

Editor's Notebook: Steve Edelson, Ph.D.**The Autism Research Institute and Defeat Autism Now!: Who we are, and what we do**

When the phone rings in our office, callers often ask two questions. The first is, "What is ARI?" The second is, "What is Defeat Autism Now!?"

Now that I'm sometimes on the receiving end of those calls, I realize that the answers to these questions aren't so simple. If you're a parent who's new to autism, or a parent or professional who is just discovering our Institute and its work, here's a quick explanation of what ARI and Defeat Autism Now! are, and what both are doing to help children and adults with autism.

What is the Autism Research Institute (ARI)?

The story of ARI begins with Dr. Rimland's son Mark, who was born in 1956 and diagnosed with autism at the age of two. At the time of Mark's diagnosis, doctors blamed unfeeling "refrigerator mothers" for autism. Dr. Rimland immediately recognized that this theory was both wrong and terribly destructive. He dedicated the next several years to researching autism, an effort culminating in the publication of his 1964 book, *Infantile Autism*, which demonstrated conclusively that autism was a biological disorder and ended the era of parent-blaming.

In the course of his research, Dr. Rimland discovered that applied behavioral analysis (then called behavior modification) was an outstanding intervention for autism. He founded ARI in 1967 to spread the word about this then little-known intervention, as well as to foster the search for effective biomedical treatments.

From these beginnings, ARI grew into an international clearinghouse and research organization that now leads the way in finding safe, scientifically proven treatments designed to correct the root causes of autism. Today, our ever-expanding agenda includes:

- Conducting, funding, and facilitating cutting-edge research on effective treatments—over one million dollars worth in the past 1-1/2 years (see Defeat Autism Now! below). ARI focuses on funding state-of-the-art treatments that can help autistic children *today*.

- Maintaining two websites, autism.com and autism.org, which are the Internet's largest resource for biomedical and educational information on autism. This material, nearly all of which is free, is also being translated into several languages.

- Collaborating with the National Institute of Child Health and Human Development/University of Maryland on a whole-body tissue bank to provide research material for scientists investigating the systemic causes and effects of autism.

- Compiling parent surveys to determine which treatments for autism are beneficial and which are ineffective or even harmful.

- Publishing an e-newsletter and quarterly research review newsletter.

- Conducting a rural outreach program to serve areas with few autism resources.

- Creating and "growing" a powerful network of parents and professionals involved in identifying and exploring new treatment avenues.

- Signing formal agreements with other autism organizations to allow us to combine our resources and maximize our services.

- Running the Autism Resource Call Center (1-866-366-3361, toll-free). This service provides free information and support for parents.

- Offering logistical support for the Autism Network for Hearing and Visually Impaired Persons.

- Funding the distribution of a physician awareness handbook for all pediatricians west of the Mississippi (<http://www.HelpAutismNow.com/>).

This year marks ARI's 40th anniversary, and we are involved in more important projects than ever before. We also work hard to maximize the value of every dollar contributed to ARI. Charity Navigator gives ARI its highest rating for fiscal responsibility.

What is the Defeat Autism Now! Project?

As ARI grew, Dr. Rimland began to identify treatments that aided autistic children—for example, high-dose vitamin B6 and magnesium—but the slow pace of these discoveries frustrated him. A turning point came in 1994, at a meeting with Sidney M. Baker, M.D., who described his own frustration in trying to pull the different threads of autism symptoms—biochemical, immunologic, and gastroenterological—into a unified whole that would point the way to new biomedical treatments.

Dr. Baker suggested a solution: a revolutionary project to bring together leaders in every area of autism research in order to share knowledge, spark new ideas, and jump-start progress into finding effective biomedical treatments and even cures for autism. Dr. Rimland immediately accepted this challenge, and with the help of Dr. Baker and Dr. Jon Pangborn, the Defeat Autism Now! Project was born.

Since that time, Defeat Autism Now! has brought together hundreds of experts in biannual think tanks that are accelerating the progress of autism research and taking it in exciting and rewarding directions. Defeat Autism Now! currently hosts two standing-room-only conferences each year, along with mini-conferences in the U.S. and elsewhere. (Video presentations from the large conferences can be watched free of charge on our website.) Other Defeat Autism Now! projects include:

- Publishing *Autism: Effective Biomedical Treatments* (updated in 2007), by Dr. Baker and Dr. Pangborn.

- Spreading the word that recovery from autism is possible for many children. Hundreds of parents of recovered or nearly-recovered children are now actively helping us to overturn the myth that autism is untreatable and always incurable. This summer, I began touring the country to collect documentation of their children's remarkable recoveries.

- Publishing books on effective autism treatments, including *Recovering Autistic Children* (edited by Dr. Rimland and myself) and a book by Judith Chinitz and Dr. Sidney Baker on the Specific Carbohydrate Diet, *We Band of Mothers*.

- Offering clinician training (we are the only organization providing this service).

Dr. Rimland believed that the greatest advances in the field of autism occur when professionals collaborate with parents, who are the true experts on what works and what doesn't. As a result, clinicians and researchers affiliated with Defeat Autism Now! do something remarkable: they *listen* to parents and to other health professionals who report success with investigational treatments or who offer ideas about possible interventions. They investigate the scientific basis for these treatments or ideas, often do clinical trials and analytical studies, discuss the results in think tank forums, and extensively evaluate each approach's safety, efficacy, and appropriateness. If a treatment or strategy passes muster, it is formally presented at a think tank and then at a general conference.

The goal of this rapid, intense study is to put information quickly into the hands of the parents and professionals who need it. Typically, Defeat Autism Now! participants can accumulate enough solid information about a new treatment within a year or two to know if it is both valuable and safe.

Because there are no guarantees that any intervention can help a particular child, Defeat Autism Now! does *not* tell parents and doctors what approaches to use. Instead, we empower parents and physicians by giving them the information they need to make informed treatment choices. The result: growing numbers of autistic children who are making great strides, and many who are recovering.

The work of ARI and Defeat Autism Now! is leading to exponential advances in our ability to treat autism. As Dr. Rimland always said, "ARI funds research that makes a difference!" We hope that you will join the vast network of people—parents, physicians, researchers, and donors—who are investing in the future of autistic children and their families by participating in the work of ARI.