

Online Autism Registry Opens Door on Research

BY PATRICE WENDLING
Chicago Bureau

Decades ago, researchers banded together to help fight childhood leukemia and, in doing so, transformed the disease from a virtual death sentence to one that the vast majority of children survive.

Researchers at Baltimore's Kennedy Krieger Institute are hoping to repeat that success with the debut this month of the Interactive Autism Network (IAN), the nation's first online autism registry.

"IAN will affect the entire research process and accelerate it manyfold," Dr. Paul Law, director of the project, said in an interview. "For leukemia, it was a gradual process that took 30 years. It's my hope the answers for autism will come faster than that."

Through IAN, families of children with autism spectrum disorders can participate in a national online research project or they can be linked to other local and national research projects for which they qualify. By year's end, project organizers hope they will have the largest collection of family-provided data ever compiled on autism spectrum disorders.

Of the 250 families that participated as pilot registrants, 80% had never participated in any autism research, even though many of them live in the Baltimore area with access to several major medical institutions. Still others live in remote areas of the country like upper North Dakota, where IAN may be the only research project available, said Dr. Law, a pediatrician whose own son was diagnosed with autism in the 1990s.

For researchers, IAN provides access to an invaluable database and a potential pool of study participants. For example, if a researcher is interested in studying 8- to 10-year-old children with autism and a history of regression living in a particular region, he or she can contact the network to determine how many children meet the specific criteria. E-mails will then be sent by the network to the families, notifying them of the study. The names of the families will not be divulged, leaving families in control of their privacy.

Typically, researchers rely on broadly targeted recruitment vehicles such as newspaper advertisements, e-mail lists, and local autism support groups. Few are successful because "they put the burden on families, whereas IAN finds them in a very deliberate and qualified way," explained Dr. Law, director of informatics at the institute.

Families that live near urban areas have access to more facilities for evaluation and are overrepresented in current autism studies, said Dr. Michael Burke, chairman of pediatrics at St. Agnes Hospital, a community hospital in Baltimore. Using the Internet will allow a much broader base of participants for autism research and allow broader access to available resources, he commented on the project.

With 1 in 150 children now estimated to have autism spectrum disorders, according to the Centers for Disease Control and Prevention, IAN is attractive to Autism

Speaks, a nonprofit association that provided \$6 million to fund IAN through 2008. Not only does IAN link researchers with families, but it's a safe place families can go for evidence-based research and a sense of community, Mr. Mark Roithmayr, president of Autism Speaks, said in an interview.

Once given a diagnosis of autism by their pediatric care provider, families of children with autism spectrum disorders are faced with a host of day-to-day issues

and often feel alone. It's also challenging for families and their physician to keep up with and interpret the latest autism news, whether it be new genetics findings or the recent widely publicized claim that autism is caused by watching too much television.

"It's an additional resource that's out there that has scientific credibility and also has community safety," Mr. Roithmayr said. "Knowledge is empowerment."

The site, www.IANproject.org, is populated with 300 pages of evidence-based

information, a glossary of related medical terms, news articles, weekly polls, and an asynchronous online discussion forum. The site also will explain the value of research in general to help make parents knowledgeable consumers of research, Dr. Law said.

Greater access to study participants should improve the planning of clinical trials and quicken the pace of research. But Dr. Law suggests IAN also could encourage more Internet-mediated research on

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autism and affect how other disease states are studied as well. That would allow the family in North Dakota and others affected by disease to participate in a variety of research projects rather than being constrained by geography.

"It would certainly promote research and facilitate investigators being able to obtain a large enough data set for the different types of autism," said Dr. Chris Johnson, co-chair of the American Academy of Pediatrics Autism Expert Panel and medical director, Village of Hope, Center for Children with Disabilities in San Antonio. "One of the problems with the genetics research thus far is some-

times trying to compare apples to oranges when you've got children with Asperger's being compared to children with more severe autism and mental retardation and they are all thrown together in the autism spectrum disorders."

The network is free to all users, and all information provided is governed by the privacy and security rules of the Health Insurance Portability and Accountability Act.

Joan DiPietro, R.N., who has experience implementing a surgical information system in a hospital, participated in the beta testing for IAN and said that it satisfied her concerns about privacy. She admits being cautious about providing any information on her son and on his diagnosis of Asperger's syndrome, and she was curious about what questions would be asked and how the information would be passed back and forth.

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Still, she felt it was safe, easy to use, and provided a variety of content in the margins, such as frequently asked questions, that moves a parent through the process.

Ultimately, IAN may help sharpen the public's focus on the reality that there is no magic cure for autism spectrum disorders but rather a course of scientific discovery that must be followed. "If there is anything that we can eventually find that is causing all these children to have autism, it's going to happen through research as opposed to someone saying they have the magic answer," Ms. DiPietro said in an interview. ■

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