Study Title
Estimating the Prevalence and Genetic Risk Mechanisms of ARFID in a Large Autism Cohort

What was the research about?
Researchers wanted to know how common one type of eating disorder is in people with autism, and whether it can be inherited. The disorder, Avoidant/Restrictive Food Intake Disorder or ARFID, involves very picky eating, fear of new foods, and avoiding foods for sensory reasons. People with ARFID do not have a distorted body image. In this study, researchers also looked for genes that play a role in this eating disorder.

How was the research done?
Researchers analyzed information and surveys about eating behaviors and gastrointestinal (GI) symptoms experienced by 5,157 people with autism, and 4,985 of their parents. All participants were enrolled in SPARK. Researchers also looked at genetic data from participants in the study.

What did the researchers learn?

- An estimated 21 percent of the participants with autism are at high risk for having ARFID, a higher percentage than believed to occur in the general population. Survey responses revealed behaviors similar to those found in people with an ARFID diagnosis.

- Up to 17 percent of the parents of autistic children are at risk for ARFID.

- A much smaller percentage of the participants (about 1 percent) — 53 autistic people and 35 parents — were diagnosed with ARFID previously.

- Researchers found a genetic link near the ZSWIM6 gene. This gene is associated with neurodevelopmental conditions.

- The likelihood of having ARFID runs in families.
What was new and innovative about the study?
This study marks the first time that researchers have used both genetic data and surveys to look at the link between ARFID and autism. This study is believed to be the first associating ARFID with the ZSWIM6 gene.

What do the findings mean?
ARFID appears to be more common in people with autism and their parents than previously known. It may also be underdiagnosed. Diagnosing this condition could lead to therapies that improve eating habits, nutrition, and overall health.

What are participants and scientists saying?

Study participants:

• “We are beginning to experience stomach issues with our autistic child, and would love to see the results and recommendations as a result of this survey.”

• “My child has been in feeding therapy with an SLP [speech language pathologist] for the past year and a half, and it has been life changing! We still have far to go with feeding, so I think this is a super important topic for research!”

Researcher Jacob J. Michaelson, Ph.D., associate psychiatry professor, University of Iowa:
“A lot of people, and probably a lot of clinicians, don’t have ARFID on their radar as something that needs attention. But over the long term, the poor nutrition it causes will have a cumulative effect on a person’s health, and that might not be fully apparent until adulthood.”

What’s next?
Michaelson’s team plans to conduct a larger study, with two to three times more participants, to look at other genetic changes that may be linked to the likelihood of having ARFID in autistic people. “Our estimates suggest this is a strongly genetic trait,” he says.

References

About SPARK Research Match
This SPARK program matches families with research studies that they may want to join. These studies have been evaluated for scientific merit and approved by a scientific committee at SPARK. The program is free to researchers and families. SPARK does not endorse or conduct these studies. Families choose if they want to participate in a particular study.