

Study to Explore Early Development, Teen Follow-up Study SEED Teen

SEED Teen *Consent for Future Contact*

Thank you for taking part in SEED Teen. Because of participants like you, we hope to learn more about the health and development of teenagers with and without autism spectrum disorder (ASD) and other developmental disabilities (DDs).

There is much we still don't know about ASD and other DDs. We will continue to consider how research from SEED might help answer important public health questions.

In the future, SEED researchers might want to contact you and your child to talk about new study opportunities. You would not be under any obligation to say YES to these opportunities. We are only asking for permission to contact you.

If your child is no longer living at home, we may ask you to help us contact your child to find out if they are interested in taking part in a new study.

The decision about whether we can contact you is completely up to you. If you decide you do not want to be contacted in the future, you can still take part in SEED Teen. There will be no penalties if you decide not to consent. If you give permission now for us to contact you and want to end this authorization later, contact **<site PI>**, at **(xxx) xxx-xxx**.

All responses that you give on this consent will be kept private. Any information that identifies you or your child will be used only for this project. Your information will remain confidential unless otherwise required by law. Project staff who access your information will have a legal and professional obligation to protect your privacy and maintain your confidentiality.

This Statement is provided pursuant to the Privacy Act of 1974 (5 U.S.C. § 552a):

The information you are being asked to provide is authorized to be collected under the System of Records Notices 09-20-0136, Epidemiologic Studies and Surveillance of Disease Problems. Providing this information is voluntary. The purpose for this consent is to determine whether you are willing to be contacted for future research opportunities for you and/or your child. The information that you provide through this consent will only be used to contact you if future research opportunities become available and you have consented to future contact. The responses that you provide on this consent will be included in a Privacy Act system of records, and will be used and may be disclosed for the purposes and routine uses described and published in the following System of Records Notice (SORN): 09-20-0136: Epidemiologic Studies and Surveillance of Disease Problems, [Federal Register: December 31, 1992 (Volume 57, Number 252)] [Notices] [Page 62812-62813].

Please complete [Part A](#) on page 2. If applicable please complete [Part B](#) and ask your child to complete [Part C](#) on page 3. We would appreciate if you and your child would sign this form ([Part D](#)) on page 3 and return it to us for our records, whether you AGREE or DO NOT AGREE to be contacted in the future.

[Type here]

To be completed by PARENT OR OTHER LEGAL GUARDIAN

Part A

Please indicate whether we may contact you to discuss future research opportunities for you and/or your child.

Please *initial one*:

_____ (initials) I **AGREE** to be contacted to about future research.

_____ (initials) I **DO NOT AGREE** to be contacted about future research.

If you answered AGREE, please fill out Part B. If you DO NOT AGREE, go to Part D to sign this form.

Part B

Parent or Other Legal Guardian's Indication of Whether Child Assent Applies

Because your child is younger than 18, he/she cannot **consent** to be contacted for future research studies. However, if your child is able to understand this consent form he/she can tell us if he/she **assents** (agrees with your decision).

If your child is able to understand our request but does NOT give assent, we will NOT contact you or your child about future studies.

Does your child have a disability or other condition that prevents him/her from understanding our request? (*please initial one*)

___ Yes

___ No

If you answered **YES**, your consent as the legal guardian is all we need. Your child does not need to fill out Part C. Please go to Part D to sign this form.

If you answered **NO**, please ask your child to complete the CHILD section (part C) below.

[Type here]

Part C

To be completed by CHILD if parent answered NO in Part B.

Legally you cannot consent to be contacted for future research studies because you are younger than 18. However, we want to know if you agree with your parent or guardian's decision to be contacted to talk about opportunities for future studies.

Your parent or legal guardian gave us permission to be contacted to discuss future studies and help us get in touch with you. But we will not contact them if **you do not also agree (assent)**.

If you AGREE to this request, you are not under any obligation to be in a future study. We are only asking for permission to contact your parent or guardian to talk about future studies.

Please initial one:

_____ (initials) I **AGREE** to be contacted about future research

_____ (initials) I **DO NOT AGREE** to be contacted about future research.

Part D

Signatures of PARENT OR OTHER LEGAL GUARDIAN and CHILD

I have read this consent form and indicated my decisions about being contacted in the future by initialing the options above.

Printed Full Name of CHILD

Signature of CHILD

Date

Printed name of PARENT OR LEGAL GUARDIAN

[Type here]

Signature of PARENT OR LEGAL GUARDIAN

Date