EDITOR'S NOTEBOOK/Bernard Rimland, Ph.D.

The use of secretin in autism: some preliminary answers

The secretin story broke in early October. In quick succession, there appeared our secretin editorial in ARRI 12/3, Victoria Beck's superb presentation on October 3rd at our DAN! conference in Cherry Hill, NJ, and the *Good Morning America* and *Dateline* TV shows on October 6th and 7th.* Dozens of newspaper and magazine articles followed. The Ferring Company sold out of secretin by October 16th. Parents, doctors, and university medical centers are scrambling to purchase new supplies as more secretin trickles into the pipeline. Efforts are underway to increase the supply.

The good news is that confirmatory evidence of the power of secretin keeps coming. A national newspaper told of Florida pediatrician Jeff Bradstreet's own four-year-old son Matthew shocking his parents by holding his first normal conversation with them the day after his first secretin infusion. And Virginia pediatrician Lawrence Leichtman told me of his "miracle case:" a five-year-old who had previously said only two words amazed all in the office by saying, 15 minutes after his infusion, "I am hungry. I want to eat." Most cases are much less dramatic, but the autism world is excited, and for good reason.

More good news: the Feds, including the FDA, are eager to help! Dr. Duane Alexander, Director of the National Institute of Child Health and Development, and his assistant for autism affairs, Dr. Marie Bristol-Power, have been extremely helpful and supportive. I have been to two NICHD secretin-related meetings in Washington in the last 30 days, arranged by Dr. Bristol-Power.

Following is the abstract of the presentation I gave at the December 14th meeting arranged by Dr. Bristol-Power to expedite the clinical trials the FDA requires.

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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*
- 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.

Q. 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.

Q. 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.)

Q. 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.

Q. 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 behavioral 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.

Q. 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.

** Editor's note: A videotape with both TV shows is available from ARI at $12.00, postage paid. Victoria Beck's book,* Unlocking the Potential of Secretin, *is also available, for $12.00 plus $3.00 postage. With Victoria Beck's book, any MD can give secretin.*