

Assent from Pediatric Subjects (6-16)

Title: Characterization of 3q29 Deletion Syndrome and 3q29 Duplication Syndrome

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We are asking kids who have the 3q29 deletion or 3q29 duplication and who do not have the 3q29 deletion or 3q29 duplication to help us learn more about this medical condition. We want to understand how kids with the 3q29 deletion or 3q29 duplication grow and develop. We would like to invite you to be in this research study.

Your parent or guardian has agreed that you can do this study, but it is up to you to decide for sure. You will not be punished if you decide not to be in the study. Your parent or guardian can stop you from being part of this study at any time. If you want to stop being in the study, tell your parent or guardian. If you take part in this study, you will help us learn more about the 3q29 deletion or 3q29 duplication.

Your parent or guardian will complete several questionnaires about your childhood. If you are over the age of 12, we will ask you to complete one online questionnaire about your feelings. We will ask your parent or guardian to make some short videos of you. You can choose to do the questionnaire and not to do the video. If you have the 3q29 deletion or 3q29 duplication, we will get a copy of your medical record that states those results. We will recontact you once a year to complete a new questionnaire and to get new videos.

Please choose the assent option that applies:

[box here] I am a study participant between the ages of 6-16 years old and I have read the form, or the form has been read to me, and I agree to participate.

[box here] Not applicable. The participant with 3q29 deletion syndrome or 3q29 duplication syndrome is not between the ages of 6-16 years.

[box here] Not applicable. The participant with 3q29 deletion syndrome or 3q29 duplication syndrome is between the ages of 6-16 years but is not able to provide assent.