

Genes for Good Consent Form - ONLINE VERSION

Version 3.0

Introduction

Genes for Good is an IRB-approved research study conducted at the University of Michigan.

Genes for Good has been reviewed and approved by a University of Michigan Institutional Review Board following federal, state and institutional regulations. An Institutional Review Board is a group of science and ethics experts who review research studies to help and protect research participants. They are happy to answer questions about your rights as a research participant; you can find their contact information at the end of this consent form.

Our goal is to accelerate genetic and health research through social media and mobile devices. When using the Genes for Good app, you will be asked to participate in surveys about your health and optionally provide a sample of your saliva, from which a complete copy of your DNA can be extracted.

We will use the information you provide to advance our understanding of genetics, disease, behavior, human ancestry, and our relationships around the world. The findings from this research may benefit many individuals, for generations to come, as we learn more about how our genes affect our lives. You can also use capabilities in Genes for Good to track your lifestyle, habits and activities, and compare yourself to other participants.

Eligibility and Participation

To participate, you must be at least 18 years old and currently living in the US (including US territories and military addresses overseas).

After you join, you can immediately participate by completing surveys. We will occasionally send emails about your progress and monthly updates to keep you informed about analyses and new features we're working on.

You will not receive payment for participation in this project or receive payments from scientific discoveries made using the information or samples you donate.

Withdrawal

You can withdraw from Genes for Good at any time by using the withdrawal link in the App under "Your Account". We will delete your name, e-mail, unique Facebook ID, IP address, and phone number from our database but will continue to use your remaining data for future research. We may continue to use your zip code and address to link your information to geo-

coded databases like the US Census, but will not use it to contact you or share your address with others.

Withdrawing is also possible by emailing us at genesforgood@umich.edu or by calling us at (734) 647-7773.

Upon withdrawal, we will keep your age, sex, your survey responses, your address and zip code, and your genetic data if you have provided a sample. After you withdraw, your address and zip code will only be used to link your data to geo-code databases (weather, air pollution, the US census, and others) but will never be used to contact you. We will not share your mailing address with anyone outside our research team.

Only you can remove the Genes for Good App from your Facebook account, which you can do through your Facebook Account Settings page.

Details about Participation

Participation is voluntary. Your participation in the research will last as long as you use the app. You can participate according to your own schedule.

There are two main components to participating: the survey questionnaires, and the optional saliva sample. There is a minimum survey requirement before we collect a saliva sample, analyze your DNA and share results with you. We may not be able to collect saliva samples from all eligible participants.

Survey Questionnaires: These surveys ask about many aspects of your life, including your health, your habits, your attitudes, and your relationships. You can complete any, all, or none of these surveys.

- Health History surveys: answered once
- Daily Tracking surveys: answered daily, weekly, etc.
- Health Conditions module: optional; updated as needed

Saliva Sample: Saliva samples are collected on a first-come, first-served basis, i.e. in order that participants become eligible to provide a sample. To be eligible to provide a saliva sample, we ask that you complete 15 Health History Surveys and 20 Daily Tracking Surveys. The Daily Tracking Surveys can be answered in whatever combination you like, and each is very short. Genes for Good will mail you a "spit kit" to collect your saliva sample, free of charge. Providing a saliva sample is completely voluntary. If you choose to provide a saliva sample, we will send you a hard copy version of this consent form for your signature. If you withdraw from the study, we will keep your signed consent form in a locked office or as a secure electronic copy. We will obtain genetic information (DNA) from your saliva for research, such as testing genetic variants for association with environmental factors, health and disease information that you and others provided through the surveys. The DNA will be frozen and stored indefinitely in a secure laboratory (a biorepository).

Contact Information

If you choose to provide a saliva sample, we will require your name, mailing address, and email address. We will not distribute your name, street address, or email for others to contact you. We may use your zip code and/or mailing address to generate new variables by linking your address to outside data sources.

Using addresses to generate variables about one's environment can be very helpful in research by adding valuable information to our dataset. We could link with information such as census data, satellite data, built environment variables, and other useful information. For instance, we may be able to determine pollution levels in your area. This information about the different exposures you are subject to on a daily basis could help shed light on some of the more complex relationships between genes and disease.

Re-Contact

You may be re-contacted.

We will occasionally use your email address or Facebook to communicate with you. For example, you may be contacted by email to answer additional surveys or provide additional saliva samples for future studies. There is no obligation to participate in these future studies.

Sharing and Use: Science works best when scientists work together. To achieve this, we will release your genetic data and survey results to scientists from other institutions. When we distribute data we will not include your name and e-mail address and will require others to sign a data use agreement where they promise not to identify or contact you.

Return of Information

When you provide us with your information, be it survey responses or DNA, we believe we have an obligation to return interesting results to you. Currently we return summaries of your survey results, ancestry information, and raw, un-interpreted genetic data.

Survey Results: Genes for Good will allow you to view and download the health and behavior information you provide through surveys, and compare it to summaries of the health information others have provided.

If you provide a saliva sample, we will also provide you with:

- **Ancestry:** Your DNA contains information about your genetic ancestry. It can tell you, for example, how much of your DNA came from ancestors from Europe, Africa, East Asia, the Americas, and so on.

- **Genetic Data:** You have the option to receive your raw, un-interpreted genetic data. Raw genetic data will be contained in a securely encrypted computer file.

Risks and Protections

We will carefully protect all information you provide, including your survey results and genetic information. For example, we will only release your coded genetic data to scientists who agree not to attempt to identify or contact you.

This research study is covered by a Certificate of Confidentiality from the National Institutes of Health. The most important protection is that with this certification, the members of our research team may not disclose or use information, documents, or biospecimens that may identify you in any federal, state, or local civil, criminal, administrative, legislative, or other action, suit, or proceeding, or be used as evidence, for example, if there is a court subpoena, unless you have consented for this use.

Information, documents, or biospecimens protected by this Certificate cannot be disclosed to anyone else who is not connected with the research except if there is a federal, state, or local law that requires disclosure, such as to report child abuse; if you have consented to the disclosure, including for your medical treatment; or if it is used for other scientific research, as allowed by federal regulations protecting research subjects.

To help us protect your privacy, we have obtained this Certificate of Confidentiality from the National Institutes of Health, which allows us to refuse to disclose your data or that you have participated in the study. Disclosure of your research information may only occur in limited instances, for instance when sharing your de-identified research data with other researchers who have agreed not to attempt to identify you.

This Certificate prohibits us from disclosing information that may identify you in any federal, state, or local civil, criminal, administrative, legislative, or other proceedings; for example, if there is a court subpoena. This means that the University of Michigan will not disclose that you have participated in the study or the contents of your answers and resist any demands for information that would identify you. The Certificate of Confidentiality also applies to the data that we share with external researchers.

The Certificate of Confidentiality does not, however, apply to Facebook. Facebook may see that you are using the Genes for Good app, but they cannot see the contents of your answers. Facebook may disclose or confirm that you have participated in the study in accordance with its own policies and practices.

Facebook cannot access survey answers collected through the App, any saliva sample you provide, or any information we will give back to you. However, your individual Facebook privacy settings will determine who can see the App in your profile, your posts regarding the App, and

when you invite your Facebook friends to participate. This information, as well as whether and when you use the App, can also be viewed by Facebook.

A Certificate of Confidentiality does not prevent you or a member of your family from voluntarily releasing information about yourself or your involvement in this research. If an insurer, employer, or other person obtains your written consent to receive research information, then we cannot use the Certificate to withhold that information.

Legal Protections: Genetic Information Nondiscrimination Act

If you choose to provide saliva, you should know that your saliva contains genetic information about you. You should also know about the Genetic Information Nondiscrimination Act (GINA). GINA is a federal law that prohibits certain kinds of discrimination on the basis of genetic information. GINA applies to any genetic information obtained by this project.

- GINA prohibits health insurance companies and health plan administrators from asking for genetic information about you or your family members. It also prohibits them from using genetic information for decisions about coverage, rates, or pre-existing conditions. For example, if someone has a gene that causes breast cancer, an insurance company cannot use that information to charge that person higher rates, even though they may be more likely to use medical services to treat cancer.
- GINA prohibits employers with 15 or more employees from using genetic information for hiring, firing, or promotion decisions, or for any decisions regarding terms of employment.
- GINA protections do not apply to other kinds of insurance like life, disability, or long-term care insurance. For more information about GINA, go to:
<http://www.genome.gov/10002328>.

Genes for Good cannot guarantee that the genetic information we extract will never be used to identify you. If your genetic information is used in some way to identify you, it is possible that you could suffer psychological or emotional harm, or other unforeseen consequences. If you choose to view your DNA ancestry results, it is possible that you could discover or suspect non-paternity and/or secret adoption. For example, you could discover that your parents are not your biological parents.

Contact Information

Genes for Good is overseen by

Gonçalo Abecasis, PhD, Professor of Biostatistics at the University of Michigan.

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If you have questions about your rights as a research participant, or wish to obtain information, ask questions or discuss any concerns about this study with someone other than the researchers, please contact:

University of Michigan Health Sciences and Behavioral Sciences Institutional Review Board
2800 Plymouth Road, Building 520, Room 1169
Ann Arbor, MI 48109-2800
Phone: (734) 936-0933 [or toll free, (866) 936-0933]
Email: irbhsbs@umich.edu

By clicking Decline you decline to participate in this study.

By clicking Accept, you affirm that you have read and understand this document, received answers to any questions you may have had, and that you consent to participate in Genes for Good. You will be given the option to download a PDF copy of this document, and another copy will be kept with study records.

I affirm that I am 18 years of age or older and currently live in the U.S.