

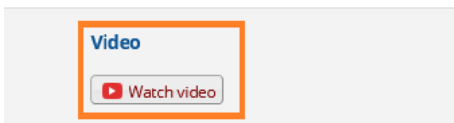
The GeneRosity Registry Step-by-Step Instruction Sheet

The instructions below will walk you through the steps involved in answering the GeneRosity Registry questions and help guide you in uploading the correct genetic files to the proper location. If you have further questions, please feel free to contact us at generosityregistry@imail.org

The GeneRosity Registry Agreement Page

1. When you first arrive on the GeneRosity Registry agreement page you will note an instructional video about the GeneRosity Registry and the GeneRosity agreement that describes the nature of the study and your rights as a study patient. Watch the GeneRosity video and review the GeneRosity Registry Agreement.

GeneRosity Registry Agreement



2. If you agree to participate, select 'Yes' on the agreement question and click each checkbox to indicate that you meet the criteria.

Agreement: I am 18 years old or older, I have already purchased and obtained direct-to-consumer DNA testing, and I am willing to provide these results without any monetary or other forms of compensation. I understand the risks and benefits for participating in this study. I willingly agree to participate in this study.

Agreement: * must provide value	<input checked="" type="radio"/> Yes, I agree to participate in this study <input type="radio"/> No, I do not agree to participate in this reset
* must provide value	<input checked="" type="checkbox"/> Yes, I am 18 years old or older.
* must provide value	<input checked="" type="checkbox"/> Yes, I have already purchased direct-to-consumer DNA testing.
* must provide value	<input checked="" type="checkbox"/> Yes, I am willing to provide these results without any monetary or other forms of compensation.

3. Enter your full legal first, middle, and last name. Click the Submit button to acknowledge your information. You will receive an email shortly after containing a copy of the agreement you just completed.

Enter Your Full Legal First Name <small>* must provide value</small>	<input type="text"/>
Enter Your Full Middle Name	<input type="text"/>
Enter Your Full Last Name <small>* must provide value</small>	<input type="text"/>
Email <small>* must provide value</small>	<input type="text"/>
Please re-enter your email <small>* must provide value</small>	<input type="text"/>
<input type="button" value="Submit"/>	

The GeneRosity Registry Questions

General Questions Section

1. You will be taken to a new screen to answer Generosity Registry Questions. The first section contains general questions regarding contact information, demographics, and how you heard about the Registry. Please complete these questions.

General Questions

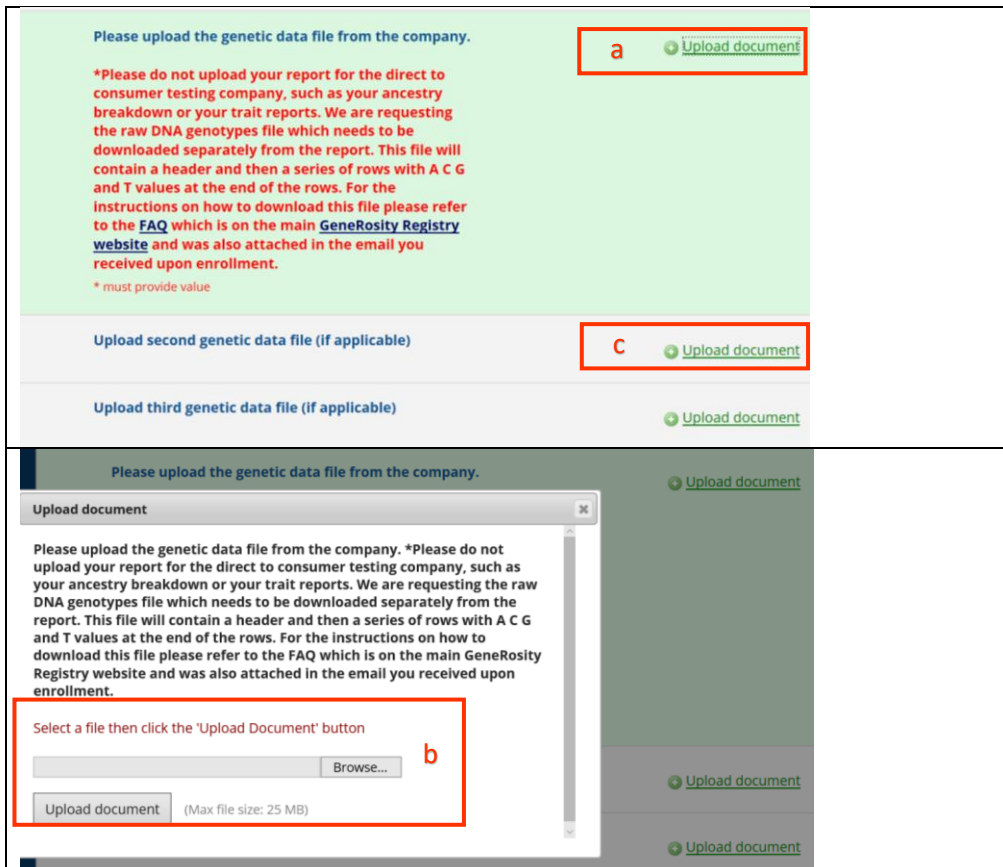
Registration Email:	<input type="text"/>
Address:	<input type="text"/>
City:	<input type="text"/>
State:	<input type="text"/> ▼
Zip:	<input type="text"/>
Phone Number:	<input type="text"/>
Birth Date: <small>* must provide value</small>	<input type="text"/> M-D-Y
Gender: <small>* must provide value</small>	<input type="radio"/> Female <input type="radio"/> Male reset
Are you adopted? <small>* must provide value</small>	<input type="radio"/> Yes <input type="radio"/> No reset
How did you hear about the GeneRosity Registry?	<input type="checkbox"/> Brochure <input type="checkbox"/> Friend <input type="checkbox"/> Family member <input type="checkbox"/> Poster <input type="checkbox"/> Radio <input type="checkbox"/> RootsTech <input type="checkbox"/> TV <input type="checkbox"/> Other

Genetic DTC DNA Questions Section

1. Select the company that did your genetic testing. If you have had genetic testing from more than one company, select all companies that apply.

Company doing the DNA testing? Ancestry / AncestryDNA
 * must provide value 23andMe
 MyHeritage
 Other

2. The next step requires you to upload the raw DNA genotype file that you have downloaded from the company website. Please do not upload your report for the direct consumer testing company, such as your ancestry breakdown or trait reports. We only need the raw genetic result file. This file contains a series of rows with genetic results (e.g., A C G and T values). For information about how to download these files please review the FAQ section on our website.
3. To upload a genetic data file,
 - a. Click the button 'upload document.'
 - b. An 'upload document' box will appear. Click the 'browse' button and then select upload document.
 - c. If you have additional files from other genetic testing companies, you may add them in the additional upload lines.



Questions about Future Research Participation

1. The first two questions in this section ask about future contact for either genetic or medical research. If you select “yes” to either of these, a question (with drop-down arrow) will appear asking how you prefer to be contacted for future research opportunities. Use the arrow to choose the contact option you prefer.
2. The last two questions in this section relate to your willingness to share your raw genetic data and/or your health questionnaire results with other researchers outside of Intermountain Healthcare.

Questions about Future Research Participation	
Are you willing to be contacted for future genetic research studies? <small>* must provide value</small>	<input checked="" type="radio"/> Yes 1 <input type="radio"/> No reset
Are you willing to be contacted for future medical research studies? <small>* must provide value</small>	<input type="radio"/> Yes <input type="radio"/> No reset
How would you prefer to be contacted for future research opportunities?	<input type="text"/> 1 reset
Are you willing to have your genetic data shared with researchers outside of Intermountain Healthcare?	<input type="radio"/> Yes 2 <input type="radio"/> No reset
Are you willing to have your health questionnaire data shared with researchers outside of Intermountain Healthcare?	<input type="radio"/> Yes 2 <input type="radio"/> No reset

General Health Questions

1. Please check each condition for which **you** have been diagnosed, treated or medicated from the list of diseases under the General Health Questions.
 - a. If you check a disease with the statement (“*specify types below*”) or (“*specify below*”), a text box will appear allowing each disease type to be entered.
 - b. If you have multiple diseases or types of diseases to enter, separate each type with a comma.

General Health Questions

For which conditions have you been diagnosed, treated, or medicated? (check all that apply)

- a Cancer (specify types below)
- Diabetes (specify types below)
- Thyroid disease
- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Other lung disease (specify below)
- Kidney disease
- Liver disease
- Bi-Polar disorder
- Depression
- Other mental illness (specify below)
- Stroke
- Seizures
- Coronary Artery Disease
- Heart Failure
- Heart Arrhythmia (specify types below)
- Heart attack
- High blood pressure
- High cholesterol
- Other heart condition (specify below)
- Osteoporosis
- Alcoholism or drug abuse
- Other (specify below)

Cancer type(s)

b colon, breast, pancreatic

Expand

2. Please check each condition for which any of your **blood-related family members** have been diagnosed, treated or medicated from the list of diseases under the General Health Questions.
 - a. Similar to the above instructions, if you check a disease with the statement (“*specify types below*”) or (“*specify below*”), a text box will appear allowing each disease and/or type of disease to be entered. If you have multiple diseases or types of diseases to enter, separate each type with a comma.

3. Select if **you** had genetic testing done for a specific medical condition.
- If **you** have had genetic testing done for a specific medical condition, list the medical condition in the text field below.
 - If **you** have had genetic testing done for a specific medical condition, indicate if a mutation in a gene was found to be associated with that condition using the drop-down box.
 - If a mutation in a gene was found to be associated with that condition, list the name of the gene in the text box.

Have you had genetic testing done for a specific medical condition? <small>* must provide value</small>	<input checked="" type="radio"/> Yes <input type="radio"/> No	reset
For what was the medical condition was the genetic testing done?	a	<input type="text"/>
Was there a mutation in a gene found to be associated with that condition?	b	Yes <input type="text"/>
What was the name of the reported gene?	c	<input type="text"/>

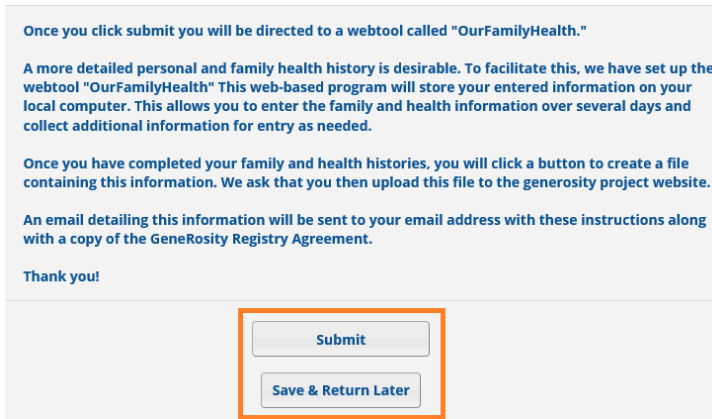
4. Select if **anyone in your family** has had genetic testing done for a specific medical condition.
- If **anyone in your family** has had genetic testing done for a specific medical condition, list the medical condition in the text field below.
 - If **anyone in your family** has had had genetic testing done for a specific medical condition, indicate if a mutation in a gene was found to be associated with that condition using the drop-down box.
 - If a mutation in a gene was found to be associated with that condition, list the name of the gene in the text box.

Has anyone in your family had genetic testing done for a specific medical condition? <small>* must provide value</small>	Yes <input type="text"/>
For what was the medical condition was the genetic testing done?	a <input type="text"/>
Was there a mutation in a gene found to be associated with that condition?	b Yes <input type="text"/>
What was the name of the reported gene?	c <input type="text"/>

Submitting the Questionnaire

At the end of the questionnaire, you will be given the option to:

1. submit the information you have entered, **OR**
2. save your information and come back later to finish entering your data and uploading your genetic files.
 - a. If you would like to save the information and come back later, click the 'save and come back later' button. An email will be generated by the system and sent to your provided email address. The email will contain a link that you will need to click to get back to your individual questionnaire. The email will also contain a code that you will need to 're-access' your questionnaire.



Once you are ready to submit all your information, click the "submit" button. **Note:** Once you submit, you will not be able to get back to your information. Please make sure you've completed all the questions before you click submit.

OurFamilyHealth

Once you click submit you will be directed to a webtool called "OurFamilyHealth." **The OurFamilyHealth webtool is not integrated into the GeneRosity Registry database and you will be required to upload a file with the information generated from this webtool into the GeneRosity Registry.** This web-based program will store your entered information on your local computer. This allows you to enter the family and health information over several days and collect additional information for entry as needed.

Once you have completed your family and health histories, you will click a button (on the upper right corner of the tool) to create a file containing this information. We ask that you then upload this file to the GeneRosity Registry.

An email detailing this information will be sent to your email address with these instructions along with a copy of the Generosity Registry Agreement.

A separate instruction sheet on the OurFamilyHealth webtool is providing in the FAQ page of the GeneRosity Registry website.