

## **Information sheet for a child who enrolls in this study.**

### **Why would we like you to read this document?**

We want to tell you about being a part of something called a research study. A research study is when researchers collect information to learn more about a condition. If you have any questions while reading this sheet about this study, you can contact us through the Autism DRIVE website. You can ask your question at any time.

Researchers at the University of Virginia are doing this research study to learn more about people with autism. After you read this information sheet, the website will ask you if you'd like to be in this research study or not. If you decide to be in this research study, you will be asked to keep a copy of this sheet.

It's okay to leave the registration page if you don't want to be in the study. It is also okay to be in the study now and leave it at any time. You should speak with your parent/guardian about your decision.

This research study is not about getting treatment. If you are getting care or services at University of Virginia, you will continue to get this care/service(s) whether or not you agree to be part of this research study.

The researcher in charge of this study is *Rose Nevill, PhD, BCBA, Assistant Professor of Education, University of Virginia*.

This study will take place online through the University of Virginia and will be ongoing.

### **Why are we doing this research study?**

By joining this research registry, you will have a chance to join and learn about current and future autism-focused research studies being done at the University of Virginia. By completing the registration process, we will also be able to connect you and your family to autism research studies. You and your family will fill out a set of online questionnaires one time. Your answers to these questions will help us match you with potential research studies.

### **What will happen to you if you are in the research study?**

- 1) *If you agree to be in the research study, this is what your parents/guardians will be asked to do:* Create a login account on the Autism DRIVE website
- 2) Answer questions with a parent/guardian about where you live, what grade you are in, your medical history, etc.

Creating an account and answering these questions will take about 10 to 15 minutes.

### **What things may bother or hurt you about being in this study?**

There are no drawbacks to joining this registry. If you do not want your information to be part of the registry anymore, you can cancel your account at any time. To cancel your account, you or your caregiver can tell us by emailing [m4ee@hscmail.mcc.virginia.edu](mailto:m4ee@hscmail.mcc.virginia.edu) (PI's email). We do not anticipate that anything negative will happen to you or your family by joining the autism research registry. We do not think there will be any risks to joining this registry.

**Will this study help me?**

People also may have good things happen to them because they are in research studies. These are called benefits. You might or might not receive benefits from being in the Autism Registry. Possible benefits include being matched with research studies that you may want to participate in (with your parent/guardian's permission). In addition, information researchers get from this study may help other people in the future.

**Will you be paid for being in this study?**

No, you will not be paid for being part of the registry.

**Do you have to be in this research study?**

No and no one will be upset with you if you do not want to be in this research study. If you don't want to be in this research study, just tell us. If you want to be in the research study, tell us that. And, remember, you can say yes now and change your mind later. It is up to you.

Please talk this over with your parents/guardians before you and your family decide whether or not to be in the research study. Your parents/guardians have said that it is okay with them for you to be in the research study. Even though your parents/guardians have said it is okay with them, you can still say 'No'.

You do not have to join the registry to get the services/care that you normally get at the University of Virginia. If you decide to stop being in the study we will ask you to cancel your account under the "Your Profile" page of the Autism DRIVE website. Even if you do not change your mind, the study leader can take your information out of the study.

**What if you have questions?**

You and your family may ask questions at any time through the Autism DRIVE website.

**Who will see your private information?**

Researchers running the Autism Registry will see your information to match you with potential research studies. The information collected from you might be published in a research journal. This would be done in a way that protects your privacy. No one will be able to find out from the article that you were in the study. Information obtained from you during this study may be used in future research. Your information may be shared with other researchers inside of the University of Virginia. They will not be sent with information that could identify you such as name, address or phone number.

If you join the registry, it means that you have read this and you have talked with someone about it. It also means you have had all your questions for today answered and you want to be in the research study. If you don't want to be in the study, don't join the registry.