

NEWS

Interactive Autism Network, home to dozens of studies, set to shut down

BY HANNAH FURFARO

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The first online registry dedicated to autism research is closing down on 30 June, ending a 13-year run.

The project, called the Interactive Autism Network (IAN), launched in 2006 and was designed to link autistic people with scientists interested in studying the condition. Over its tenure, the network has enrolled about 60,000 participants, including about 26,000 with autism. It has led to more than 50 scientific papers, including studies of traits of **autistic children's siblings** and **conditions that accompany autism**.

IAN generated the first online randomized clinical trial in autism, which explored the effect of omega-3 fatty acids on hyperactivity¹. Because the network tracked many families for years, its data offer a longitudinal look at the lives of thousands of autistic people and their family members. Several researchers credit IAN with helping launch their careers.

But in the past few years, the database has become too expensive to maintain, says **Paul Lipkin**, who has directed IAN since 2013. Its annual budget is about \$1.5 million, Lipkin says. (The network is funded in part by the Simons Foundation, *Spectrum's* parent organization.)

Some of IAN's efforts are also being eclipsed by other ambitious research projects. One of them, called **SPARK**, which is fully supported by the Simons Foundation, aims to collect genetic data from more than 50,000 families affected by autism. SPARK also helps match scientists to families interested in enrolling in studies.

The foundation's staff first approached IAN about merging the network with its other projects, Lipkin says. After the foundation launched SPARK, the two organizations agreed to recruit participants to that effort rather than to IAN, he says. He and other IAN staff have notified participants of the upcoming closure and encouraged them to sign up for SPARK.

Data from the network will still be available, however: The team plans to strip the participants' data of identifying information and archive the data at the Kennedy Krieger Institute in Baltimore, Maryland, the network's headquarters; researchers will still be able to request the data for studies, Lipkin says.

Still, scientists who have used IAN's resources say they are disappointed to see the project end.

"It's kind of a catastrophe that it's closing," says **John Constantino**, professor of psychiatry and pediatrics at Washington University in St. Louis, Missouri, who published several studies using IAN data. Constantino calls the network a "national treasure," and says it could have continued to yield important results for years to come.

Gold mine:

Paul Law launched IAN along with his then-wife, **Kiely Law**. The pair have a son with autism.

When their son was young, it was difficult to find basic information about autism therapies and schooling options, says Kiely Law, who is now also a research consultant for SPARK. Online searches turned up few results, she says, but families she met at support groups had a wealth of helpful resources.

At the same time, she and Paul Law both knew that scientists struggle to enroll participants in such studies. They launched IAN in 2006 with seed funding from the advocacy organization **Autism Speaks** and organizational support from the Kennedy Krieger Institute.

They designed the network to include an online platform for parents to complete autism assessments such as the Social Responsiveness Scale and questionnaires about their child's language abilities and behaviors. Parents could also submit family medical histories and log information about their typically developing children.

Thomas Frazier was a junior investigator at the Cleveland Clinic in Ohio in 2007 when he and about 40 other scientists were invited to a meeting at Kennedy Krieger to learn about IAN. By that point, he learned, thousands of parents had already signed up — a treasure trove for any researcher.

"I wanted to apply [for the data] that day," says Frazier, now chief science officer at Autism Speaks. The resource turned out to be a "gold mine," he says, and fueled several major research publications from his team in high-profile journals.

Luke Kalb, a Kennedy Krieger scientist, published his first scientific paper based on IAN data in 2010. He later used the network to develop a tool that helps families determine whether an autistic family member is experiencing a mental health crisis and needs to visit the emergency room. A

related study based on IAN data is under review, he says.

“It’s just been an incredible resource for my career, and I think for the field in general,” says Kalb, assistant professor at Kennedy Krieger.

IAN also hired staff to write more than 1,000 articles geared toward parents, on topics such as self-injury, medication and autism in adulthood. The articles will be available online until 2021 and at Kennedy Krieger thereafter. SPARK has enlisted former IAN staff to update some of these articles for publication on SPARK’s website, Lipkin says.

Bigger and better:

IAN has faced challenges in the past few years, however. Some families who signed up to participate stopped responding to the network’s research recruitment emails. It is not clear why.

The diminishing returns also made the network too expensive, some researchers say. Researchers who used the network to recruit participants for studies were required to pay a fee — but as the number of participants who responded declined, the cost began to outweigh the benefit.

“Had we received hundreds of participants through it, it would have been cost-effective,” says **Helen Tager-Flusberg**, director of the Center for Autism Research Excellence at Boston University, who paid several thousand dollars to recruit participants through IAN. “But because we didn’t get that many families through IAN, it ended up, relatively speaking, being expensive.”

Also, thousands of participants who were enrolled as children are adults now. The network would need to collect permission from these people to continue using their data.

Keeping the study going would have been difficult, some researchers say — but might have been worth it. The collection lent itself to studies on how autism affects people over time, Constantino says.

“Nobody who really understands the scientific process would ever throw away prospective longitudinal data,” he says.

Those closest to the project, however, say they are pleased IAN could pave the way for bigger projects.

“They are going to refine our ideas and visions and make them bigger and better,” says Paul Law.

REFERENCES:

1. Bent S. *et. al. J. Am. Acad. Child Adolesc. Psychiatry* **53**, 658-666 (2014) **PubMed**

