



Share Your Experience Participating In the GSDIa DTX401 Ph1/2 Clinical Trial

If you are living with GSDIa and participated in the Ultragenyx DTX401 Phase 1/2 clinical trial, we invite you to participate in a confidential interview. During this interview with a third-party agency, you will share feedback on steps you took to receive a gene therapy and the general experience of being a participant in this study. This interview will not focus on details of the study such as safety, efficacy, and impact of the gene therapy on your overall health.

Sharing your story, knowledge, and experiences is one of the most powerful ways to advocate for yourself and the community. During the interview you will have the opportunity to:



Provide your insights as a clinical trial participant and someone living with GSDIa



Inform future Ultragenyx gene therapy research and DTX401 programs



Communicate your needs and the needs of the GSDIa community

WHEN is the interview?

November through December 2023

The day and time will be based on your schedule and availability

WHO is conducting the interview?

Representatives from the Kith Collective – a partner to Ultragenyx – will conduct the interviews and provide an anonymous report summarizing all the feedback to Ultragenyx. Ultragenyx will not participate in the interviews and the identity of participants will not be disclosed to Ultragenyx.

WHERE will it take place?

Online

You will meet with the interviewer using a secure video conferencing platform

HOW do I participate?

If you are interested in participating in an interview or have questions, please email Kim McCleary at kim@kithcollective.com. Please include your name, your time zone, city and state/country in which you live, and the clinical trial site where you participated in the study. All discussions will be conducted in English and materials will also be written in English.

You will be compensated for your time spent participating in one 75-minute virtual interview.

By contacting Kith Collective, you are consenting to Kith Collective using your personal information to contact you about participation in this program. Kith Collective will store and use your personal information in accordance with applicable laws and regulations. We may not be able to accommodate all who express interest. Ultragenyx may have other opportunities to provide feedback in the future.