion, by means of a "push" IV injection, taking just a minute or two. A few have received the secretin transdermally, and a few others have been treated by sublingual drops. The usual IV dose is 2 clinical units (CUs) per kg of body weight. A few physicians have given as many as 300 infusions, and quite a number of physicians have given in excess of 100 infusions. I am aware of several patients having been given nine or more infusions. So far, initial fears that repeated infusions may sensitize the patient, and thus cause problems, have not proven justified.

Supply:

The biggest problem is the serious shortage of secretin, which has been made from pig tissue. Synthetic human secretin is believed to have several advantages over the natural pig source secretin. Several laboratories have begun manufacturing it. Clinical trials comparing the synthetic human secretin with the porcine and a placebo are scheduled to begin soon at a number of university medical centers. Once the clinical trials have been completed to the satisfaction of the Food and Drug Administration, synthetic human secretin will be placed on the market and that should considerably decrease the present problems with supply and cost. I have, regrettably, not been able to get any firm estimates of when the supply situation will improve, but I'm hoping it will be better in a few months.
Efficacy: We continue to receive very positive reports from both the families of autistic children, and the physicians who are using the secretin. It is difficult to get a clear estimate of what percentage of autistic children and adults show benefit but our best estimate is still in the neighborhood of about 70 percent. Parents continue to report greatly improved eye contact and interest in the child's surroundings, fewer tantrums, better sleeping, greatly accelerated language development and toilet training, and a number of other benefits.

The Wall Street Journal article was generally very positive, although it mentioned an unpublished study by neurologist Michael Chez, M.D., of Chicago, who reported seeing no benefit from the secretin he had given to some of his patients. We have heard from dozens of physicians that they are seeing very good results, so Dr. Chez's negative report is puzzling. Dr. Chez is well known for his work with seizure disorders in children, so it is at least possible that his failure to find good results was a result of the subjects' being seizure-prone and/or on anticonvulsant medication.

Adverse effects:

About 5 to 10 percent of the children seem to grow worse immediately after the secretin is given, for a few days, or in a few instances, up to a few weeks. The adverse reactions are hyperactivity and in a few cases, aggressiveness.
Although the reports of hyperactivity and sometimes aggression are infrequent, they are a bit worrisome. However, one must remember that such problems are quite common in autistic

children, and may have occurred whether or not the child was given secretin..... A few untoward incidents, such as the above, even though coincidental rather than causative, could easily derail an emerging form of treatment. Thus far that has not happened with secretin, and as time goes on it becomes even less likely that any significant harmful effects will be attributable to secretin.

Some physicians are reluctant to give secretin to children who have a history of seizures, or are on anticonvulsant medication, for fear, which may or may not be justified, that the secretin may have adverse effects on such children. One youngster had a seizure while the secretin was administered but, after investigation, it was concluded that the secretin was probably not the cause of the seizure. The child's family has a history of seizures, the child had an abnormal EEG to begin with, and the child had struggled against the infusion, so the stress of the situation might have led to the seizure.

For more information about secretin, visit www.repligen.com.

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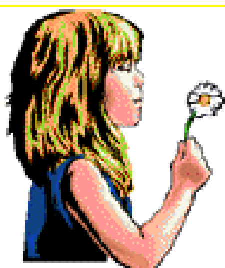

Family Portraits

Frederique

This newsletter's family portrait was sent by Catherine Jarrold and Normand Davidson of Quebec, Canada.

Frederique is a beautiful blond girl born 7 years ago on January 8, 1992. She has a brother 16 months older and a sister 20 months younger. At 36 weeks and weighing 4 lbs., she was delivered by Cesarean after doctors noticed that there was very little prenatal growth. She stayed in the hospital for two weeks before we could take her home. There were no abnormal signs that anyone detected at the time. She was breast fed for six months. She did have colic, and her weight gain was very slow.

About 1 1/2 years after the diagnosis, our geneticist suggested we have blood samples as well as skin biopsies taken from my husband, daughter, and myself so that further testing could be done at Children's Hospital / Harvard Medical School in Boston. Our daughter also participated later in the Elwyn research. It was also recommended to us that we get Frederique into an early stimulation program as soon as possible, as well as start physiotherapy, occupational therapy, speech, and play therapy. Until age 4 she had weekly appointments with many of the above therapists with whom she either cooperated or did not. She was also going to a play group three half days a week. By then she was traumatized by all professionals who tried to approach her. She had had her share of poking and testing. Even a simple trip to the hair dresser was a major traumatic event for everyone involved.

She learned to walk at age 2. She still has trouble with her balance, therefore, she seems to wobble. With age and greater strength, her walking has improved. She most often runs on the tips of her toes to get from one place to the next because of her equilibrium problem. She has a hint of cross eye or lazy eye. At age 4 1/2 she had inguinal hernias repaired. By age 3, Frederique had a repertoire of 50 words. Now at 6, she is making sentences of 4-5 words and can make herself reasonably well understood. We are confident she will improve some more. Being able to communicate has relieved much frustration and tension on her part. She also has a deep love for music which she enjoys and can also be used to calm many tantrums. She knows and sings the words to many songs.

Frederique has a high tolerance to pain as well as to the heat and the cold. She loves to be around heat sources such as the oven door or the cooking elements when in use. Therefore, she needs constant supervision. Frederique learned to ride a tricycle when she was 5 and can now ride a bicycle with training wheels. When we watch her go, everything seems so “normal”. She seems very happy when she can follow her siblings and neighborhood friends around. Since she doesn't watch for traffic, she needs to be supervised.

We try, as a family, to include her and to get her to participate in as many family outings as possible. In the winter, she tries to skate and to ski. In the summer, she loves to play in the pool. Our priority again this summer is to get her toilet trained. We have been trying off and on for 1 1/2 years.

When Frederique was 4, she started school full time in a special class, in a regular school, with other handicapped children. She is finishing her 2nd year soon. She has made tremendous progress and enjoys being in the company of other children. Even though she is now 6, she has the weight and height of a 4 year old. As a result, older school children tend to want to mother her and play with her. We have tried, and are still trying to get her integrated into her neighborhood school with her brother in kindergarten, but the regular school system doesn't seem prepared nor willing to give Frederique a chance. I believe it is our greatest frustration as parents. I feel that I am constantly having to fight battles for Frederique to ensure that her needs are met and that her rights are respected.

It is a daily challenge to live with Frederique, one that brings some ups and downs, some tears, a lot of laughter, and much love. If any readers wish to write to us to exchange experiences, views, comments, or to simply chat, we would be happy to hear from you and to reply.

Catherine Jarrold and Normand Davidson
194 Rosedale Avenue
Beaconsfield, Quebec, Canada H9W2H8

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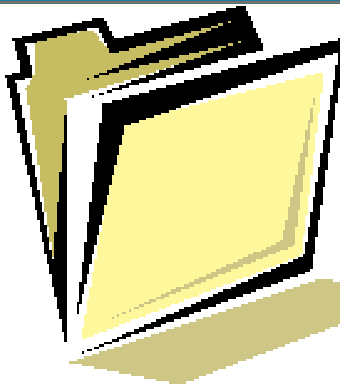

RECORD-KEEPING: A SUB-SPECIALTY IN PARENTING CHILDREN WITH SPECIAL NEEDS

by Maria Kerber & Julie Siebold,
Excerpted with permission from: Parent Network *bulletin board, 2nd Quarter, 1997*

Once your child enters special education or early intervention, the paperwork can quickly seem overwhelming. What do you do with medical and educational reports, teacher evaluations, individualized education plans, communication between home and school? If you have to dig out from under special education paperwork, here are some ideas for managing. The first question to ask yourself is, "Do I really need all this paperwork? The answer is YES! The more information you have that is well organized, the better prepared you will be for meetings where your child's program is designed.

1. GET A FILE

To begin, consider what type person you are. If highly organized, get a three ring binder and hole punch. If not, buy a huge folder with at least five pockets. Designate five sections for your system and label them:

Meetings and Outcomes
Professional Evaluations
Research
Teacher Evaluations & Correspondence
Test & Homework Samples

2. WHAT TO PUT IN EACH SECTION

Meetings and Outcomes

This section has the IEP's, notifications of meetings from the school and your minutes of the meeting. Highlight times, dates and other pertinent information. File things in chronological order.

Professional Evaluations

Include all medical, psychological, & psychiatric reports. Include comments from the school nurse made to you about your child showing signs of stress or other medical problems. Highlight dates and important findings and place in chronological order, with most recent in front.

Research

Be your child's best advocate by keeping current with their disability and putting reprints of relevant articles, seminar handouts and other data in your file. Many organizations have information on disabilities and are good resources.

Teacher Evaluations and Correspondence

This section should include interim reports, report cards, notes to and from your child's teacher, disciplinary notices, notes from phone calls. Be sure your notes on phone calls include the date, content, the person you talked with on the phone.

Text and Homework Samples

You can gauge your child's progress by including samples of his or her work from the beginning and end of the school year. You will want to keep examples of both weak and strong areas of his or her work.

A NOTE ON MEDICAL RECORDS..........

Medical records are like insurance - you never realize how valuable they are until you need them. Children with idic(15) tend to see a lot of doctors, and over a lifetime that means a lot of records! It is often difficult to get records "after the fact", but if you make a habit of requesting records each time your child is evaluated, the job is much easier.

- *At the time of your child's medical appointment, hand the office staff a request in writing that you receive copies of all reports and correspondence*
- *Keep in mind that as your child's guardian, you DO have a right to all reports.*
- *If you have trouble obtaining records, enlist the help of a health professional (nurse, genetic counselor, etc.) to help put some clout behind your request.*

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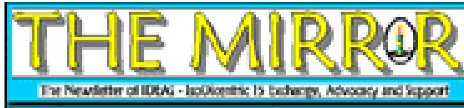

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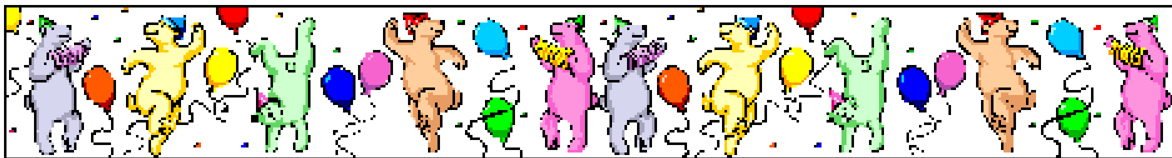
Happy Birthday!

Name	Date	Name	Date
Clare	07/25/80	Ashley	09/02/84
Emily	07/31/80	Cheyenne	09/08/92
Rachel	08/04/86	Jovan	09/09/94
Devon	08/07/93	Elana	09/09/88
Jesse	08/12/94	Thomas	09/10/93
Eli	08/14/92	James	09/11/93
Spencer	08/15/94	Waawiija	09/11/93
Austin	08/15/96	Breauna	09/15/95
Kacey	08/30/93	Cheyanne	09/27/93
Joshua	09/01/94	Evan	09/28/94
Brenda	09/02/89	Cara	09/30/92



Isodicentric 15 Computer Listserve Up and Running!

We recently set up a free email listserve on the Internet to provide a forum for families to connect with each other. Families and professionals can post messages related to isodicentric 15. Once you register, these messages will appear on your email as they are posted. Never used a listserve? Don't worry - listserves are easy to use and can be a great way for families to help each other and learn. To sign up for the isodicentric 15 listserve online, go to:

http://www.egroups.com/group/idic15/

On the top left corner, click "group info", then click "Join this group" and complete the registration form. You can then post a message or simply follow the conversation. We look forward to hearing from you!

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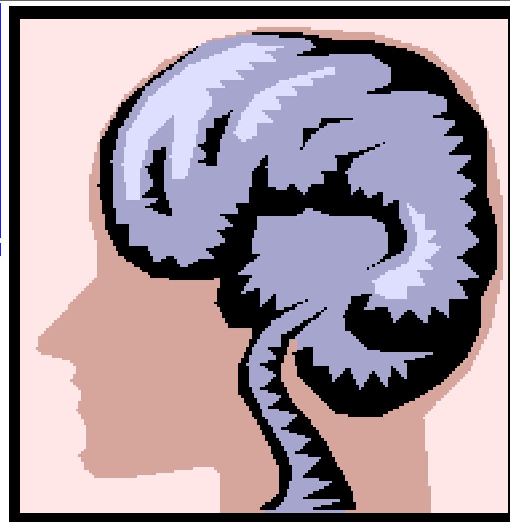
Autism Research



Many IDEAS families have helped to further research into isodicentric 15 by participating in a telephone questionnaire about autistic symptoms in their children. The results of that research were published last year and have established a clear connection between autism and idic15.* Now, researchers Suzanne Rineer, Elliott Simon, and Brenda Finucane of Elwyn, Inc. are doing a follow-up study of the families who participated in that research. Look for updated results in a future issue of *The Mirror*.

** Rineer S, Finucane B, and Simon EW (1998): Autistic symptoms among children and young adults with isodicentric chromosome 15. Am J Med Genet 81:428-433.*

Our Deepest Sympathy..............

Dear Donna,

I wanted to let you know that my son Ryan passed away last year in April. He had hip surgery (which went well) but developed complications a day later and died a couple of days after that. It was unexpected and quite a shock to all of us. His last year was his healthiest year ever but given his overall medical condition, surgery was always a risk. He was still severely delayed in all areas (was not walking or talking and was still tube-fed), but he was making progress slowly and had a good year at school. His death has left a big void in my life. His care was never a burden to me, but I never realized how much time I spent taking care of his needs. I hope to stay involved with children with disabilities but I haven't decided in what capacity yet. I want to thank you for all the work you have done with IDEAS. Please keep me on your list. I would be happy to share information with other families.

Jodie Kopala

We send our heartfelt sympathy to John and Jodie Kopala and family of North Carolina on the death of their beloved son, Ryan. Ryan was featured in our Family Portrait in the Fall 1994 issue of The Mirror.

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