

**ASSENT
FOR CHILDREN 7-17 YEARS OF AGE AND ADULTS UNABLE TO CONSENT**

Sponsor / Study Title: RARE-X / "RARE-X Data Collection Program"

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Instructions for Parents/Legal Guardians of Child Participants or Legally Authorized Representatives of Adult Participants Unable to Consent

If the participant is 7–17 years old or is an adult who is not able to provide consent and cannot read, we ask that you read to them the following information before you enroll them in the RARE-X Data Collection Program (this research study).

If your child or the adult for whom you are a legally authorized representative *does not agree* to participate in this program, you may *not* enroll them in this program.

Script to Read to Your Child or the Adult Unable to Consent

Some scientists are doing a research study. A research study is a way to learn more about something. The researchers would like to learn more about illnesses that only a small number of people have. To learn more about these rare illnesses, the researchers will collect health information from a lot of different people. The researchers will study this information. They hope to learn things that can be used to help people who are sick.

If you agree to join this study, the researchers will ask me some questions about you and your health. Researchers will use my answers for their studies. The researchers will not know your name.

Joining this study may not help your health. But researchers might learn something that will help other people with rare illnesses someday.

You do not have to join this study. It is up to you. No one will be mad at you if you don't want to be in the study.

You can say okay now and change your mind later. All you have to do is tell me that you want to stop. No one will be mad at you if you change your mind and stop.

*Do you have any questions? *wait for the person to respond**

If you have any questions about this study, I will email or call the study staff to get answers to your questions.

- Parent/legal guardian of child or legally authorized representative of adult: you can email or call the study staff at the phone number listed on the first page of this form.

If you type your name in the box on the webpage, it means you agree to take part in this research study.

CHILD/ADOLESCENT/ADULT UNABLE TO CONSENT ASSENT

Printed Name of Child/Adolescent/Adult Unable to Consent

Signature of Child/Adolescent/Adult Unable to Consent

Date of Signature

Printed Name of Person Obtaining Consent

Signature of Person Obtaining Consent

Date of Signature

CHILD/ADOLESCENT/ADULT UNABLE TO CONSENT WHO IS ABLE TO READ ASSENT:

Please read the below information before you agree to enroll (take part) in the RARE-X Data Collection Program (this research study).

If you do not want to participate in this program, you do not have to enroll.

Some scientists are doing a research study. A research study is a way to learn more about something. The researchers would like to learn more about illnesses that only a small number of people have. To learn more about these rare illnesses, the researchers will collect health information from a lot of different people. The researchers will study this information. They hope to learn things that can be used to help people who are sick.

If you agree to join this study, the researchers will ask your parent/legal guardian/legally authorized representative some questions about you and your health. Researchers will use your parent/legal guardian/legally authorized representative's answers for their studies. The researchers will not know your name.

Joining this study may not help your health. But researchers might learn something that will help other people with rare illnesses someday.

You do not have to join this study. It is up to you. No one will be mad at you if you don't want to be in the study.

You can say okay now and change your mind later. All you have to do is tell your parent/legal guardian/legally authorized representative that you want to stop. No one will be mad at you if you change your mind and stop.

Do you have any questions?

Check yes or no:

YES NO

If you have any questions about this study, you can call the study staff at the phone number listed on the first page of this form.

If you type your name in the box on the webpage, it means you agree to take part in this research study.

CHILD/ADOLESCENT/ADULT UNABLE TO CONSENT ASSENT

Printed Name of Child/Adolescent/Adult Unable to Consent

Signature of Child/Adolescent/Adult Unable to Consent

Date of Signature

Printed Name of Person Obtaining Consent

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