

Experts launch largest-ever autism research study in US

April 25 2016, by Jonel Aleccia, The Seattle Times

Autism experts at the University of Washington are bracing for a flood of interest starting Thursday as they help launch the nation's largest-ever autism research study, which will seek DNA and other information from 50,000 U.S. families.

Nearly 300 Seattle-area families have enrolled already in the pilot stage of the study, dubbed SPARK, which is sponsored by the Simons Foundation Autism Research Initiative, or SFARI, based in New York.

Now, the university and the Seattle Children's Autism Center will join with nearly 20 other sites across the country to compile a database of genetic, behavioral and environmental information about people with [autism](#), from toddlers to adults.

"We really want to involve as many families as possible where the child has been diagnosed with autism," said Raphael Bernier, a UW associate professor of psychiatry and behavioral sciences. "We want to get every child involved."

The goal of the project is to identify [genetic markers](#) for autism, a range of brain-development disorders that affect 1 in every 68 children in the U.S., according to the Centers for Disease Control and Prevention.

Families who agree to participate will provide DNA through saliva samples, which will then be analyzed through whole exome sequencing, a technique to identify genetic markers for known and unknown

conditions.

Scientists will screen for markers for autism, which is known to have a strong genetic component, Bernier said. To date, about 50 genes have been identified that almost certainly play a role in autism, and an additional 300 or more may also be involved. Ultimately, as many as 800 to 1,000 genes could be implicated in autism disorders, Bernier said.

By studying the genes, along with associated biological and environmental factors, scientists may be able to learn the causes of the disorder and link them to symptoms of people with autism.

"We'll invite families to come back in to see how that gene impacts that particular kid's expression of autism," said Bernier, who is also clinical director of the Seattle Children's Autism Center.

For parents like Lynn Vigo, whose 19-year-old daughter, Carolina, was diagnosed with severe autism and intellectual disability at age 2, such a study offers new hope for finding not only potential causes of the disorder but also possible treatments.

"Parents are really eager for this," said Vigo, 57, a mental health therapist in the UW autism program. "The more specific we can get about our child's unique autism profile, the better. This disorder we call autism is not the same for every child. It's really pretty different."

In addition, knowing the genetic underpinnings of the disorder could be useful for other family members concerned about future children, she said.

Vigo has received a test kit to collect [saliva samples](#) from the entire family. Within six months, she expects to get results and begin conversations about what they mean.

The UW was one of three centers to pilot the SPARK study; the others are the University of North Carolina, Chapel Hill, and the University of Missouri.

Data from the project are expected to fuel many studies about the nature of autism. The effort is funded by SFARI, which has a \$60 million budget and supports 175 investigators and projects.

Bernier expects at least 1,000 participants diagnosed with autism, along with their family members, in the early months of the project. Participants will receive a \$50 gift card and access to online resources and research news.

Vigo and Bernier expect many families to express interest.

"There are so many of us," Vigo said. "Let's put the volume of the group here together and figure some of this out so we can improve the quality of life for our families."

Those interested in SPARK can visit the website www.sparkforautism.org.

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Citation: Experts launch largest-ever autism research study in US (2016, April 25) retrieved 1 May 2024 from <https://medicalxpress.com/news/2016-04-experts-largest-ever-autism.html>

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