

Testimony

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Given To

Government Reform Committee Hearing on Autism – Present Challenges, Future Needs – Why the Increased Rates?

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Thank you for the opportunity to speak for my son and the tens of thousands of children, and the hundreds of thousands, if not millions of parents, siblings and grandparents suffering from "autism." (See Exhibit 1, Yazbak study). To be brief, our problems are severe, and they are exacerbated by ignorance and resulting inability to help on the part of doctors, health insurance companies, and schools.

Consider the following circumstances in your home, with your child:

- Your child urinates or defecates somewhere on the floor every day. He does the same every night in his room, because he is up at least two to four hours between one and five AM every night. If you go to visit friend or relative overnight, his behavior will be even worse, because he is in a strange environment.
- If you don't know where he is, and what he is doing, you know that you may regret it. He likes to play in the toilet, leave the water running in the upstairs tub, and open the door and leave. He doesn't know about traffic.
- When your child is up at night, he moves the furniture in the room regularly, sometimes pushing an entire dresser through the drywall. He spends hours jumping from the highest places he can climb to onto the hardwood floor. He laughs or screams uncontrollably, as if drunk. Noone in the house can really sleep ... night after night.
- Your child only eats a few things: carbohydrates and sugars. He carries the food all over your home, and crumbs are everywhere. When you take him to a restaurant, he runs to strangers plates and begins eating their french fries without any acknowledgement. Or he puts his hand in their drink to get some ice. He may do this at any time during your restaurant visit, while regularly crawling to the floor to eat someone else's food left there.
- He will not sit, but must jump from all of the furniture in your home for hours at a time. He will push any lamp, picture, book, papers or porcelain pieces on the floor without thought, sometimes clearing an entire counter with one sweep of his arm. He is not angry, can't be disciplined, and doesn't seem to feel pain.
- He sometimes opens the car door while you are driving.

This happened to us for two years, and we are not unique among these families. In our experience, it is hard to find babysitters for a child like this. Only grandparents have the love to help out, and many families do not have these. Some families have two or three autistic children!

The result is that life, as the family knew it before the child, stops. Time and possibilities for children's activities, friendships, and vacations are transformed into doctor's visits, laboratory tests, behavioral and speech therapist sessions, IEP and school educational struggles. Insurance companies refuse to pay medical bills for treatment. Friendships end for lack of communication. Siblings lack the attention they deserve.

Financially, the costs can be devastating. In 1998, we spent over \$30,000 on treatments, programs, medicine and tests for our son John. We couldn't afford this, and needed financial help. Many families don't have such help available to them. They are stuck in a poor neighborhood with this condition, and no place to go for help.

Treatment programs for our son have included Auditory Integration Therapy, Vision Therapy, Speech Therapy, Occupational Therapy, and Sensory Integration Therapy. We have participated in swimming and horseback riding, the Option Program, and picture exchange programs. Tests have included CAT scans, allergy testing, elemental hair analyses, antioxidant tests, urine profiles, stool analyses, and numerous blood analyses.

The uproar over Secretin should be a teaching lesson to everyone that parents are desperate for results. And many ignorant, uncaring, or outright fraudulent providers of "services" of different kinds are preying on us. Our son lost the few words he had after Auditory Integration Training. We saw doctors charging \$1,000 and more for a dose of Secretin.

Our school system would not tell us what programs were available to us, and denied us options we found out should have been fully available until we hired an attorney in the second year of the process. Now we are struggling with the nibbling away of the fifteen hours per week that our son is supposed to be receiving. The provider is subtracting time to prepare materials, take notes, write down observations, and talk to us. Our son is lucky to get 12.5 hours per week, and usually that is spent sitting on a swing observing, or watching him watch the weather channel rather than interacting with him. He is supposed to get 1 hour of speech therapy per day minimally, and gets twenty minutes twice a week from the system that receives federal funds for his autism. But we have learned that our school system is overwhelmed with the increase in incidence of these kinds of children. According to a recent Indianapolis Star article, the State of Indiana is so desperate for Special Education teachers that they will allow anyone with a college degree to be one. What kind of special education is this?

The insurance companies will pay nothing for a child with autism. We found no company without this exclusion in their contracts. The waiting list for Indiana's Medicaid waiver, if you get on the list and they don't "lose" your spot in the meantime, is now three years. Because early intervention can be critical, the wait can be devastating to a child's ability to recover.

But we now have great hope. After years of reading books about autism, trying to understand why some children come out of the condition and some do not, we have learned that the term "autism", as used today, is a *behavioral diagnosis* and *not a medical diagnosis* because of its expanded definition to include so many children with different degrees of anti-social/behavioral conditions. (see Exhibit 2, Washington Post article). However, for most children, the behavior is caused by an underlying medical condition and these children can be treated. None of the insurance companies, school or program providers, or even physicians in Indiana with whom we met, including the pediatric immunologist at our local children's hospital, made this distinction. Ignorance is rampant.

Perhaps because it is not their lives that are altered each day, they are not compelled to interrupt their lives to learn. For example, the pediatric immunologist said he did not treat autism. We said, "we're not asking you to treat autism; we are asking you to find out if he has an immune system disorder." He refused to assist us because: 1) the tests are not traditionally run in cases like John's, and 2) he could not justify running them to an insurance company. When we offered to pay for the tests ourselves, he still refused to order them. He told us that if we wanted these done, we would have to go to California and see Dr. Goldberg. He had Dr. Goldberg's information from us prior to the appointment, but still refused the logic of the reasoning for running the tests.

My wife Denise and I followed the secretin story carefully, as well as Dr. William Shaw's work at Great Plains Laboratory. We called and interviewed the physician who spoke on the television program Dateline, spent significant time on the phone with Dr. Shaw, and read about the peptide work being done. We followed every thread we could find on the Internet, trying to understand all of the pieces of the puzzle and the conditions necessary for it to work, as Dr. Rimland and DAN (Defeat Autism Now) seemed to be promoting the use of Secretin for some children. During this time, I followed the web site of Dr. Sydney Baker, one of the DAN Protocol authors (see Exhibit 3), and found his conclusion "*my present view is that autism and related developmental problems in children will turn out to be of viral origin*" and his link to Dr. Goldberg's website, neuroimmunedr.com. (see Exhibit 4).

On Dr. Goldberg's site, I found, for the first time in two years, a cogent medical explanation backed with systems for diagnosis, treatment, and scientific measurements of progress toward healing for children tested to be immune deficient. (see Exhibit 5). The site is an oasis of understanding and treatment possibilities for children with autism, attention deficit disorder (ADD), and progressive developmental disorder (PDD) caused by neuroimmune disorders. It made sense to me that if there is viral or autoimmune cause to the illness, the treatment for such cause would be fundamental to a cure.

We learned, by having blood tests and immune panels prepared from our son John's blood tests (something no physician before had thought to do), that he had high HHV6 titers and low Natural Killer (NK) cells, a condition which is not caused genetically, but which is a disease probably brought on by genetic susceptibility. However, John is now curable! Treatment began a year ago, and despite two setbacks due to illness in the process, John is improving very steadily. The life described in the beginning of this short presentation has dramatically changed, in too short a period to be attributed to maturity. We have a relationship with him. We all laugh

and play together now. He always listens and sometimes follows simple directions. He doesn't mess the floor anymore. He has been sleeping through the night since December. His HHV6 titers are down. Dr. Goldberg expects John to mainstream in the next two years. With your help, it could be sooner.

John seemed to developed normally until about age twenty months. We thought he was the brightest of all of our children, and his brother, in eighth grade, just scored 1390 on the college SAT. The immunization schedules of John and his siblings show that John received the Hepatitis B vaccine the day he was born, May 11, 1995, and the third injection before he was age one. This was *before* his older siblings, who received theirs in 1996. (see Exhibit 6). In addition to this, Denise had gestational diabetes during her pregnancy with John, and he had a history of chronic ear infections beginning at two months of age. (see Exhibit 7). Perhaps, with Denise's diabetes, his pediatrician, a Carmel physician now specializing in the area of autism and ADD who, I am told, now treats over 400 children, should have been more prudent about the use of vaccines on the day he was born, and thereafter as his ear infections signaled a weak immune system. At some point, with all of the stress put on his immune system, perhaps because of the MMR/DPT vaccine or one of his many ear infections by age two, we believe that he suffered the equivalent of an immunological "stroke". We are now trying to recovery from this.

Families with autism need the following kinds of help to deal with this life-changing condition:

- Doctors educated to know that this behavioral condition may be caused by a treatable medical illness, and willing to learn new methods of diagnosis and treatment;
- Schools in which teachers and staff understand that many, if not all of these children are sick, not defective, and can be helped and rehabilitated to have a bright, normal future;
- Education for parents and the medical profession about the difference between the old, classic definition of autism and the new form of acquired autism;
- Insurance companies to recognize that these children are sick, but can and need to be made well;
- Money for research and education, to assist those qualified medical professionals who understand the problem to fill in the answers in the next two years and speed recovery of these children so that they resume normal development and become productive citizens.

In May, 1999, 45 days into treatment for John, I attended a conference on Neuroimmune Dysfunction Syndrome at the National Institute of Mental Health. The curriculum vitae of most of the speakers, and a short summary of the presentations, is attached. (See Exhibit 8).

While I have great respect for the many physicians and professionals toiling to help these children, to my knowledge only the NIDS Medical Research Board combines the application of

real science to make many autistic children well today with 1) predictable results, 2) scientifically measurable markers, and 3) commitment to the safety and well-being of the patients. They have a business plan and are confident in their ability to quickly speed their already predictable solutions for autism caused by neuroimmune dysfunction in a short time. (See Exhibit 9). We are only one of the many families seeing significant, predicted improvement. (See Exhibit 10). Independent medical research supports their scientific approach. (see Exhibit 11). Political affiliation among different autism camps will not affect the knowledge gaps needed to be filled for quicker neuroimmune solutions, but can delay the process necessary to attain it. Even if a genetic solution is attainable in ten years, we parents are willing to drive an earlier version of solutions today with our children. For the sake of our children and our families, please support the NIDS research team and the science that produces results now.

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