

Following Dr. Bernard Rimland's Vision

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While there have been many changes at the Autism Research Institute (ARI) described in previous issues of the *Autism Research Review International*, published in our monthly e-newsletter, and posted on ARI's website, www.autism.com, ARI continues to follow the visionary path set forth by Dr. Bernard Rimland.

Dr. Rimland, the founder of ARI and the Autism Society of America, was a true pioneer and advocate for almost 50 years. His death 4 1/2 years ago left a void in the autism community, and all who knew him still grieve his loss.

I was a close friend and colleague of Dr. Rimland for nearly 30 years, and spent the last six months of his life visiting with him in his living room and, toward the end, sitting by his hospital bedside. During this period, he would reminisce about the early days of autism research, and provide me with additional context and background information regarding many of his accomplishments. But more importantly, we spent time talking about the future of ARI. I shared with him my ideas and plans, and he was in general agreement. Dr. Rimland also gave me valuable feedback and advice on how best to proceed. We discussed topics such as networking, distributing information, and giving hope. I will share our conversations on a fourth topic, science, in a future issue of the ARRI.

Networking

Dr. Rimland was constantly on the telephone, day and night, talking with parents, clinicians, and researchers. He would ask parents and clinicians which treatments they tried, and if the treatment helped, hurt, or made no difference. He would take careful notes, and then he would share this information with researchers.

Dr. Rimland would also share information—especially on treatment—with parents, since there were few “accepted” interventions. After hearing from a number of parents and clinicians about a new treatment, Dr. Rimland would contact at least a dozen researchers and experienced clinicians and ask them for their input. If the consensus was that the treatment made sense given the biology of autism, and if it had little or no anticipated adverse effects, Dr. Rimland would begin sharing this information with parents and clinicians. But he understood and always stressed the need for research in order for these treatments to be accepted by the autism community, recommended by pediatricians, and covered by insurance.

Some people in the autism community seem to think that ARI is no longer fostering “cutting edge” ideas and treatments; this is not the case. We simply took Dr. Rimland's personal network approach and transformed it into an active discussion through our private Internet listserv and our think tanks. When there is general agreement among researchers and experienced clinicians, we then share this information with the community. In fact, we now consider even more ideas and treatments because many more professionals are participating.

Distribution

Dr. Rimland felt strongly that a big part of the future in autism research and treatment would be the distribution of information. He was thrilled when I pointed out the need to make an effort to share information beyond our borders by networking at a global level, translating important articles, and developing reliable channels to distribute this information. In 2010, ARI was instrumental in establishing two global networks: the Global Autism Collaboration (GAC) and the Global Autism Alliance (GAA). The GAC is involved in networking, communicating, and distributing information among non-profit organizations worldwide. Today, there are over 70 non-profit members. The GAA is an active network of over a dozen organizations from around the world; the goal is to distribute quality information about diagnosis, treatment, and education to government and professional agencies, families with a son or daughter on the autism spectrum, and the general public.

In addition to these two global initiatives, we are developing new ways to distribute information to parents and professionals. We publish a monthly e-newsletter that is growing fast, with over 26,000 subscribers worldwide. Lenny Schafer, publisher of the Schafer Autism Report, has agreed to distribute an ARI supplement online at least once a month. In addition, we have established an autism app for smart phones, available in English, Spanish, and French.

Dr. Rimland was concerned about support for children on the spectrum as adults. His last book project involved contacting parents with adult children on the spectrum and inviting them to write chapters containing advice for parents of young children as well as other parents with grown children. When the chapters arrived in

the office, Dr. Rimland enjoyed reading them, but he was too ill to do any editing. Eventually, the book was published by Jessica Kingsley Press and titled *Families of Adults with Autism: Stories and Advice for the Next Generation*.

ARI has recently made great strides regarding adult considerations and services. We hold monthly conference calls with “movers and shakers” in the adult community, and we publish a quarterly e-newsletter titled *ARI Adults with ASD E-Bulletin*. Furthermore, we recently established a new program, the Autistic Global Initiative, in which twelve accomplished adults on the spectrum are working together to establish an adult agenda for ARI, and to provide much-needed awareness, guidance and services to the autism community.

Hope

Dr. Rimland and I spent quite a bit of time discussing the word “hope.” Too many professionals argue that autism is simply a genetic disorder and there is no reason for hope. But there is growing evidence that autism is a result of an interaction between genetics and the environment. In any case, many, if not most, individuals with a genetic-based disorder can be helped. Although hope is a message that ARI has promoted since the 1960s, as professionals we of course need to be mindful about the dangers of providing families with false hope. ARI is helping Dr. David Black of the National Institute of Mental Health on a research study on recovery in autism.

We appreciate the continued support of the autism community, and we want to reassure everyone that ARI will continue to follow Dr. Rimland’s vision.