

### **Experimental Research Subject's Bill of Rights**

California law, under Health & Safety Code Section 24172, requires that any person asked to take part as a subject in research involving a medical experiment, or any person asked to consent to such participation on behalf of another, is entitled to receive the following list of rights written in a language in which the person is fluent. This list includes the right to:

1. Be informed of the nature and purpose of the experiment.
2. Be given an explanation of the procedures to be followed in the medical experiment, and any drug or device to be utilized.
3. Be given a description of any attendant discomforts and risks reasonably to be expected from the experiment.
4. Be given an explanation of any benefits to the subject reasonably to be expected from the experiment, if applicable.
5. Be given a disclosure of any appropriate alternative procedures, drugs or devices that might be advantageous to the subject, and their relative risks and benefits.
6. Be informed of the avenues of medical treatment, if any, available to the subject after the experiment if complications should arise.
7. Be given an opportunity to ask any questions concerning the experiment or the procedures involved.
8. Be instructed that consent to participate in the medical experiment may be withdrawn at any time and the subject may discontinue participation in the medical experiment without prejudice.
9. Be given a copy of the signed and dated written consent form.
10. Be given the opportunity to decide to consent or not to consent to a medical experiment without the intervention of any element of force, fraud, deceit, duress, coercion, or undue influence on the subject's decision.

Checking this box below indicates that you have read the Experimental Research Subject's Bill of Rights.

I have read and understand the Experimental Research Subject's Bill of Rights.

## **Research Informed Consent to Participate in Research and Health Insurance Portability and Accountability Act Authorization Form**

**TITLE:** Genetic Data Sharing

**PRINCIPAL INVESTIGATOR:** Helané Wahbeh, ND, MCR

**FUNDED BY:** Institute of Noetic Sciences

### **PURPOSE:**

You have been invited to be in this research study because you are interested in the genetics of psychic ability or extended human capacities. If you participate in all research activities, you will complete this online survey and share genetic data you have received from a direct-to-consumer genetic service like 23andMe or Ancestry.com with the Institute of Noetic Sciences.

The purpose of this study is to learn more about whether extended human capacities have a genetic characteristic. Genes are the units of DNA—the chemical structure carrying your genetic information—that determine many human characteristics such as the color of your eyes, your height, and whether you are male or female. The data you provide will be used to determine if psychic abilities are associated with specific genes or genetic networks.

Your genetic data will be stored in a repository. This means that the data will be stored indefinitely and may be used and disclosed in the future for research, which may include additional genetic research. See the “Confidentiality” section below for procedures used to protect your personal identity.

There may be up to 5,000 participants enrolled in this study.

### **PROCEDURES:**

If you decide to join the study after reading this consent form, you will continue to the next page to complete several questionnaires. These questionnaires will ask you about yourself, whether you have specific psychic abilities, your health, mood, and thoughts and beliefs about psychic abilities and related topics. The questionnaires should take about 20 minutes to complete. At the end of the survey, you will be given instructions on how to share your genetic data file that you received from a direct-to-consumer genetic service company with IONS. Your data will be securely shared with our collaborators to analyze whether there is a relationship between genetics and psychic abilities and related factors. Our collaborators will also keep your personal identification information confidential and will not be able to share your data with anyone else.

The data you have completed and shared with us will be kept indefinitely and may be used for other research studies in the future. These studies may include genetic research. Your data will be labeled as described in the **CONFIDENTIALITY** section.

**ACCESS TO YOUR TEST RESULTS:**

We may or may not find any relationship between the genetic data and psychic abilities or related factors. Regardless, you will not receive any personal results about your genetic data and its relationship to psychic abilities and related factors. That said, the results of this research study will be published and made available to the public. If any genetic factors are found to be related to psychic abilities you may be able to compare the results in the report against your own genetic data.

I understand that I will not receive personal results about relationships between my genetics and psychic abilities.

**RISKS AND DISCOMFORTS:**

Some of these questions we ask in the questionnaires may seem personal or embarrassing and may upset you. If the questions make you very upset, please let us know and we will refer you to your mental health provider or help you find one.

**BENEFITS:**

You will not directly benefit from being in this study. However, by serving as a participant you may help us learn if psychic abilities have a genetic component.

**ALTERNATIVES:**

You may choose not to be in this study.

**AUTHORIZATION TO USE YOUR PROTECTED HEALTH INFORMATION:**

The Health Insurance Portability and Accountability Act (HIPAA) of 1996 requires that the research team obtain your permission to use health information that is linked to you, called “protected health information.” This section of this form explains what type of information will be collected for this research study and describes what that information will be used for. It also explains how your information will be kept confidential.

By signing this document, you will authorize the Helané Wahbeh, ND and her research team access to your protected health information. Protected health information is any health information through which you can be identified. This information may be collected, created, used and disclosed in this research study.

The identifiers that will be used in this research study include the results of your genetic analysis you received from direct to consumer companies. We will not be collecting any other protected health information or identifying information from you.

### **WHO ELSE WILL BE ALLOWED TO SEE INFORMATION ABOUT ME?**

The investigators, study staff, and others at IONS may use the information we collect and create about you to conduct and oversee this research study and store in a repository and conduct future research.

We may release this information to others outside of IONS who are involved in conducting or overseeing research, including:

- The Food and Drug Administration
- The Office for Human Research Protections, a federal agency that oversees research involving humans.
- The Institute of Noetic Sciences Institutional Review Board
- Michael Woodley, collaborator conducting statistical analysis

Those listed above may also be permitted to review and copy your records. Data from this study may also be shared with other investigators for this and future research studies. These investigators will not be able to share your data with others. We may continue to use and disclose your information as described above indefinitely. We will not release information about you to others besides the cases mentioned above, unless required or permitted by law. We will not use your name or your identity for publication or publicity purposes, unless we have your explicit permission.

You are giving the research team permission to use your personal health information indefinitely. This authorization has no expiration date.

### **CAN I WITHDRAW MY PERMISSION TO USE MY PERSONAL HEALTH INFORMATION?**

Once you submit your genetic results data to this study you will not be able to withdraw it. This is because we are not collecting any information that can identify you or your data and we will not be able to identify which results file is yours.

### **CONFIDENTIALITY:**

We aim to keep your personal health information strictly confidential, but we cannot guarantee total privacy. We will create and collect health information about you through the online survey. Health information is private and is protected under federal law.

A federal law, called the Genetic Information Nondiscrimination Act (GINA), makes it illegal for health insurance companies, group health plans, and most employers to discriminate against you based on your genetic information. Be aware that this federal law does not protect you against genetic discrimination by companies that sell life insurance, disability

insurance, or long-term care insurance. GINA also does not protect you against discrimination if you have already been diagnosed with a genetic disease.

Although we have made every effort to protect your identity, there is a small risk of loss of confidentiality. If the results of these studies of your genetic makeup were to be accidentally released, it might be possible that the information we will gather about you as part of this study could become available to an insurer or an employer, or a relative, or someone else outside the study. Even though there are genetic discrimination and confidentiality protections in federal law, there is a small chance that you could be discriminated against if a release occurred.

**COMMERCIAL DEVELOPMENT:** Information about you or obtained from you in this research may be used for commercial purposes, such as making a discovery that could, in the future, be patented or licensed to a company, which could in turn result in a possible financial benefit to that company, IONS, and its researchers. There are no plans to pay you if this happens. You will not have any rights to ownership or financial interest in or arising from products or data that may result from your participation in this study. Further, you will have no responsibility or liability for any use that may be made of your information.

**COSTS:** It will not cost you anything to participate in this study.

**PARTICIPATION:**

If you have any questions, concerns, or complaints regarding this study now or in the future, contact Dr. Helané Wahbeh, hwahbeh@noetic.org

This research is being overseen by an Institutional Review Board (“IRB”). You may talk to the IRB Chair, Dr. Garret Yount at gyount@noetic.org if:

- Your questions, concerns, or complaints are not being answered by the research team.
- You want to talk to someone besides the research team.
- You have questions about your rights as a research subject.
- You want to get more information or provide input about this research.

Your participation in this study is voluntary. You do not have to join this or any research study. You do not have to allow the use and disclosure of your health information in the study, but if you do not, you cannot participate in the study.

**CONSENT:**

Checking this box below indicates that you have read this entire consent and authorization form and that you agree to be in this study.

I have read and understand this consent and authorization and agree to be in this study.