

Why Participate in ADHD Research?



BY MEGHAN MILLER, PHD

ADULTS AND FAMILIES AFFECTED BY ADHD often ask this question. They may wonder if it's really worth the effort or if their input will actually make a difference. It certainly does! Participation in research is important and crucial for three primary reasons:

- Participating in research offers a powerful way to make a difference in the lives of individuals affected by ADHD. It is the only way we can find new treatments and improve existing ones so they work more effectively.
- Participating in research helps us understand how ADHD develops so that we can work toward new approaches to prevent the impairments often associated with ADHD.
- Participating in research provides you an opportunity to tell researchers what issues are important to the people most impacted by ADHD—children, adults, and family members directly affected by the condition.

An even more common question is, “What does research participation involve?” The short answer is that it varies depending on the type of research being conducted. For example, a study testing the effectiveness of a new medication will have different requirements than a study focused on understanding academic skill in children with ADHD. It is important to ask questions about the goals of the research and methods involved to determine if the research study is a good fit for you or your family member. For example, you might ask:

- “Will my child be given an IQ test?”
- “Will I be placed inside an MRI scanner?”
- “Will my family member be asked to take medicine?”

Many research studies will conduct a thorough diagnostic evaluation for ADHD, often including IQ testing and sometimes including neuropsychological and academic testing. Oftentimes these studies will provide you with verbal or written feedback based on these tests—if you ask for it. Most studies also provide you with monetary compensation for your time or a small gift for your child's efforts.

Hopefully the question you're asking now is, “How do I get involved in research?” Here are a few resources to help get you started:

- Head to CHADD.org where a list of research studies from all over the country has been compiled

(www.chadd.org/Support/Research-Studies.aspx).

- If you're located near a college or university, contact their psychology or psychiatry departments and ask if they have any ongoing research studies focused on ADHD. Sometimes this information will be featured on departmental websites. For example, at my institution, the UC Davis MIND Institute, we list studies in need of participants on our website (<http://www.ucdmc.ucdavis.edu/mindinstitute/research/index.html>). Examples of our current research studies focused on ADHD include a project focused on infants with a family history of ADHD in order to better identify ADHD early in life, a study of medication to treat ADHD in teens, and a longitudinal brain imaging study of self-control in adolescents and young adults with ADHD.
- Ask your doctor. Sometimes physicians who treat patients with ADHD know about local research studies and can point you in the right direction.

Here at the MIND Institute, we are excited to be embarking on a new project that will link people with ADHD with clinicians, researchers, advocates, support groups, and each other through an innovative, privacy-assured online platform called Platform for Engaging Everyone Responsibly, or PEER, a project of Genetic Alliance. Led by Julie Schweitzer, PhD, this will involve partnering with local and national ADHD support groups, including CHADD and the Parent Education Network. The hope is that families affected by ADHD will be able to learn from one another by using a computer from their own homes. And, by sharing their health information, they will help researchers who are determined to develop better treatments for people with ADHD.

Ultimately, participating in research involves collaboration among individuals and families affected by ADHD, and researchers who hope to better understand ADHD. 🧠

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