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## Consent Form



### Introduction

Donating your genetic data is an easy way to contribute to the advancement of science. Before you share your data, we want to tell you about the research we do and a few other things about us. Open Genomes is a worldwide research institution and international public charity. You can donate your genetic test results, including those you *already* have, to Open Genomes. This will help all of us find out about our origins and history, understand how genetics affects people's health, and even help save lives.

For more about our organization's registered charitable mission, please see: <http://www.open-genomes.org/mission.html>.

For details about our official charitable status and our regulatory oversight, please see: <http://www.open-genomes.org/imprint.html>.

If you decide to participate, you may withdraw your consent at any time, no questions asked. Your participation is entirely voluntary.



### Purpose

We will help you freely and anonymously store and share your genome with the world, enabling both academic researchers and other interested people to make new discoveries for the benefit of all humanity. Your DNA test results are permanently stored for free in the International Nucleotide Sequence database, which operates in cooperation with scientists and governments around the world. This is where the human genome is stored, and your genome will be stored alongside it. Once stored, your genetic data can be easily accessed and displayed in genome browsers, downloaded, and compared with other people's results.

All of your own genetic sequence data, from whatever testing source and kind of test, will be grouped under one single entry for you. This way, researchers will be able to know that different genetic sequences, test results, and analysis all belong to one person. If you want, you can add information about yourself and your

ancestry which will help people understand your results. This is different from the typical genetics research study, where a single set of genetic sequences from one test are shared and cannot be updated with new and more complete test results, and where there is very little information about the ancestry and health of the people being studied. We want to make it possible for people to update and share new genetic sequences as they get them, and also empower people to share information about themselves. The information about your health and ancestry that you choose to share can help researchers understand important things about your genetic heritage and the genetics you share with other people.

No one else can own your data. Because the International Nucleotide Sequence Database (INSD) is cooperatively funded and administered by various governments around the world, and researchers and governments have all agreed to freely share every kind of genomic data there (including plant, animal, microbial, and viral genomes), your anonymous data will always be freely available. The INSD will never be shut down, never privatized, will never charge money for storage, and your genomic sequence data will never be removed unless you say so. This is different from every other database in the world.

We encourage ordinary people to participate in scientific research and discovery, and we want to help people get credit for their own research as well as for the funding and crowd sourcing of genetic sequencing.



## Participation

Your participation will consist of creating a personal profile and securely uploading your genetic data. Open Genomes will provide a way to access your data directly in a genome browser, and give you a way to enter and edit as much (or as little) detail about your ancestry and health as you'd like. You'll be able to change your information at any time. We may contact you for additional information and/or testing. Your sequences will be added to worldwide genetic trees which will show how you are related to everyone else in the world, how everyone's genes evolved, and where your ancestors came from.

As more and more people add their sequences to the International Nucleotide Sequence Database, the information you get out of it will become more accurate and comprehensive. That's because you will have more sequences to compare yours to, more genetic matches, and more freely available analysis will be done using all these sequences, including yours.

Knowing the family tree of a person who has had genetic sequencing is extremely

important for the interpretation of their sequences. You can choose to share information about your family tree by uploading your pedigree in standard GEDCOM format to the International Nucleotide Sequence Database. You will be able to show as much or as little about your family tree as you wish, and you can edit and update it at any time. There will be no limits on the size of your GEDCOM or the amount of information you can enter. You just need to make sure you don't show any identifying information about living people. You will always have free access to your GEDCOM. Your pedigree can offer important clues for scientific research that no one would otherwise know, and now you can contribute it to science along with your genetic sequences. No one will be able to own or commercially exploit your pedigree either.

After you upload your family tree in GEDCOM format, you can anonymously indicate other relatives who have also shared their genetic sequence data in the International Nucleotide Sequence Database by their INSD sample accession numbers, provided they agree and choose to share these with you. This way, researchers can understand how two people who have shared their genetic sequence data are related.

Open Genomes offers this to you free of charge and does not compensate you for participating. Your contribution of your genetic data can be considered a charitable donation in kind in some countries. We will continue developing our site and may make changes along the way.



## Confidentiality

Open Genomes values your contribution to the scientific community and your privacy. We pledge to adhere to the following guidelines which in our perspective will reduce the risks, while maximizing the scientific impact.

- We will not share any explicitly identifying or contact information connected to your genetic sequence without your direct personal approval. Your International Nucleotide Sequence Database profile is identified by a unique accession code.
- Our system provides a method for researchers to contact you while keeping your identity anonymous. You can decide if you want to respond.
- If you do decide to connect your social media profiles with Open Genomes, we will never share information with any of the social media websites that would associate you with your genomic data.

Likewise, you have the opportunity to share your contact information and accession code with blood banks and transplant registries because your genetic data will show who you could match. This could save lives.



## Code of Conduct

Open Genomes assumes the following social norms and ethical behavior: You agree not to use Open Genomes pages to integrate, promote or disseminate hate, discrimination, or violence towards any individual or group. We reserve the right to moderate and delete any data, including disparaging statements based on race, ethnicity, religion, sexual preference, gender, age, income, family heritage, disability, or health trait. We also reserve the right to moderate and delete any commercial advertising or promotion.



## Risks

There are no physical risks involved in participating, but there may be unintended consequences. Sharing your data publicly may allow people to deduce your identity from your genetic data. As mentioned earlier, we will do our very best to protect your personal identity and contact information from unintentional release. Risks may include unexpected findings about yourself or your family including:

- predisposition for a disease or undesirable trait
- non-paternity event or unrecorded adoption



## Potential Benefits

Being part of Open Genomes will benefit you in the following ways:

- You will have free perpetual storage for your genetic data.
- You will have unlimited access to your genetic data directly through a genome browser allowing you to personally check and analyze your results.
- Independent researchers and larger biological studies will utilize your data in their analysis and you will have access to published results of their analysis.
- Knowing your genetic traits empowers you to make informed decisions about your health and lifestyle. Any genetic risks you carry you already have even without genetic sequencing, but knowing what they are can help you take action to avoid them and minimize your risk.
- You can easily share your genetic data with your personal healthcare providers and they can use your results to improve your family's health. This is the new field of personalized medicine.
- Your genetic data will be easily available in case of an emergency, for example, to find a compatible blood donor or help doctors decide on the proper dosage of a

medication. This could save your life.

- You can easily volunteer to participate in genetic studies. You can direct researchers to your already available public genetic data.
- You can sign up on your own for independent ongoing analysis of your genetic data from multiple sources. You will find out interesting and valuable things about your ancestry, and you may find relatives you didn't know about.
- If you wish, you and/or someone who has funded your sequencing and helped you with your research can receive credit as an author for the work.
- There is no limit on the amount of genetic sequence data you can store in the International Nucleotide Sequence Database. Because the INSD is publicly funded by governments, storage space is not an issue. Because irreplaceable genetic data is stored there, everything is backed up at multiple sites around the world. No data will ever be unintentionally lost.
- Because there are no limits on the amount of data stored or what can be displayed to everyone, unlike all other genetic databases, there will be no limit to the number and kind of genetic matches you can find. You will even be able to find everyone who shares a rare sequence or mutation which you may have thought only belonged to you.
- If you choose, you can upload your family tree in standard GEDCOM format and include as little or as much information as you'd like, provided it doesn't directly identify living people. There will be no limit on the size of your GEDCOM pedigree.

Here are some things other researchers may be doing with your genetic data without any effort or cost on your part. They can:

- help prevent and cure diseases
- study history, human migration patterns, and human evolution
- research genealogy and ancestry



## **My Legal Rights Against Genetic Discrimination**

There is a possible risk that loss of confidentiality with regard to or misuse of genetic information could lead to discrimination against participants. The chance of this happening is remote.

Importantly a US Federal law, the Genetic Information Nondiscrimination Act (GINA), generally makes it illegal for health insurance companies, group health plans, and most employers to discriminate based on your genetic information. Under this law, health insurance companies and group health plans may not ask for genetic information obtained during this research project; health insurance companies and group health plans may not use genetic information when making decisions about eligibility for insurance or your premiums; and employers with 15 or more employees may not use your genetic information obtained during this research study when making decisions to hire, promote, or fire, or when setting the terms of employment. GINA, however, does not protect against discrimination by companies that sell life, disability, or long-term care insurance.

In 2008, the European Union published a general mandate prohibiting genetic discrimination in member states, the Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Genetic Testing for Health Purposes. In the mandate it states that “The member States of the Council of Europe ... reaffirm the fundamental principle of respect for human dignity and the prohibition of all forms of discrimination, in particular those based on genetic characteristics.”



## **Contact**

Dr. Nathan Bowen PhD is the principal investigator and Dr. Brian Hamman PhD and Dr. Asa'ah Nkohkwo PhD FRSPH are the sub-investigators who are in charge at Open Genomes.

If you have questions, please email us at: [info@open-genomes.org](mailto:info@open-genomes.org)

If you have any concerns, complaints, reports of violations, questions about your rights as a research subject, or you are unable to reach the research team, you may contact a person who is independent of the research team at Fox Commercial Institutional Review Board, Ltd. at +1-217- 492-1369 [www.foxirb.com](http://www.foxirb.com).



## Consent

I have read this consent, my participation is voluntary, and I freely contribute my data to Open Genomes.

- I expressly authorize the collection, processing, use, and disclosure of my data for use in research as indicated in the Confidentiality section.
- I permit Open Genomes to recontact me as part of the study.
- I confirm that the data submitted to Open Genomes belongs to me personally and that I am over 18 years of age.

The information served by Open Genomes is only for educational and research purposes and it is experimental by nature. It is not intended for us to diagnose, treat, cure, or prevent any disease.

We encourage you to share your data with licensed healthcare professionals.

Open Genomes has the right to change the terms of this consent in the future.

By accepting the terms of this consent form I have not given up any of my legal rights. I am free to withdraw my consent at any time without having to provide a reason. At any time after the sequence is made public, I can request that my genetic sequence results be removed from the International Nucleotide Sequence Database and the Open Genomes site.

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**Signature**

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**Date**

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**Print Name**

Open Genomes Foundation, Inc., is a US §501(c)(3) tax-exempt non-profit organization EIN: 46-2725903 officially registered in the US State of Massachusetts, headquartered in the US State of Arizona. Open Genomes e.V. is a non-profit organization founded in accordance with notice of exemption Tax No . DE 43 250 78057 from 07.25.2014.

Your donations are tax deductible in the United States and the European Union.

Open Genomes is financed by charitable donations.

For more information, see <http://www.open-genomes.org/imprint.html>