

University of Minnesota Department of Pediatrics
Alport Syndrome Treatments and Outcomes Registry
Assent Form
(For participants 13 – 18 years of age)

We are asking if you are willing to be in our registry because we are trying to learn more about how to help people with the kind of kidney disease you have. Because you have Alport syndrome, we are asking if you want to work with us and be in a study. Our goals are to find treatments for Alport syndrome that work and to find out when treatment should begin.

If you agree to be in this study, we will ask you to provide information about your medical health and your family's health history. The information you provide will be kept in our central office and only the doctor and a few staff members on the team will be able to look at it. We might want to look at the information we keep in the central office about you at some other time. This will not mean that you will have to provide more information because we will use the information we have on hand.

You will still have the same doctor if you say no to being in this study.

And, if you change your mind during the study, you can stop at any time.

Being in this study is totally up to you, and no one will be mad at you if you don't want to do it.

You can ask any questions that you have about this study. If you have a question later that you didn't think of now, you can ask any time.

Signing here means that you have read this paper or had it read to you and that you are willing to be in this study.

If you don't want to be in this study, don't sign. Remember, being in this study is up to you, and no one will be mad at you if you don't sign this or even if you change your mind later.

Signature of participant_____

Signature of person explaining study_____

Date_____