

A Parent-Friendly Guide to Research at the Center for Autism and Related Disorders

Parents who bring their children to the Center for Autism and Related Disorders (CARD) are often asked about participating in research during their visit. This might be for a project within our clinic or for one coordinated by our research program, Research and Education for All Children (REACH).

The decision of whether to participate in research can be overwhelming, especially if you're uncertain about what questions to ask or what the terms and phrases related to research mean.

If you've ever thought about joining a research project before, this guide will answer many of your questions and help you feel comfortable if you choose to participate in a research study.

Why is Research Important?

Research allows scientists to explore ideas about why things happen, how they are related to one another and whether a particular treatment works. Research findings provide evidence that can influence the programs and services offered in schools, clinics and communities.

The Basics of Research

Why participate in research?

- It gives you an opportunity to share your experiences and make your voice heard.
- You can help researchers find answers to important questions that may benefit the autism spectrum disorder (ASD) community in the long term.
- You may receive valuable services or evaluations for free through a research study.
- You may learn more about your child's development, strengths and weaknesses, and the best treatments.

Joining a Research Study

How much time does it take? Every research study is different, and each requires a different amount of time and energy. Some studies require only that you sign a consent form, while other studies will involve hours of testing. Some may follow your family



for years, while others may take little time at all. It is important to know that research projects come in all shapes and sizes, and don't always involve a big commitment on the part of a parent. Even if you only have a few minutes to spare, chances are there are still ways to participate.

What steps are involved in joining?

Not all research studies are the same, but there are a few general steps to joining almost all research studies:

- A research study is presented, and you are asked if you would like to join.
- You will review a consent form with a research team member who can explain the study and answer your questions.
- You choose whether to sign the consent form. If you decide to join the study, the next steps depend on what is involved in the study, and might involve filling out questionnaires or scheduling an appointment for a study visit.
- Remember, you may leave the study at any time for any reason.

We are all born with great potential.
Shouldn't we all have the chance to achieve it?



Center for Autism and Related Disorders
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Frequently Used Terms and Definitions

Consent: In order for researchers to use information from you or your child, you must first give consent or permission. This usually involves reviewing a consent form with a study team member and providing a signature or verbal agreement to join the study.

Eligibility criteria: Requirements that must be met for you to join the study.

Exclusion criteria: Things that will prevent you from participating in the study.

Institutional review board (IRB): This group reviews research studies and is responsible for protecting the rights and welfare of study participants. All studies must get approval by an IRB before anyone can even be asked to participate.

Principal investigator (PI): The PI is the person who oversees the study and is responsible for all aspects of the study.

Research and Education for All Children (REACH): REACH is the research program at CARD. The REACH team is dedicated to studying ASD and identifying causes and treatments through research.

Screening: Some studies require that participants be screened before they may sign up, to be sure they meet certain requirements. This screening may include evaluations and questionnaires.

Research Checklist

Before you agree to join a study, be sure to ask yourself these basic questions to decide whether to participate. Don't forget to add your own questions at the end of the list.

- What is the goal of this study?
- How much time will it take for me to participate in this study?
- What steps will be taken to protect my privacy and my child's privacy?
- Are there any possible risks that come with participating in this study?
- Are there any possible benefits that come with participating in this study?
- How will this research help me to understand my child's condition?
- Whom do I contact if I have questions?

How to Get Involved

CARD Research Contacts

To learn more about the research projects at REACH, please send an email to REACH@KennedyKrieger.org or call **877-850-3372** (toll-free) or **443-923-7892** (local).

Other Research Resources

- **The National Institute of Child Health and Human Development:** a website on ASD research can be found at nichd.nih.gov/health/topics/autism
- **Autism Speaks:** a list of research findings and studies is available at autismspeaks.org

Contact Information

Center for Autism and Related Disorders at Kennedy Krieger Institute

For more information or to schedule an appointment, please call **443-923-7630**, or call toll-free at **888-554-2080**. TTY users, please contact us at **443-923-2645**, or dial **711** to make a Maryland Relay call.

KennedyKrieger.org/CARD

Physicians and Healthcare Professionals

To make a referral, call our Physician Referral Line at **443-923-9403**.

Main Locations

3901 Greenspring Avenue
Baltimore, MD 21211

1741 Ashland Avenue, 5th Floor
Baltimore, MD 21205

For information about other locations, please call the numbers above.

Mailing Address

707 North Broadway
Baltimore, MD 21205

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