

EDITOR'S NOTEBOOK**The Defeat Autism Now! Conference**

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The Defeat Autism Now! conference was held in Dallas, Texas, January 20th through 22nd, 1995. Attendees were 27 physicians and scientists with special competence and a strong interest in developing effective treatments for autism. Six of the attendees were parents of autistic children, another was a grandparent, and one has an autistic nephew. Three came from Europe; the others came from throughout the United States.

Over the past four decades there have been many autism conferences—probably hundreds, and possibly thousands. This conference was different. This conference, as its title implies, was dedicated to defeating autism now!—not 15 or 20 or 50 years from now. The attendees were hand-picked because it was felt that these scientists and physicians could contribute to the cutting edge in a treatment approach that had special promise for bringing about significant, near-term improvement in autistic children.

The Dallas meeting was the first conference sponsored by the Autism Research Institute (ARI) since the ARI was established in 1967. We sponsored this meeting because we—like most parents of autistic children—are disappointed at the lack of progress the traditional medical establishment has made in developing effective treatments for autism. Thousands of parents have spent millions of dollars at major medical centers with little or no benefit. Certainly a lot of drugs have been tried on autistic children—with poor to middling results. The basic cause of autism is not a deficiency of any drug. Most of the physicians we invited to the Dallas conference have a positive track record in bringing about significant—and in some cases remarkable—improvement.

Despite the fact that we did not (could not) pay more than their travel and hotel costs, all but two of our 30 first-choice invitees immediately accepted our invitation! They gave up their weekend and came because they *wanted* to come. They wanted to share what they knew and they wanted to learn what their colleagues could tell them.

The puzzle we call autism has many pieces. The Dallas conference was an intensive effort to put the pieces together. The attendees were MDs and PhDs in genetics, neurology, immunology, psychiatry, biochemistry, neuroscience, pharmacology, allergy, endocrinology, gastroenterology, toxicology, and related fields.

We all sat around the tables, conference style. There were no formal presentations, no posturing, no pedantic criticism—just interested people coming together to share pent-up ideas. Never before has there been a roomful of people in such diverse fields, all keenly interested in sharing autism-related thoughts, ideas, and best of all, plans! What a joy it was for all those present to see and experience the animated, excited and productive discussions:

Friday, January 20th, the invitees flew in and met each other, in most cases for the first time, at an informal buffet dinner. Vitae of all the attendees had been circulated in advance, so the attendees were intellectually well acquainted with each other prior to the conference, although not yet personally.

Saturday, January 21st: each person gave a brief overview of his or her findings and ideas without interruption or criticism, followed by questions, discussions, and more questions. The interaction was intensive and productive.

Sunday, January 22nd: coalescing and crystallizing of information and ideas. Plans laid for developing a collaborative research and treatment network and research database.

OUTCOMES:

1. THE CONFERENCE. The conference went better than we had ever expected. The leading advocates of each of the major etiological schools listened carefully and attentively as the competing theories were explained by their leading advocates. Mutual respect quickly led to a developing consensus: immunological and/or gastrointestinal dysfunction, leading to food intolerance in genetically susceptible persons, and/or viral or fungal infections and metabolic imbalances, may interact in intricate but plausible ways to bring about autism. Understandings developed as to why certain interventions helped. Collaborative thinking and collaborative planning evolved.

One exciting and unexpected development: several participants established a private Internet network to permit the attendees to communicate with each other easily after the conference on an individual or collective basis. (If this network is later opened to other professionals, we will announce such plans in the ARRI.)

2. IMPLEMENTATION OF CONFERENCE FINDINGS. Several participants—in my opinion the most qualified people in the world to do this task—have volunteered to make up a clinical testing protocol which lists the most important tests to conduct on autistic children, indicates the exact manner in which the tests are to be conducted, and the laboratories to which the blood and/or urine samples are to be sent. This protocol will have two major goals: 1) determining the best treatment for each individual child, and 2) improving our understanding of the nature and causes of autism. A lesser, but still important goal will be identification of subtypes of autism, if possible.

The protocol will be circulated among the attendees before being finalized.

3. TRAINING SEMINARS. Once the protocol has been finalized and approved, and a small pilot study completed, a series of weekend training seminars will be set up in various cities throughout the United States. Physicians interested in learning how to administer and interpret the clinical tests indicated in the protocol will be able to en-

roll in these training sessions, so that parents who wish to take advantage of the diagnosis and treatment approaches developed at the Dallas conference will, it is hoped, be able to find a qualified physician in their local area who can undertake the clinical management of their children.

In the meantime, arrangements will have been made with the various laboratories which will be doing the actual analysis of the blood and urine samples so that the data taken from the laboratory analyses of the children can be collected and reported in standard ways, and then stored in a research database. (Obviously, the permission of the participating parents and physicians will be necessary.)

After data on several hundred cases has been accumulated, which should not take too long if we are able to get a substantial network of participating physicians throughout the country, it will be possible to correlate the data collected with the outcomes for each of the children, and for each of the subtypes, to determine the value of the various tests and treatment modalities recommended.

FUNDING. Some of the laboratory work required by this project is routinely funded by insurance companies. Other testing may be too innovative or advanced to be paid for by insurance funds, and it will therefore be necessary to obtain funding from the families, or from foundations or other sources.

Additionally, it will be necessary to hire at least one, and possibly two, research assistants to compile and keep track of the research data as it comes in from the various laboratories.

We will not know the exact cost of this project until we have more information from the people who are developing the protocol.

I have heard directly from a number of the participants, and indirectly from a number of other people, that many, if not most, of the participants regard the Defeat Autism Now! conference as perhaps being the most important and most productive they have ever attended. I certainly feel that way, and I am proud that the Autism Research Institute was able to undertake this effort.

The Defeat Autism Now! conference was merely the first step in a process. The purpose of the process is to defeat autism, in its various manifestations and with its various causes, as quickly as humanly possible. Your help and cooperation, as well as your financial support, are earnestly solicited.

IMPORTANT NOTICE: We realize how tempting it must be for parents to contact ARI immediately to ask how their children may participate. Please don't! At least, not yet. As soon as it becomes possible for us to announce the training seminars, send out the lists of physicians who have taken the training, and provide other information, we will do so in the ARRI. We appreciate your patience.