# What is the Duke Registry for Autism Research?

The Duke Registry for Autism Research is a way for the Duke Center for Autism and Brain Development to partner with community members who have a diagnosis of Autism Spectrum Disorder (ASD) and their families.

People of all ages and abilities who have a diagnosis of ASD, their family members and friends, as well as those without autism, are invited to join the registry and to learn more about opportunities to participate in Dukesponsored research.

### Who can participate in the registry?

- · People of all ages with an ASD diagnosis
- Family members
- Friends
- Individuals without autism



# Duke Registry for AUTISM RESEARCH

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Duke Center for Autism and Brain Development

# Duke Registry for AUTISM RESEARCH



## The Duke Registry for Autism Research:

- Involves Families
- Improves Understanding
- Enhances Treatment
- Extends Resources

## What does being in the registry mean?

Being in the Duke Registry for Autism Research means that you agree to be contacted periodically about autism related studies for which you or your child may be eligible.

# Who has access to information about me or my family?

Your personal information will be safely stored in secure files in accordance with federal, state, and university guidelines. Any information you share will only be available to registry personnel. You will be given the option to release information to studies you are interested in or you may ask for contact information so you can contact the studies directly.

# What is the difference between joining the registry and being in a study?

Joining the registry does not mean that you are signing up for a study. We will let you know about upcoming studies that you may be eligible for, and you will decide if you want to participate. If you do decide to participate and change your mind later, you may withdraw from a study at any time. You may also withdraw from the registry at any time.

#### What kind of studies will be conducted?

Duke is committed to a comprehensive and cutting-edge approach to research. Studies may include behavioral or medical interventions, brain imaging, cognitive testing, or computer-based questionnaires. Studies will be ongoing and might require a visit to Duke, time in your home, or just responding to questions online. Each study will be different and you can choose what works for you and your schedule.

## What will I get from the registry?

- E-mails, letters, or calls about upcoming studies that might be a fit for you or your child.
- A postcard every six months to update contact information or preferences.
- Occasional newsletters describing ongoing activities of our research group.
- If you participate in a study you may be compensated for your time and effort and/ or receive a summary of results.

## How do I become part of the Duke Registry for Autism Research?

Please call or send an email. We will answer any questions you may have and send you enrollment and consent forms. The forms will explain your rights and protections as a voluntary member of the registry. We will ask you to share your preferred contact information. In addition, if you or your child have an ASD diagnosis, we will ask for a few related details.



Questions?

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