

RARE-X DATA COLLECTION PROGRAM (DCP)
ASSENT
CHILDREN 7-17 YEARS OF AGE AND ADULTS UNABLE TO CONSENT

Title: RARE-X Data Collection Program

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Instructions for Parents/Guardians and other Legally Authorized Representatives

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

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 initiative.

Script to Read to Your Child

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 your parent 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 patient to respond)

If you have any questions about this study, I will email the research Program team to get answers to your questions.

- *Parent: you can email or call the research team at (716) 427- 2739 or support@rare-x.org.*

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

Child/Adolescent Assent

Full Name