

"Autism" October / November 1998

The events unfolding around Secretin illustrate the good and bad of "Autism" and in medicine in general . That so many parents would say that "I know its unproven, not fully evaluated, but I'll try anything reasonable . . ." One can understand a mother's desperation, a parents willingness to consider anything reasonable. But with the many potential downsides (see evolving discussion Secretin _ Webboard _ "Ask Dr. Goldberg), it's potential good, and potential message is likely to be lost in all the "noise" surrounding it. The fact that a child can change significantly by the usage of **any** agent, via infusion, orally, and so forth, should say loudly to parents and "existing organizations and leaders" that at least a group of your children **are not consistent with any concept of pre-existing brain damage, congenital disorder etc.** (these could not be changed by any infusion or therapeutic agent) and it's time for a new focus on this enlarging group of children. A focus that must finally come from the acknowledgement that at least a group of these children start off in theory with good brains and potentially highly productive lives, and we are losing them to a process that could be changed. Through efforts mounting behind the N.I.D.S. Medical Board and its unique abilities, it is my hope that we will see a focused effort on these children's behalf to apply good science as rapidly as possible. To understand, instead of guess, at what are the right choices medically. While so far not appearing a long term safe choice, the "wonder" of Secretin is only a sample of what could be done with the right choices of agents and therapies. There are no silver bullets, no new usage of old "tonics" to solve this problem on a wide level, these choices have not existed, will likely never exist. But there is a new chance to utilize science and technology rapidly on behalf of these children. With recent developments in research, there is no medical or technological obstacle to finding excellent, "peer review level" researchers and clinicians ready to join in, if this network is launched. The ability to do this worldwide, should ultimately maximize the ability to look at potential new therapeutic agents, anywhere reasonable.

At the recent AACFS meeting in Boston, abstracts were presented confirming scientifically, the association of viral reaction with low NK cells, and the likely usage of NeuroSPECT to understand the brain better. As clinicians, many of us commented, "there was nothing presented we didn't know before" but now it has begun to be verified at appropriate, academic, peer review levels. At least some part of this large heterogeneous group they have called CFS/CFIDS, has something significantly wrong. Being as I have a similar marker in at least 38 _ 40% of the children I have evaluated (NK cells below 6%), it time to approach this with the appropriate knowledge and level of concern. As CFIDS, emerges from the "nightmare" of denial, a feat that has merely taken (depending on how one counts) 8 _ 16 years, we do not have another 6 _ 8 years (or longer) to wait for our children. It's been four years since the first meeting of DANN. In another four years, children young four years ago, will be significantly older, with significantly decreased odds for full recovery.

With the connection I have seen to children with variants of ADHD, CFIDS, etc., another important observation disserves noting clinically. If as I have a speculated the same type of immune and/or viral process is linked in adults and adolescents with CFS / CFIDS, children, older children with ADHD, younger children Autism / PDD, then to just feel things can be corrected "educationally" or behaviorally, is a grave disservice to

many of your children. If an adult with a full college education cannot remember things or function well cognitively, if an older child or teenager, both with well developed early language and social skills will have difficulty by junior high (or sooner), what chance does an "Autistic / PDD" child have, if their brain is not helped to work and develop. As I have questioned at this point many times, as much as many children under "Lovaas / ABA style" programs may make kindergarten, 1st or 2nd grade ("miraculous" if one perpetuates the old images of Autism / PDD), I have yet to hear of parents at any successful replication site talk of children doing well by 3rd, 4th, or 5th grades (as higher cognitive functions are required).

Researchers, physicians, psychologists and other health related personnel have made a very profitable industry of helping children with "Autism;" but instead of objectively analyzing developments and changes, have merely looked at developments in terms of the "old model", not the "new reality." As discussed in the "NIDS BOARD UPDATE" (also posted on this website) its formation, its concept, the idea, has created a potential linkage of "academic" centers world wide - focused on unifying objective data and evaluations of your children, such that "true" new therapies, might be evaluated and applied in the shortest amount of time possible.

These efforts will not proceed without financial support, and increased political and patient focus in this country and world wide. Interestingly, while often "official views" are very backward or still primitive for this field, there is in general a much more open, greater willingness to analyze and understand new models by researchers in other countries, rather than as most of our groups and organizations have done, cling to old models, old concepts. But just as what many of us were saying re Chronic Fatigue Syndrome / CFIDS, was clinically ahead of its time years ago. so are these concepts for your children. In a world where clinicians and researchers have less freedom to do anything beyond the "dictated path", it is urgent we capitalize on the freedom researchers still have. The chance (with funding) to mobilize top researchers and clinicians in a "focused" effort for your children truly exists. Whether we can create the right "focus" to make this happen, to go around the "organized" obstacles in your children's way" is the only large challenge left. As noted, with recent developments there is not a medical or technological barrier to this happening, only time, effort, and money. With the passage of time, I wish to address one further issue. As I have children who have been with me 2 – 3 years now, their pediatricians are seeing them back for check-ups and commenting how they are growing better, developing better, by every criteria we can use as Pediatricians healthier, *even though on medication*. While noting the need to monitor the medication, can find no problem in continuing the current program due to its success. This is a very important point from a number of directions. One, as a Pediatrician, as much as I may be willing to do something differently, everything is based on if I can succeed, does one have a healthier mind and body. Fortunately, time is showing this to be true. I have many patients who no longer maintain their "Autistic" labels, such that for every "wonder cure" promoted over the last 3 – 4 years, I am confident I can provide a dozen, more likely 2 – 3 dozen similar or better children. Two, this goes back to how we view these children. If viewed in the old ideas of Autism, likely brain damaged, likely mentally retarded, then many programs will continue to argue how successful they are with your children, while missing the major fact (as illustrated by Secretin or any "wonder" solution), **this is a disease**, changeable,

potentially treatable process, not a developmental disorder in a large number of your children. If there is going to be any hope for substantial change by the "new millenium" , we must see these new efforts succeed. For all of you and your children, I hope, believe they will.

With great respect and concern for all of you and your children

Michael Goldberg, MD