

Why Take Part in Research

TIPS AND RESOURCES FOR FAMILIES



What is research and why is it important?

Research is investigating a subject to discover new information, or to revise existing information. It allows us to better understand ourselves and the world around us. In the field of intellectual and developmental disabilities research, such inquiry can aid in understanding the role of genetics in development, in testing drug effectiveness, and in developing new treatments that improve quality of life. Research can take place anywhere from a laboratory to a community, investigating something as small as genes or as large as public policies.

Who participates in research?

In research involving children and adults, studies have eligibility requirements for participants. Requirements will differ from study to study, and may include something as broad as being over age 18, or as specific as having a particular genetic diagnosis.

Why do people participate in research?

Reasons differ. Some may want an opportunity to contribute something meaningful to society, to “give back,” or to improve the lives of others. Some people participate in order to learn more about their particular condition or to receive treatment. Others may be motivated by compensation a study offers, such as money or gift cards.

Are there risks to participating in research?

Different studies may have varying degrees of risk. Any risks involved in the study will have been identified prior to

the start of the study, and will be disclosed to participants during the consent process (more on consent below). All research studies that involve humans are required to undergo rigorous review by Institutional Review Boards (IRB) prior to taking place. IRBs are made up of groups of people (scientists and non-scientists) whose job is to protect the rights and welfare of research participants and to assess risk. Vulnerable populations, such as children or people with intellectual and developmental disabilities, are especially protected. Prior and during research, IRBs ensure that the study is adhering to ethical norms and that the participants’ rights are protected.

What is informed consent?

Informed consent is the process during which potential participants learn about the details of a study and decide whether to volunteer. Generally, the informed consent process will include learning about the purpose of the research, an outline of what will take place during the research, if there is any compensation, what risks are involved, what benefits may occur, how information will be kept confidential, and who to contact with questions. If the participant decides to volunteer, a consent form is signed. It is important that a participant understands what is being described. If the information is not clear, it should be restated until it is understandable.

If the participant is a child, parental permission may replace informed consent. However, the child’s assent also must be collected. Depending on the age, the child may be asked to sign or to verbally agree to participate. Some adults with intellectual and developmental disabilities may also require parental/caregiver permission and need to be asked for their assent. Adults with intellectual disabilities should be presented with the information in a manner they understand.

What rights do people have?

First and foremost, people who take part in research are volunteers. At any point during the research project a person can decide to quit the study. It does not matter if it is the first day or the last hour, a participant can withdraw from a study at any time.

Vanderbilt University has developed the *Research Participant Bill of Rights*. It is printed on the reverse side



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RESOURCES

Research Participant Bill of Rights

Anyone who is asked to participate in a research study at Vanderbilt University or who is asked to consent on the behalf of another has the following rights:

- To be fully informed of the nature and purpose of the research study including all procedures to be performed/followed.
- To be treated with respect in every aspect of the research process.
- To have adequate time to consider whether to participate.
- To be given a description of any risks, discomforts and/or inconveniences reasonably expected from participation.
- To be given a description of any benefits you may reasonably expect from participation or be informed of no possible benefit.
- To be provided an explanation of any alternative procedures that might be available to you, as well as the relative risks and benefits.
- To ask any questions about the research study or other procedures involved.
- To be told about how you may be withdrawn and that you may ask to withdraw, at any time, without changing your rights to healthcare or other services.
- To decide whether to participate in the research study without force, fraud, deceit, duress, coercion, or undue influence.
- To be given a signed and dated copy of the consent form, when one is required for the research.
- To be provided an explanation of any alternative drugs, biologics, or devices that might be available to you, as well as their relative risks and benefits, for biomedical research.
- To be informed of where to get medical treatment if problems arise.

Who We Are and Who We Serve

The **Vanderbilt Kennedy Center** (VKC) works with and for people with disabilities and their family members, service providers and advocates, researchers and policy makers. It is among only a few centers nationwide to be a University Center for Excellence in Developmental Disabilities, a *Eunice Kennedy Shriver* Intellectual and Developmental Disabilities

Research Center, and a Leadership Education in Neurodevelopmental and Related Disabilities Training Program.

Two Easy Ways to Take Part in Research

The Vanderbilt Kennedy Center serves families through research studies. **StudyFinder** is a searchable database that lists current VKC studies, including ASD research. Studies seek people of all ages with and without developmental disabilities. See kc.vanderbilt.edu/studyfinder, (615) 936-0448. **Research Match** is a secure place for volunteers and researchers to connect. Once you sign up and get added to the registry, a researcher will contact you if you're a possible match for the research study. See www.researchmatch.org.

Tennessee Disability Pathfinder

Tennessee Disability Pathfinder is a free statewide phone, web, and print referral service in English and Spanish. It connects the Tennessee disability community with service providers and resources. Its website database has over 3,000 agencies searchable by Tennessee county and service. Pathfinder is a project of the VKC, TN Council on Developmental Disabilities, TN Department of Health, and the TN Department of Intellectual and Developmental Disabilities. Contact www.familypathfinder.org, (615) 322-8529, toll-free (800) 640-4636.

Vanderbilt Autism Resource Line

The Vanderbilt Autism Resource Line is a free intake and referral service for a broad range of Vanderbilt clinical and research programs and resources. For information and referral to Vanderbilt clinical and research services contact (615) 322-7565, or toll-free 1-877-ASD-VUMC (273-8862), or by email autismresources@vanderbilt.edu.

Vanderbilt Human Research Protection Program

www4.vanderbilt.edu/irb/

Other Resources

U.S. Department of Health & Human Services Office for Human Research Protections www.hhs.gov/ohrp/

Contact the Vanderbilt Kennedy Center Nashville

(615) 322-8240

Toll-Free (866) 936-VUKC [8852]

www.kc.vanderbilt.edu

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