

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 approached about participating in research during their visit. This might be a project from within our clinic or one coordinated by our research program, Research and Education for Autism in Children (REACH).

The decision of whether or not 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 disorders (ASD) community for 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 whether or not you want 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 or not 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 can 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
at Kennedy Krieger Institute

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 in order to join the study.

Exclusion Criteria: Items or traits 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 you 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 Autism in Children (REACH): REACH is the research program at CARD. The REACH team is dedicated to studying autism and identifying causes and treatments through research.

Screening: Some studies require that participants be screened before they can 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 or not 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?
- Who do I contact if I have questions?

How to Get Involved

CARD Research Contacts

To learn more about the research projects at REACH, please call **1-877-850-3372** (toll-free) or **443-923-7892** (local), or email reach@kennedykrieger.org.

Other Research Resources

- **Interactive Autism Network (IAN)** – an online project designed to accelerate the pace of autism research by linking researchers and families. Visit IANresearch.org.
- **The National Institute of Child Health and Human Development** – a website on autism research can be found at nichd.nih.gov/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

To make a referral or schedule an appointment, please call **888-554-2080**. For more information about our program, call **443-923-7680**. TTY: **443-923-2645** or Maryland Relay **711**

CARD.KennedyKrieger.org

Physicians & Healthcare Professionals

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

Clinic Locations:

3901 Greenspring Avenue
Baltimore, MD 21211

1130 Annapolis Road, Suite 200
Odenton, MD 21113

Mailing Address:
707 North Broadway
Baltimore, MD 21205

Kennedy Krieger Institute recognizes and respects the rights of patients and their families and treats them with courtesy and dignity. Care is provided in a manner that preserves cultural, psychosocial, spiritual and personal values, beliefs, and preferences. We encourage patients and families to become active partners in their care by asking questions, requesting resources, and advocating for the services and support they need.



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