Genes for Good Consent Form

Version 2.1

The next few screens contain information about Genes for Good and the benefits and risks of participating. This is called "informed consent", because we want you to be informed about the study before you agree to participate.

About the Study. 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.

Genes for Good is different from other Facebook Apps you use. Our goal is to accelerate genetic and health research using social media. When using this 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.

On the next few screens we document the information you should understand before you agree to participate. The purpose of this information is to confirm our commitments to you and your agreement to participate in Genes for Good.

Joining.

- Genes for Good is a research study. You can find more information about the study at http://genesforgood.sph.umich.edu.
- You will not receive payment for participation in this project or receive payments from scientific discoveries made using the information or samples you donate.
- You can withdraw from Genes for Good at any time. You can stop participating in the study by using the withdrawal link in the App which can be found under “Your Account” at the upper right corner. Withdrawing is also possible by emailing us at genesforgood@umich.edu, or by calling us at (734) 647-7773.
- After withdrawing we will delete your name and unique Facebook ID from our database. We will also remove your addresses (IP address and physical address) and phone number (if you provided them to us). We will keep your age, sex and zip code, and use these limited data for future research; this includes also your DNA, if you have provided a sample. Only you can remove the Genes for Good App from your Facebook account, which you do through your Facebook

Account Settings page.

Participating. You should understand that:

- **Participation is Voluntary**: Your participation in the research will last as long as you use the App.
- **Survey Questionnaires**: We will ask you to complete surveys related to many aspects of your life, including your health, your habits, your attitudes, and your relationships. There are two types of assessments: Health History Surveys that are only meant to be answered once, and short Health Tracking Surveys that can be answered daily or weekly. You can complete any, all, or none of these surveys.
- **Saliva Sample**: To be eligible to provide a saliva sample you have to complete 15 Health History Surveys and a total of 20 Health Tracking Surveys. The 20 Health Tracking Surveys can be answered in whatever combination you like – don’t worry, each Health Tracking Survey is very short. For example, you could complete the same Health Tracking Survey on 20 different days, or five different surveys each day on four days, or seven different surveys on three days. It’s up to you. These criteria will apply until we distribute 5,000 spit kits. If the criteria change or 5,000 spit kits are distributed, we will inform you. Genes for Good will send you a mail-in "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 this consent form in hard copy together with the spit kit and ask for your signature. Without this signature we will be unable to process your saliva. If you choose to 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 and mailing address for shipment, and email address for tracking. We will then mail a spit kit to you. We will under no circumstances release your name, address, or email, or directly link it with any other information you provide.
- **Re-Contact**: You may be re-contacted. We will occasionally use your Facebook email address 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 DNA and de-identified data to qualified scientists from reputable institutions for further research, under relevant law and with appropriate regulatory approval. Any release of your information will be

approved by relevant Institutional Review Boards, which are panels of ethics and science experts who protect research participants.

Return of Information. When you provide us with your information, whether survey results or DNA, we believe we have an obligation to return interesting results of our research to you.

- **Survey Results**: Genes for Good will allow you to view and download the health information you provide, 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. You will be given the option to view these results for your DNA.
- **Genetic Data:** In addition we will give you the option to receive your raw genetic data for your own purposes. Raw genetic data means we will give you the genetic information that we extract from your DNA, in a securely encrypted computer file.

Risks and Protections. Finally, you should understand that:

- 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 qualified scientists from reputable institutions who agree not to attempt to identify participants, consistent with the norms and regulations of other major research projects. We will never make your genetic information available to the general public.
- To help us protect your privacy, we have obtained a Certificate of Confidentiality from the National Institutes of Health. We can use this Certificate to legally refuse to disclose 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. The researchers will use the Certificate to resist any demands for information that would identify you. This means that the University of Michigan will not disclose that you have participated in the study or the contents of your answers.
- The Certificate of Confidentiality does not, however, apply to Facebook. Although Facebook cannot access your survey answers collected through the App, any saliva sample you provide, or any information we will give back to you, 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. Facebook may disclose or

confirm that you have participated in the study in accordance with its own policies and practices.
- You should understand that 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, so you may want to know what protections GINA provides before you decide whether you donate saliva to this research.
  - 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 true parents.

Contact Information.

Genes for Good is overseen by:

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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, 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.

☐ By checking this box, I affirm that I am 18 years of age or older and that I currently live in the U.S.