

# Online Autism Registry Offers Research Portal

*Researchers can use the Web site as a go-between to gather information and contact families for trials.*

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 collaborative 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 manifold," Dr. Paul Law, director of the project, told CLINICAL NEUROLOGY NEWS in an interview.

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," said 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 non-profit 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, Mark Roithmayr, president of Autism Speaks, said in an interview.

Once given a diagnosis of autism by their pediatrician, 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 pediatricians 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.

The site, [www.IANproject.org](http://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

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 sometimes 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. For families without computers, the staff at Kennedy Krieger is working on models to provide access, possibly through grassroots organizations or by designing a telephone registration system, Dr. Law said.

Missouri had planned to launch its own autism registry but is now working with Kennedy Krieger to develop a state-level model for state agencies, universities, researchers, and support groups to utilize the national IAN registry. ■

## CLASSIFIEDS

Also Available at [www.clinicalneurologynews.com](http://www.clinicalneurologynews.com)

### 2007 CLASSIFIEDS

#### Clinical Neurology News Rates

4 Column Classified Ads

From 1" to 12"

Sizes from 1/48th of a page  
to a full page

#### For Deadlines and More Information Contact:

Robin Cryan

360 Park Avenue South

New York, NY 10010

800-379-8785

212-633-3986

or fax your ad to: 212-633-3820

Email ad to: [r.cryan@elsevier.com](mailto:r.cryan@elsevier.com)

### PROFESSIONAL OPPORTUNITIES

#### Saratoga Springs-Glens Falls, NY

BC/BE Neurologist to join a well-established 4 member private practice serving the Saratoga-Glens Falls, NY region and Glens Falls Hospital, a 410-bed comprehensive community hospital. Easy access to Lake George and the Adirondacks. Hiking, boating, skiing, and numerous cultural opportunities year-round. Only 3 hours to NYC, Boston, and Montreal.

Contact: Jennifer Metivier, 518-926-1946  
or [jmetivier@glensfallshosp.org](mailto:jmetivier@glensfallshosp.org)  
Not a J-1 Opportunity.

#### BUFFALO AREA

Hospital-sponsored private practice in dynamic bedroom community of Buffalo associated with 205-bed Health system. Huge potential - no Neurologist in 83,000 pop. service area. Excellent income guarantee including all start-up and overhead expenses.

800-831-5475 Fax 314-984-8246  
E-mail: [donohueandassoc@aol.com](mailto:donohueandassoc@aol.com)

#### Disclaimer

CLINICAL NEUROLOGY NEWS assumes the statements made in classified advertisements are accurate, but cannot investigate the statements and assumes no responsibility or liability concerning their content. The Publisher reserves the right to decline, withdraw, or edit advertisements. Every effort will be made to avoid mistakes, but responsibility cannot be accepted for clerical or printer errors.



### NEUROLOGISTS

OCHSNER HEALTH SYSTEM is seeking BC/BE NEUROLOGISTS with the following training or expertise:

#### New Orleans NEUROMUSCULAR DISEASE MULTIPLE SCLEROSIS

While primarily an outpatient position, there is also responsibility on the hospital consult service and the opportunity to teach residents, house staff, and medical students. Candidates currently completing a fellowship and/or with practice experience are welcomed to apply. New Orleans offers a unique blend of colorful traditions, diverse cultures, and some of the nation's best food and music.

#### Baton Rouge GENERAL NEUROLOGIST

This is primarily an outpatient position; however, there is also responsibility for hospital coverage. The department performs neurodiagnostic testing to include EMG, EEG, VER and BAER. Baton Rouge, our state capital with a population of 730,000, provides a wide range of cultural and sporting activities and is home to Louisiana State and Southern Universities.

Ochsner Health System is a non-profit, academic, multi-specialty, healthcare delivery system dedicated to patient care, research, and education. The system includes five medical centers, two hospitals, and 28 health centers throughout Southeast Louisiana. Our staff includes 600+ physicians in 80 medical specialties and sub-specialties. Ochsner conducts over 750 ongoing clinical research trials annually. Please visit our website, [www.ochsner.org](http://www.ochsner.org) for more information.

Salary is competitive and commensurate with experience, and we offer an excellent benefits package. We also enjoy the advantage of practicing in a favorable malpractice environment in Louisiana. Join the Ochsner Team and explore your role in discovering cures, improving the quality of life, and making your mark on mankind.

Please e-mail CV to [profrecruiting@ochsner.org](mailto:profrecruiting@ochsner.org) Ref #ANEUJ04, or call 800-488-2240.