

Editor's Notebook: Steve Edelson, Ph.D.**ARI's ambitious agenda for 2007**

This year marks the 40th anniversary of the Autism Research Institute (ARI), and as many of you know, Dr. Bernard Rimland is not here with us to celebrate—but he is with us in spirit!

For the past four decades, ARI has focused on improving the lives of autistic individuals and their families by conducting and sponsoring research; organizing think tanks and conferences; networking among scientists, physicians and parents; and providing families with relevant, science-based information they needed to understand and treat their children.

Last year Dr. Rimland and I spent many hours each day talking about the past, present and future of ARI. I shared my plans for the 2007 and beyond, and he gave me constructive feedback about how to best proceed. Given my new directorship, Dr. Rimland and I thought 2007 was the appropriate time to expand ARI's approach to helping autistic individuals and their families. As you can imagine, these were emotionally difficult discussions since we both knew he would not see the completion of these projects—but Dr. Rimland took great joy in knowing that these efforts would touch many lives as ARI vastly expands its efforts to reach "autism families" around the world.

Among the projects we planned together:

ARI's Web site

ARI's Web site and the Web site of the Center for the Study of Autism (CSA), my previous organization, continue to serve as leading autism resources on the Internet. According to Google, CSA's and ARI's Web sites rank second (CSA) and sixth to eighth (ARI) respectively for hits resulting from "autism" searches. ARI's Web team is working hard to create one combined site, expand and update its content, and enhance usability and navigation. The address of the new site—set to premiere in March, 2007—is www.Autism.com. Our goal is to make www.Autism.com the most comprehensive and informative resource on the Internet. Suggestions for content are always welcome!

ARI is also working with the "Autism Network for Individuals with Hearing and Visual Impairments" to manage their family and professional database while developing a Web page on ARI's Web site.

ARI's site new site will provide targeted support for families and individuals living with Asperger syndrome (with help from Stephen Shore), address adult issues (with help from Drs. Ruth Sullivan and Temple Grandin), provide advice to families of adopted children (with Dawn Rossi), and offer information specifically for military family issues (with help from military families).

Adult Issues

Dr. Rimland was deeply empathetic and committed to helping families dealing with adult issues. A few years ago, we asked parents of adults with autism to write down their advice for other families. Last month, we compiled those submissions into chapters to be published later this year. In addition, we recently filmed two talks on sexual issues—one on sexuality in males, and the other on sexuality in females. The presenter, Lucinda Waddell, is a parent of a 25-year-old autistic woman. Lucinda is a knowledgeable and experienced autism consultant who has counseled hundreds of families about these issues. Production is complete and the videos will be available for free on ARI's new Web site starting in March.

Beyond Borders

There are no borders when helping autistic individuals and their families. ARI receives letters and faxes daily from families around the world who desperately need information to help their children, and we are making a concerted effort to reach out internationally. Among our projects:

- This spring, ARI is sponsoring a major two-day conference in Rome, Italy on May 19 and 20. In addition, we are discussing the possibility of sponsoring similar conferences in Mexico and Pakistan in late 2007 or early 2008.

- Translation of ARI papers: We've found individuals interested in translating selected ARI papers and editorials into Spanish, French, German, Armenian, Japanese, Russian, and Italian.

- Translations of *Autism: Effective Biomedical Treatment*, written by Drs. Jon Pangborn and Sid Baker: The Baker and Pangborn book was translated into Spanish last year, and a Chinese translation is now underway.

ARI's Defeat Autism Now! (DAN!) program

DAN! was founded by Drs. Rimland, Baker and Pangborn in 1995, and is at the leading edge of effective approaches for treating autism. ARI's work on the DAN! project continues in 2007 with several initiatives, including:

- A meeting of the DAN! executive advisory committee in March. Members will convene in Ojai, California to plan the future of DAN!

- DAN! USA: a network of passionate DAN! parents from around the U.S. began meeting weekly last November. The team is spearheading a number of initiatives to centralize and expand information about effective treatments. Current projects include a list of questions aimed at helping parents select a DAN! clinician, and a 65-item list of frequently asked questions and answers

on topics ranging from ABA to chelation to vaccine research.

- DAN! physician and nurse training courses on DVD. These two courses are now available for sale from ARI; visit ARI's Web site and click "Publication" for more information.

Also coming soon: a DAN! e-mail newsletter. This newsletter will inform subscribers about many of the latest developments in the DAN! movement. You can subscribe to this e-mail newsletter on ARI's Web site.

Dietary Interventions

One of the most effective treatments for autism involves special diets. Judy Gorman, a parent who was a close friend of Elaine Gottschall and is very knowledgeable about the Specific Carbohydrate Diet (SCD), recently wrote a book on this subject. ARI is publishing her book, with its release set for later this year.

ARI is also organizing a video to explain the basics of special diets to parents who know very little about them. A parent group is reviewing and selecting informative segments from the presentations on our DAN! webcast (www.DANWebcast.com). We will compile these segments into one DVD video, which should be available in the near future. The committee has also gathered written materials to supplement the DVD. A second, more advanced DVD video is now in the works.

Working with other autism organizations

Last year, ARI and the Autism Society of America (ASA) announced an agreement to work together on a number of projects. Dr. Rimland founded ASA in 1965, and his goal was to have ASA focus on parent advocacy and ARI on research. I have been in contact with Lee Grossman, President of ASA, on a regular basis, and we have quite a few plans to partner together. These plans include developing a CME course on medical conditions associated with autism, co-sponsoring a consensus conference on gastrointestinal problems, and co-sponsoring a series of conferences on topics ranging from biomarkers for early detection of autism risks to encouraging clinical treatment trials for preventing regression.

In addition, ARI co-sponsored a debate on the autism/vaccine-thimerosal issue in January of this year with Talking About Curing Autism (TACA) and UC San Diego (visit ARI's Web site to view the debate). We hope to sponsor one or two additional debates later this year.

We are also aware that families in rural areas have limited access to resources. We are developing a program to disseminate much-needed information in an efficient

continued on page 4