

MyGeneRank Study Consent Form

Please review the following Consent to Participate in Research Document.

CONSENT TO PARTICIPATE IN RESEARCH

Title: MyGeneRank

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Research Sites:

- Scripps Translational Science Institute
- The Scripps Research Institute

Welcome

This app allows you to utilize your pre-existing genetic data to understand your estimated genetic risk for disease as well as participate in a research study designed to learn more about genetic risk.

You are being invited to participate in a research study on personalized genetic risk estimates. The purpose of this trial is to evaluate how knowing your genetic risk influences health decisions you make. Accurate predictions of disease risk can lead to early detection and/or preventative treatment of disease, which can improve health outcomes. The decision to participate is entirely your choice and will not cause you to lose any medical benefits or any legal rights.

Data Gathering

You will be asked to provide access to your genetic data. Genetic data will be automatically transmitted to our servers, with your permission. We will also ask you to answer questions about yourself and your health. You will receive a personal genetic risk ranking upon transmission of genetic data and answering a health questionnaire.

You will be asked for permission to allow us to access your genetic data collected by 23andMe. A 23andMe login screen will be presented to you. Logging in will trigger 23andMe to send this app your email address and an authorization code to access your data. We will retrieve your genetic data directly from the 23andMe servers. This data will then be processed on our servers to calculate your genetic risk score, which may take a few minutes. Your genetic data, email address, and device identifier will be retained for future studies and genetic risk scores.

Privacy

The information and genetic data provided by you will be used for study purposes only. We will not share your genetic data. The research team will keep your personal information confidential whenever they can, but, as with any electronic data, there is a risk that genetic or health data provided by you does not remain private.

We will not share your individual-level genetic data. Aggregate data and summary statistics may be shared in publications and for future research.

The results of this research study may be presented at meetings or in publications. Your name will not be used in any presentation or published report. A Federal law, called the Genetic Information Nondiscrimination Act (GINA), generally makes it illegal for health insurance companies, group health plans, and most employers to discriminate against you and your family member based on your genetic information. This law generally will protect you in the following ways: Health insurance companies and group health plans may not request your family member's genetic information that we get from this research. Health insurance companies and group health plans may not use your family member's genetic information when making decisions regarding your eligibility or premiums. This Federal law does not protect you against genetic discrimination by companies that sell life insurance, disability insurance, or long-term care insurance.

Data Use

Your genetic data and the questions you answer will be used to determine how knowing your estimated genetic risk influences health decisions. Your data will be retained for future studies and to provide you with genetic risk estimates for other diseases in the future. You may withdraw permission to use your data at any time.

Study Tasks

You will be asked to complete health questionnaires prior to and after receiving your genetic results. These questionnaires are intended to gauge your short term and long term response to receiving genetic results.

You will be asked to complete one health questionnaire prior to receiving your genetic results. You will not receive results until completing this questionnaire. We will also ask you to answer two brief surveys after receiving your results - one immediately after receiving your genetic results and one six months later.

Withdrawing

You may withdraw from the study at any time. To withdraw from this study, follow the link provided in the Settings menu after enrolling. Your information will be used for this study if you withdraw, but will not be used in future studies. You do not have to be in this study. You still have all your legal rights whether you join the study or not.

Risk and Benefits

You will not benefit from participation in this study. There is a risk that genetic or health data provided by you does not remain private. The research team will keep your personal information confidential whenever they can.

Time Commitment and Duration of Study

You will be asked to complete one health questionnaire prior to receiving your genetic results. We will also ask you to answer two brief surveys after receiving your results - one immediately after receiving your genetic results and one six months later. Answering the health questionnaire and study surveys should take no more than 10 minutes. The total duration of your participation in this study is six months. We will store your information for recontact for future studies. There is no limit on the length of time we will store information. You may withdraw permission to use your data at any time.

Will I be paid?

No.

Will it cost anything to be in the study?

No.

What treatments could I take instead of joining this study?

This study does not involve treatment. You can choose not to be in the study at any time.

Will the investigators benefit from this study?

The Scripps Translational Science Institute might benefit financially from your participation in this study. If any of these parties make a profitable product from your participation, there is no plan to share any profits with you or your family.

What are my rights?

- You can call the study staff to ask any questions about this study. The telephone number is listed at the top of the first page of this form.
- If you have any questions about your rights, call the Scripps Office for the Protection of Research Subjects at (858) 678-6402. You should also read the *Experimental Subject's Bill of Rights*, which is toward the end of this form.
- You do not have to be in this study. You still have all your legal rights whether you join the study or not.
- You have the right to be told about any new information that might make you change your mind about staying in the study.

Is there anything else I should know?

The researchers may use the genetic and health information you provide for further studies. The genetic and health information may be shared with other researchers for future research. This information will not be identified with any of your personal information and will be used for research purposes only.

INFORMED CONSENT TO PARTICIPATE IN STUDY

I agree to participate.

I have read and understood the explanation of the study. The study has also been explained to me by one of the Principal Investigators or their study coordinator. I have had a chance to ask questions and have them answered to my satisfaction. I agree to take part in this study. I have not been forced or made to feel obligated to take part.

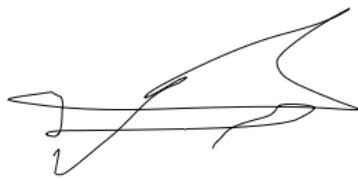
I will read the attached **Experimental Subject's Bill of Rights** and the **Authorization to use my Private Health Information** that contains some important information about research studies. I must sign this consent form, and agree to the **Experimental Subject's Bill of Rights** and the **Authorization to use my Private Health Information**. I will be given access to a signed copy of each to keep.

A description of this clinical trial will be available on <http://www.ClinicalTrials.gov>, as required by

U.S. Law. This Web site will not include information that can identify you. At most, the Web site will include a summary of the results. You can search this Web site at any time.

Test User

9/6/17

A handwritten signature in black ink, consisting of a stylized, cursive script that is difficult to decipher. It appears to be a single name or a set of initials.

Participant's Name (printed)

Participant's Signature

Date