

## Consent Form

**Title of Research Study: 1306M35301 Focus in NeuroDevelopment (FIND) Network.**

### Researcher Team Contact Information: Dr. Suma Jacob

For questions about research appointments, the research study, research results, or other concerns, call the study team at:

Researcher Name: Dr. Suma Jacob Researcher Affiliation: Associate Professor of Psychiatry University of Minnesota Phone Number: 612-625-8448 Email Address: <a href="mailto:jacoblab@umn.edu">jacoblab@umn.edu</a>	Study Staff (if applicable): Marwa Ibrahim Phone Number: 612-625-8448 Email Address: <a href="mailto:ibrah129@umn.edu">ibrah129@umn.edu</a>
Researcher Name: Dr. Amy Esler Researcher Affiliation: Licensed Psychologist and Assistant Professor of Pediatrics at the University of Minnesota Phone Number: 612-626-6340 Email Address: <a href="mailto:esle0007@umn.edu">esle0007@umn.edu</a>	

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### What is research?

Doctors and researchers are committed to your care and safety. There are important differences between research and treatment plans:

- The goal of research is to learn new things in order to help groups of people in the future. Researchers learn things by following the same plan with a number of participants, so they do not usually make changes to the plan for individual research participants. You, as an individual, may or may not be helped by volunteering for a research study.
- The goal of treatment is to help you get better or to improve your quality of life. Doctors can make changes to your treatment plan as needed.

### Why am I being asked to take part in this research study?

We are asking you to take part in this research study because you or your child have a neurodevelopmental condition such as autism spectrum disorder (ASD), attention deficit hyperactive disorder (ADHD), obsessive compulsive disorder (OCD), tic disorder, or do not have a neurodevelopmental condition but wish to be a control participant in future studies.

### What should I know about a research study?

- Whether or not you take part is up to you.

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- You can choose not to take part.
- You can agree to take part and later change your mind.
- Your decision will not be held against you.
- You can ask all the questions you want before you decide.

### Why is this research being done?

The purpose of the FIND Network is to establish a Network consisting of people with neurodevelopmental conditions, as well as control participants (those whom do not have neurodevelopmental conditions), who wish to participate in future studies. FIND investigators may share your contact information with approved researchers so they can contact you and tell you about their study, but it is up to you to respond if you are interested. By joining the network, you are under no obligation to participate in future research, but simply indicating that you would like to hear about potential opportunities when they arise. You also have the option to receive periodic newsletters via email giving updates on research, resources and events.

### How long will the research last?

You will be enrolled in the FIND Network indefinitely. If you wish to remove yourself from The FIND Network for future involvement, you may contact Dr. Jacob or a member of her study staff and request that you be removed from further follow-up. If you wish to have your previous data removed, as well as remove yourself from future follow-up, you may also request that from Dr. Jacob or a member of her study staff.

### How many people will be studied?

We expect about 3000 people to participate in the FIND Network.

### What happens if I say “Yes, I want to be in this research”?

1. If you agree to participate, you will be asked to fill out a short intake survey (the FIND Network Form) that will ask you questions intended to determine the types of research in which you might like to participate and for which you might be eligible. This should take about 10 minutes to complete.

2. If a researcher at the University of Minnesota or another site has a research study that might be a good fit for you, your name and contact information will be given to that researcher, and they will contact you to see if you are interested in participating in their study. You are under no obligation to participate in any research project, even if you enroll in the FIND Network. You may be contacted for studies as long as your data remains in the FIND Network. You can say "no" to any study you are called about if you are not interested. Only researchers whose projects have been approved by the FIND Network review committee and an Institutional Review Board (IRB) will be allowed to contact you.

### What happens if I say “Yes”, but I change my mind later?

You can leave the FIND Network at any time. Leaving will not be held against you.

If you decide to leave the FIND Network, contact the investigator so that the investigator can remove you from the pool of candidates of participants in future research, and remove your previous data.

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Choosing not to be in the FIND Network or to stop being in the FIND Network will not result in any penalty to you or loss of benefit to which you are entitled. Meaning, your choice not to be in the FIND Network will not negatively affect your right to any present or future medical treatment.

### **What are the risks of being in this study? Is there any way being in this study could be bad for me?**

The FIND Network will involve no physical risks. There is a small risk of loss of confidentiality. This is described below in the section 'What happens to the information collected for the research?'

### **Will it cost me anything to participate in this research study?**

Taking part in this research study will not lead to any costs to you.

### **Will being in this study help me in any way?**

The FIND Network offers the benefit of learning about potential research opportunities as well as being connected to updates in research, resources and events through the FIND Network Newsletter. It is expected that the FIND Network will provide general benefit to people with neurodevelopmental conditions by facilitating research, which may in the future improve care.

### **What happens to the information collected for the research?**

Efforts will be made to limit the use and disclosure of your personal information, including research study and medical records, to people who have a need to review this information. We cannot promise complete privacy. Organizations that may inspect and copy your information include the IRB and other representatives of this institution, including those that have responsibilities for monitoring or ensuring compliance.

Records of participation in the FIND Network will be maintained and kept confidential as required by law. Risk of loss of confidentiality will be minimized by storing all data securely as either password-protected, computerized records, or as hard copy records in the offices of the Center for Neurobehavioral Development, safeguarded under lock and key.

Your identity will not be revealed on any report, publication, or at scientific meetings. The University of Minnesota Institutional Review Board (IRB) will have access to your files as they pertain to this research study. The IRB is a special committee that reviews human research to check that the rules and regulations are followed.

To these extents, confidentiality is not absolute.

### **Who do I contact if I have question, concerns or feedback about my experience?**

This research has been reviewed and approved by an Institutional Review Board (IRB) within the Human Research Protections Program (HRPP). To share feedback privately with the HRPP about your research experience, call the Research Participants' Advocate Line at [612-625-1650](tel:612-625-1650) or go to <https://research.umn.edu/units/hrpp/research-participants/questions-concerns>. You are encouraged to

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contact the HRPP if:

- Your questions, concerns, or complaints are not being answered by the research team.
- You cannot reach the research team.
- You want to talk to someone besides the research team.
- You have questions about your rights as a research participant.
- You want to get information or provide input about this research.

### **Will I have a chance to provide feedback after the study is over?**

The Human Research Protection Program may ask you to complete a survey that asks about your experience as a research participant. You do not have to complete the survey if you do not want to. If you do choose to complete the survey, your responses will be anonymous.

If you are not asked to complete a survey, but you would like to share feedback, please contact the study team or the Human Research Protection Program (HRPP). See the “Researcher Contact Information” of this form for study team contact information and “Who do I contact?” section of this form for HRPP contact information.

### **Will I be compensated for my participation?**

There is no compensation for participating in the FIND Network.

Your signature documents your permission to take part in this research. You will be provided a copy of this signed document.

\_\_\_\_\_  
Signature of Participant or Parent/Guardian

\_\_\_\_\_  
Date

\_\_\_\_\_  
Printed Name of Participant or parent/Guardian

\_\_\_\_\_  
Print Name of Participant or Child

\_\_\_\_\_  
Email Address (to be sent the online registration survey)

\_\_\_\_\_  
Phone Number