
What is in this Brochure?

This brochure tells you about the National Database for Autism Research.

The database is also called "NDAR." The National Institutes of Health created NDAR.

This brochure tells you what NDAR is and what it means for you and your child.

What if I have questions?

It's okay to ask questions about NDAR. The researcher or your doctor can help answer questions. More information about NDAR can be found at <http://ndar.nih.gov>.



The National Database for
Autism Research & Your Child

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The National Database for Autism Research & Your Child

What is the National Database for Autism Research or NDAR?

NDAR stands for the National Database for Autism Research.

NDAR is a computer system that helps researchers study autism by collecting information about it.

NDAR is Important

NDAR is about sharing information on autism.

After a researcher ends a study on autism, he or she sends the information to NDAR. Another researcher can then ask to take a second look at the information.

With an easier way to share, researchers can learn new and important things about autism. Sharing could help people with autism in the future.

What goes into NDAR?

NDAR stores information about people with autism. During the study, researchers collect different types of information about your child's health and how he or she behaves.

They may want to know your child's age, take pictures of his or her brain, and watch how your child does different activities.

Researchers may also study if autism runs in your family by looking at your genes and your child's genes. Genes help decide what people look like and how they act. Researchers might try to figure out if certain genes lead to autism.

Does NDAR Know My Child's Name?

No. Before sending the information to NDAR, researchers take out information that would let others know who your child is. Researchers keep details like your child's name and address secret so others don't know who he or she is.

Who can see the information in NDAR?

Researchers who want to study autism can ask to see information in NDAR. Experts who know how to protect science information will look at every request carefully to make sure your child's information is protected.

What if I change my mind?

You may decide that you no longer want to share your child's information in NDAR. That's okay. Contact the researchers who did the study, and they will tell NDAR.

NDAR can stop sharing your child's information. But it can't take back information that was shared before you changed your mind.