May 2, 2025

Dear Autism New Jersey Community,

A few weeks ago, I wrote to you in the wake of Secretary Robert F. Kennedy's announcement of a massive research effort into the causes of autism and invited you to our webinar series: "The Complex Causes of Autism" led by Rutgers' researchers. A lot has happened since then, and the Autism New Jersey staff is following every development — with the goal of providing you with practical, balanced information, that captures the nuances of scientific understanding, quickly-evolving public-policy, and expert recommendations.

Here are some common questions individuals and families may have. If you have other questions, please call Autism New Jersey's 800.4. AUTISM Helpline.

Q: National news is moving so quickly! What is this about a registry?

Last week, CBS News reported that National Institutes of Health (NIH) Director Jay Bhattacharya announced a large-scale data collection initiative, that would link together a range of data including pharmacy records, lab testing, insurance claims, and smartwatch or fitness tracker data. Additionally, the NIH would create a new national registry of individuals with autism.

Since then, the federal Department of Health and Human services, which oversees the NIH, has retracted his statements.

> "We are not creating an autism registry. The real-wo*rld data platform will link existing datasets to support research into causes of autism and insights into improved treatment strategies,"* an official for the department told CBS News in an emailed statement.

Q: What is the point of a registry?

There are various registries for various reasons. All of them should be secure and ensure personally identifiable information remains safe. In these large, medically focused registries, scientists can use data to learn what treatments are most effective, or if they have something specific they want to study, they can use the registry to find people who may want to participate in a clinical trial.

The NIH already maintains a list of dozens of registries for various diseases or medical conditions. The registries on that list are all voluntary and operated by national non-profits or government entities that follow strict laws to keep participants' information private.

Q: Okay, so right now, there is no national autism registry in the works. What about the NJ state autism registry?

The NJ Department of Health made the following statement earlier this week (you can read the full version on the DOH website):

- The registry is a vital tool that helps us understand autism in New Jersey and improve planning and services that support children and families.
- Being listed in the NJ Autism Registry can help families connect to free, county-based case management services, available through age 22.
- The registry was established by state law in 2007 and is not federally funded.
- By law, registry data cannot be made public in any way that could identify a person.
- The registry has never shared individual-level or identifiable data with federal agencies or studies, including the CDC's autism research. [The NJ Autism Registry] shares only summary data, that does not identify any individual, to protect privacy.
- Parents or guardians may choose to have their child listed anonymously in the registry at any time—even if the child was originally reported by name. The process is secure, requires proof of identity, and protects families from unauthorized changes.

Q: How do I contact the NJ Department of Health if I have questions?

Visit their webpage or call 609.292.5676 and select option 4, or email: eim.bdars@doh.nj.gov.

Q: Are there other registries I may be listed on?

There are totally separate registries for individuals with autism who may need help during a natural disaster, or who want to alert their local police department that they may need additional accommodations during common interactions like at traffic stops. These are completely voluntary and individuals or their caregivers need to opt-in.

Q: If I want to, how can I protect my personal data?

One simple thing you can do if you are concerned, is check your privacy settings on your smart watches, phones and browsers. A lot of individuals use apps to track their health and if you don't want that data shared, be sure to turn those settings to off.

Consider installing a browser extension that protects your personal information on the web and following these tips from the Federal Trade Commission.

Q: Which laws protect medical data?

Researchers using medical databases and registries are required to abide by Federal Information Security Management Act (FISMA), and the Health Insurance Portability and Accountability Act (HIPAA). If those laws are followed, it is unlikely that identifiable information will be shared. Autism New Jersey calls on the NIH to follow the data-protection laws already in place.

Q: What can I do to help the autism community?

Research is incredibly important, and we must continue to support effective treatment for individuals with autism. We are calling on federal lawmakers to fully fund Medicaid and special education services. If you want to share your story about how these programs have positively impacted your life, contact your US Congressperson (calling is more impactful than emailing). Find out who represents you here.

READ MORE Q&A'S ON OUR WEBSITE

Autism New Jersey is working hard to expand our capacity and respond in real-time to the challenges our community faces statewide. If you find these community letters informative or helpful, consider forwarding them to a friend.

We may be facing new challenges, but we face them together, as one team committed to compassion and evidence-based research, with the vision of making every community an autism-friendly community.

We are with you every step of the way.

Until next time,

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