

SECTION 1: CHECKLIST

TO BE COMPLETED BY THE INDIVIDUAL ORDERING A GENETIC TEST.

The individual's DNA sample will be tested solely for the genetic characteristic below:

_____ (Name of genetic characteristic)

PROCESS TO FOLLOW PRIOR TO OBTAINING GENETIC INFORMATION:

After each of the points below have been clearly explained to the individual to be tested, or the individual's personal representative, please initial in the space provided to ensure that the informed consent procedure has been followed.

- _____ I have informed the individual that this genetic test is completely voluntary; that he/she has the option of withdrawing consent to the genetic test at any time.
- _____ I have explained to the individual the risks and benefits of having a genetic test, including:
- a description of the provisions of Oregon law pertaining to the confidentiality of genetic information;
 - a statement of the potential consequences regarding insurability, employability, and social discrimination if the genetic test results become known to others;
 - a statement explaining the implications of positive and negative test results, and the availability of support services, including genetic counseling.
- _____ I have informed the individual that it may be in his/her best interest to retain the DNA sample for future diagnostic testing, but also of his/her right to have the DNA sample promptly destroyed after the specific purpose for which it was tested (unless retention of the sample is otherwise authorized by law).
- _____ I have informed the individual about the meaning and purpose of the authorization form for disclosure of procedure to a third party payer, including:
- an explanation of the potential risks of disclosure to third-party payers that a genetic test has been performed;
 - an explanation of the individual's option to pay out-of-pocket for the cost of the genetic testing procedure.
- _____ I have asked the individual whether he/she has any further questions; and if so, I have provided the individual with an opportunity to ask questions and receive answers from either a genetic counselor, or a person who is sufficiently knowledgeable to give accurate and understandable answers about genetic testing and its implications.
- _____ I have asked the individual to read, complete, sign and date this consent form; and provided the individual a copy of this completed form for his/her personal records.

The above referenced information was explained by me, to the individual being tested, and the individual being tested signed this consent form in my presence.

Name of individual ordering genetic test: _____

Signature of individual ordering genetic test: _____ Date: _____

SECTION 2: INFORMED CONSENT OF INDIVIDUAL CONSENTING TO TESTING

TO BE COMPLETED BY THE INDIVIDUAL CONSENTING TO A GENETIC TEST.

It has been explained to me that the procedure to be undertaken is a test of my DNA sample to obtain genetic information solely for the purpose(s) listed below. It has also been explained that consent to this procedure is completely voluntary. I have been told that there are risks and potential consequences regarding employability, insurability and social discrimination that may result from the collection of my genetic information.

Please **check one**:

- I have been asked if I want a more detailed explanation of the risks and benefits of genetic testing. I am satisfied with the explanation provided to me and do not need any more information.
- I have requested and received further explanation for the proposed genetic test and more information about the potential risks and consequences for the test for me and my family. I am satisfied with the additional information provided to me and do not need any more information.
- I have requested further explanation of the proposed genetic test and more information about the potential risks and consequences for the test for me and my family, and do not consent to the collection of my genetic information at this time
- I consent to the collection of my genetic information for the purpose of _____ and acknowledge that the results of this test or procedure will be recorded in my confidential medical record.

Name of individual consenting: _____

Signature of individual consenting: _____ Date: _____

SECTION 3: NOTICE OF YOUR RIGHT TO DECLINE PARTICIPATION IN FUTURE ANONYMOUS OR CODED GENETIC RESEARCH

TO BE COMPLETED BY THE INDIVIDUAL BEING TESTED.

_____ (NAME OF HEALTH CARE PROVIDER)

The State of Oregon has laws to protect the genetic privacy of individuals. These laws give you the right to decline to have your health information or biological samples used for research. A biological sample may include a blood sample, urine sample, or other materials collected from your body. You can decide whether to allow your health information or biological samples to be available for genetic research. Your decision will not affect the care you receive from your health care provider or your health insurance coverage.

Research is important because it gives us valuable information on how to improve health, such as ways to prevent or improve treatment for heart disease, diabetes, and cancer. Under Oregon law, a special team reviews all genetic research before it begins. This team makes sure that the benefits of the research are greater than any risks to participants.

In anonymous research, personal information that could be used to identify you, like your name or medical record number, cannot be linked to your health information or biological sample. In coded research, personal information that could be used to identify you is kept separate from your health information or biological sample so it would be very difficult for someone to link your personal information to your health information or biological sample. Your identity is protected in both types of research.

If you want to allow your health information and biological sample to be available for anonymous or coded genetic research, you don't have to do anything. If you make this choice, your health information or biological sample may be used for anonymous or coded genetic research without further notice to you.

If you want to decline to have your health information and biological sample available for anonymous or coded genetic research, you must tell your health care provider by:

- Completing this form and giving it to your health care provider
- Completing this form and mailing it to your health care provider the address provided

Your decision is effective on the date your health care provider receives this form.

If you have any questions or concerns about this notice, please contact your health care provider.

No matter what you decide now, you can always change your mind later. If you change your mind, tell your health care provider your decision in writing by a means indicated by your health care provider. If you change your mind, the new decision will apply only to health information or biological samples collected after your health care provider receives written notice of your new decision.

- I decline to have my health information and biological samples available for anonymous or coded genetic research.

Printed Name: _____ Date of Birth: _____

Signature: _____ Date: _____