



Consent to Participate in jscreen

This form includes your consent to participate in the jscreen Program; a description of the jscreen Program; and the benefits, risks, and limitations of participating in the jscreen Program.

Description of the jscreen Program

jscreen is a national non-profit genetic screening program that provides education and access to genetic screening to individuals residing in the United States (the “jscreen Program” or “jscreen”). jscreen supports two types of genetic testing: reproductive carrier screening for individuals who are planning to have children, and cancer genetic testing for individuals who are interested in learning about their risk for hereditary cancers.

Your participation in the jscreen Program is voluntary. In order to participate, you must provide jscreen with personal and medical information, and that information will be reviewed by jscreen representatives. jscreen representatives will be available to answer any questions you may have about the jscreen program or genetic testing, but please note that your genetic testing and counseling services must be ordered by a healthcare provider. jscreen will provide you access to a healthcare provider (including DNAvisit, a national clinician network, if you order through the jscreen website), who will review your information and then transmit a test order with your personal and medical information and your insurance information (if applicable) to an independent testing laboratory (the “Laboratory”). If you prefer, jscreen will support using your personal physician to serve as your ordering healthcare provider for genetic testing and counseling services. You understand that you will be required to sign the necessary paperwork required by the Laboratory and your ordering provider in connection with your genetic test.

Once the order is placed by the healthcare provider, the Laboratory will provide a collection kit(s) containing instructions for specimen collection and you will return your specimen(s) to the Laboratory for analysis, and the Laboratory will provide your genetic test results to you, your ordering healthcare provider and any other healthcare providers you include in your order, and to jscreen. You will have the opportunity to speak with a genetic counselor to discuss your test results, and a consultation note summarizing your results will be made available to you. As required by law, the healthcare provider who ordered the testing will receive a copy of your genetic test results and consultation note.

Conditions of Participation in the jscreen Program

You consent to participate in the jscreen Program, and your participation in the jscreen Program is subject to your agreement that your interactions with jscreen and its representatives:

- Do not constitute treatment or diagnosis of any condition, disease or illness;
- Do not replace clinical genetic counseling;
- Do not replace the existing primary care or other relationship of a Participant with his/her physician; and
- Do not replace medical advice from a physician.

You agree to sign any additional forms or consents as necessary for the healthcare provider(s) and Laboratory to perform their roles in your genetic testing, and you understand that jscreen is not responsible for the performance of your healthcare provider(s) and Laboratory. You also understand that, even though we will guide you and provide information to support your care to the extent we are able, jscreen is not responsible for recommending or arranging for follow-up services or additional testing, diagnostic care, or treatment, and you must work with your healthcare provider for all of these items. If you have a personal medical history, a medical condition, or family history that you are concerned about, you should also discuss your concerns directly with your healthcare provider.

Consent to Release Test Results and Protected Health Information

In order to facilitate genetic screening by providing you with pre-test education about screening and helping you through the process of being screened and learning your results, jscreen must use your personal information, test results, and consultation note and must provide this information to other parties. By signing this Consent form, you authorize and consent to allow the employees and agents of jscreen, the Laboratory, and the ordering healthcare provider to release your personal and medical information, genetic test results and/or genetic counseling information to:

- The jscreen Program staff and representatives,

- Your healthcare provider(s),
- The testing Laboratory(-ies),
- Your insurance company and any other third-party payors, if applicable, and/or
- Any other people (including your reproductive partner) to whom you consent providing your information.

You additionally consent to your information being included in de-identified aggregate data that jscreen may use in publications and/or provide to others interested in the jscreen Program. This information may include, but is not limited to, demographics, the total number of participants screened, the total number of participants screened as positive carriers, and the total number of participants referred to and completing genetic counseling.

You further consent to receiving communications from jscreen, the Laboratory, and your healthcare provider(s) using the following methods:

- Email,
- Telemedicine provider (e.g., DNAvisit) or Laboratory portals,
- Text message,
- Telephone, and/or
- Fax.

You understand that these communication methods may not be secure or HIPAA compliant.

Benefits and Risks

Taking part in the jscreen Program may or may not benefit you personally. We may learn new things that will help other people who have genetic conditions. Possible benefits include gaining access to genetic screening and genetic counseling services and learning about your personal and/or reproductive health risks.

While jscreen takes great efforts to protect your test results, medical and personal information, and protected health information as defined by HIPAA (collectively “PHI”), the jscreen Program cannot guarantee that your PHI will not be released. The party to whom your information is released may be able to further release the information without your consent or authorization.

There are additionally inherent risks in receiving genetic testing. If you decide to update your reproductive carrier screening and/or cancer screening in the future, your health insurance plan may deny coverage for your genetic test. Risks associated with sample collection include dry mouth during saliva collection, and possible pain and bruising related to drawing blood, if applicable. You may

experience anxiety or other potential psychological impacts related to test results. In some instances, DNA testing may discover non-paternity or some other previously unknown information about family relationships.

Access to Genetic Testing

You may choose to seek genetic testing from the testing Laboratory or from a different laboratory without participating in the jscreen Program. Contact your personal healthcare provider for information on coordinating testing outside of the jscreen program.

Compensation

By participating in the jscreen Program you agree to pay the program fee and to be responsible for all costs of the services performed by your healthcare provider(s) and the Laboratory. jscreen is not responsible for any such payments, and you will not be compensated for your participation or for any injuries sustained by you in connection with your participation in the jscreen Program.

Cost

You are responsible for paying the jscreen program fee and for paying your healthcare provider. jscreen will collect the program fee amount when you register for your screening kit, and will collect payment for DNAvisit if you intend to use their healthcare provider services. If your personal healthcare provider serves as the ordering provider, you are responsible for payment of the healthcare provider's routine charges. Where applicable, the testing Laboratory will bill your insurance and you will be responsible for payment of any amount due to the Laboratory. If you do not have insurance, or choose not to use your insurance, you may be offered and may choose to participate in the Laboratory's self-pay rate and/or financial assistance program, if applicable.

Limitations

jscreen, its affiliates, and funding sources are not responsible for the testing, outcome, reliability or validity of your genetic laboratory screening test. By enrolling in the jscreen Program, you acknowledge that you are entering into a relationship with your healthcare provider (including DNAvisit) and with the testing Laboratory to undertake and provide the genetic testing. DNAvisit, your healthcare provider, and the testing Laboratory are each separate entities independent from jscreen, and jscreen is not responsible for the actions, services, or the testing performed by any of these entities.

In some instances, jscreen or DNAvisit may request that the Laboratory perform further analysis of your sample and/or your test results. Based on this analysis,

additional testing may be recommended. If another sample is needed, jscreen or the Laboratory will help coordinate testing or will recommend that you pursue this testing through your local healthcare provider.

Release of Genetic Testing Information

The Genetic Information Non-Discrimination Act (“GINA”) is a federal law that prohibits discrimination in health coverage and employment based on genetic information of individuals. GINA, together with already existing non-discrimination provisions of the federal Health Insurance Portability and Accountability Act, prohibits most health insurers or health plan administrators from requesting or requiring genetic information of an individual or an individual’s family members, or using such information for decisions regarding coverage, rates, or pre-existing conditions. GINA also prohibits most employers from using genetic information for hiring, firing, or promotion decisions, and for any decisions regarding terms of employment. GINA’s provisions prohibiting discrimination in health coverage based on genetic information do not extend to protect decisions made by companies or entities regarding the availability to any applicant for life insurance, disability insurance or long-term care insurance.

For more information, go to www.GINAhelp.org