

Patient Consent Form

By submitting this form, you agree to the following terms and conditions:

- You are above 18 years of age and a United States or Canada resident.
- You will not receive health care advice in response to any comment or question submitted.

By consenting via signing this form and submitting information about yourself through this registration process, you agree to participate in the Rare Disease Genes database as follows:

Differences in genes can help explain some diseases. The Rare Disease Genes database is intended to serve as a resource for researchers who study how gene variants may cause rare diseases, such as those represented in this database. We hope that researchers can learn more about these conditions by studying genes from many people with the same diagnosis.

Participants in the Rare Disease Genes database provide information relevant to the study of how gene variants may cause rare disease (the “Research Data”). For example, the Research

Data includes:

- genetic information, such as specific gene variants and their position on the gene;
- other information that researchers believe may be relevant to gene expression, such as the levels of certain biochemicals in your body; and
- demographic information, such as your gender and age.

The Research Data will not include your name, date of birth, or information that can be used to contact you (“Personally Identifiable Information,” or “PII”). To help protect your confidentiality, we maintain a copy of this informed consent form and any PII in a database that is protected with passwords and is separate from the Rare Disease Genes database. We may use your PII to contact you if there was any issue with our system receiving the data you submit. By providing your information you agree to allow Ultragenyx and its agents to collect the name and email address provided and to be contacted by Ultragenyx and its agents using this information in the future. Furthermore, you are agreeing that Ultragenyx and its agents may contact you by email. Ultragenyx will not sell, rent, or otherwise distribute your name and any PII outside of Ultragenyx and its agents.

The Research Data will also not include any information you provide about your healthcare team. We collect that information for medical research purposes, including to better understand the patient diagnostic journey. We will not make any identifiable information about your healthcare team public, through the Rare Disease Genes database or otherwise. Ultragenyx will not sell, rent, or otherwise distribute identifiable information about your healthcare team outside of Ultragenyx and its agents.

The Research Data will be included in the Rare Disease Genes database, which is widely available to researchers and others who are not affiliated with or controlled by Ultragenyx Pharmaceutical Inc. (“Ultragenyx”). For example, those who have access to the Rare Disease Genes database may be from government and academic or commercial institutions.

The Rare Disease Genes database may be used by Ultragenyx and third parties for research purposes. Results from research studies based on the Rare Disease Genes database may be published in medical journals and presented at scientific meetings. In addition, the information may be used to support applications to the U.S. Food and Drug Administration (“FDA”) and other government agencies in the United States and in other countries. The research and other uses of your Research Data may result in the development of commercial products and services. You will not receive any compensation for these uses.

We don’t think that there will be risks to your privacy and confidentiality as a result of your participation in the Rare Disease Genes database; however, we cannot predict how genetic information will be used in the future, and there is a small chance that your genetic information could be shared with others or used to re-identify you. In the unlikely event that your information was shared and linked to you, this could affect your ability to get or keep some kinds of insurance or the cost of that insurance. There is also the risk that data could be released to the public, employers, or law enforcement agencies. If family members were to see this information, it could also affect them. It is possible that you could be identified from your information if someone else has your medical record.

Participation in the Rare Disease Genes database is voluntary, and your decision will not affect your treatment options. You also may withdraw your consent at any time if you don’t want your data in the Rare Disease Genes database any longer by writing to

info@RareDiseaseGenes.com. However, the withdrawal of consent will not affect data that has already been relied upon by Ultragenyx or others for research purposes or used to create anonymized and aggregated datasets.

If you live outside the United States, the information you submit through this registration process will be transferred to and processed in the United States, where local laws may require the disclosure of personal information to the government authorities under circumstances that are different than those that apply outside of the United States. For more information about our practices and your rights, please visit <https://www.ultragenyx.com/privacy-policy/>.

Patient's Signature: _____ Date: _____

Print Name: _____