

LETTERS TO THE EDITOR

ABA and other treatments

To the Editor:

When I read your editorial titled "The ABA Controversy," I was astonished.

As one of the largest providers of ABA, I cannot believe that any of my colleagues would doubt the efficacy of such biologically based interventions as vitamin therapy or restricted diets. I see children from all corners of the world and can honestly tell you that I have personally evidenced hundreds of cases where gluten/casein free diets and vitamin B6/magnesium treatments have resulted in significant and sudden changes in the children, even prior to the start of ABA therapy.

How could anyone see these treatments as being competitive with ABA? Isn't it obvious that these biological treatments complement and accelerate our work?

I routinely recommend to families to have organic acid testing and peptide analysis, in order to assess yeast overgrowth, abnormal bacterial byproducts, or other abnormal activity in the gut or digestive tract. The percentage of children whose blood or urine tests show extremely skewed results is astounding. How can we deny the presence of a biological factor in autism, and how can anyone believe that behavioral treatment alone will alleviate these conditions?

Obviously, I believe in the power of ABA. But saying that ABA is the only effective treatment for autism is like treating a cough with extinction!

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Secretin

To the Editor:

Our 23-year-old autistic son's non-relational patterns of behavior, poor communication, uncontrollable anger, self-destructive actions, and digestive disorders not only have devastated him personally, but also have had a major impact on our family.

After one year and two months on secretin, our son is now for the first time giving us consistent eye contact as he emerges from his prison-like world. He insists on our communication, talking to us in three- and four-word phrases, pulling us into his new world. His digestive problems have virtually disappeared. He is obeying commands immediately and talks incessantly, as compared to only a basic ten-word vocabulary prior to the secretin infusions. He has had a 180-degree turn-

around regarding the negative behaviors. He is showing affection, appropriate guilt, compassion, and an eagerness to learn as never before. He has a brand-new first-time interest in TV, especially football, basketball, and music—goals we have had for him for many years. This year, he really appreciated Christmas for the first time in his 23 years.

To top it all off, our son knows that this infusion helps and that he needs it when he feels bad toward the end of the 28 days. He actually asks for the infusion and has added the words "doctor" and "shot" to his happy phrases. He smiles and says, "Love you," when the infusion takes place. It is much like a diabetic's desperate need for insulin. As a side note, our doctor is overwhelmed at the changes in Andrew, and just this week as we obtained another infusion, he agreed that it was vital for his life.

As a result of secretin we are now even able to seek reduction of his dependence on other drugs. He is now off Thorazine, and we hope to rid him of all drugs one day. This is the beginning of the life that we have prayed our son could have.

Jan and Bill Henry
Ooltewah, TN

To the Editor:

"Secretin: positive, negative reports in the 'top of the first inning'" was an article that speaks volumes as to the sorry state of affairs in the academic medical community when it comes to thinking about anything beyond the "same old, same old." I particularly found offensive the quotations by Dr. Fred Volkmar, "Pursuing unproven treatments risks depleting the financial and psychosocial resources of families," he pontificates. "It is important that physicians help families make informed decisions about treatments for autism."

Why is it always okay to put our kids on drugs on an off-label usage basis, but it's not okay to test for fungal infections, try dietary interventions, look for unusual vaccine reactions, etc.? Can it be that the doctors who have longstanding reputations and lifetimes built upon faulty premises might fight so hard to prevent changes in understanding which would ultimately cut them out of the picture?

If it weren't for parents unwilling to consign our children to the junk heaps offered to us for our "hopeless" children, we would never get anywhere. When I go to the DAN! Conference, for instance, many of those who are doing the research on biochemistry, neurobiology, immunology and the like often refer to pushy, insistent parents who pulled them kicking and screaming into looking at

autism in a way that goes beyond its behaviors. They are people who have actually done research and CHANGED THEIR MINDS about the way they perceive what this thing we call autistic spectrum disorder is all about. In fact, it's interesting to note that many of the folks who attend these conferences are parents who happen to be doctors themselves.

I find it fascinating that doctors like Fred Volkmar who write "useful" things like the DSM definitions of autism, PDD, PDD-NOS, and the like are supposedly the only ones who understand anything about our kids. As for myself, I long for the day when the DSM is no longer of any value in the study of autism. Doctors instead will run a series of tests that will determine the problems that caused a particular child's brain to malfunction, and then will know what medical interventions to try based on the child's needs. But first we must continue to study subgroups of kids and the factors that led them to their challenges. A growing number of brilliant researchers now believe that day is coming, and if parents have anything to say, it will happen in the not too distant future.

[Name withheld upon request]

Secretin Update:

Repligen Corporation has received approval from the Food and Drug Administration to begin a Phase II clinical trial of the hormone secretin for children with autism. Up to 140 autistic children between the ages of 3 and 6 will participate in the double-blind, placebo-controlled study. Each patient will receive three treatments and a follow-up evaluation over a ten-week period.

The primary goal of the study is to determine if secretin improves autistic children's social and communicative skills. In addition, the researchers will assess physiological changes, including changes in subjects' gastrointestinal symptoms, following treatment.

"We believe this to be the largest and most comprehensive clinical trial ever carried out in autism," Repligen President Walter Herlihy says. "By correlating changes in physiology with changes in the symptoms of autism, we hope to define the biological characteristics associated with response to secretin."

Phase II trial sites include the Mayo Clinic, the University of Rochester Medical Center, and the Southwest Autism Research Center in collaboration with Phoenix Children's Hospital. Parents wishing to enroll their children should contact these centers.

A synthetic form of the porcine secretin formerly produced by Ferring may be available, for diagnostic use, from Repligen in a few months. It is hoped that Repligen's synthetic human secretin will be approved for use in autism in early 2001.