



NOTICE OF YOUR RIGHT TO REFUSE PARTICIPATION IN FUTURE ANONYMOUS AND/OR CODED GENETIC RESEARCH

The State of Oregon has laws to protect the genetic privacy of individuals. These laws give you the right to refuse 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 review board reviews all genetic research before it begins. This team makes sure that the benefits of the research are greater than any risks to participants. With the exception of anonymous or coded research, use of your health information or biological samples for genetic research requires your specific written consent.

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 refuse 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; or
- Completing this form and mailing it to Health Information Services, 3181 SW Sam Jackson Park Rd., Mail Code: OP-17NP, Portland, OR 97239-3098.

If you refuse, your decision becomes effective on the date OHSU receives this form.

No matter what you decide now, you can always change your mind later. If you change your mind, complete this form and mail it to the address provided above. If you change your mind, the new decision will apply only to health information or biological samples collected after OHSU receives this completed form.

If you have any questions or concerns about this notice, please contact the OHSU Integrity Office at 503-494-8849.

By checking this box and signing below I refuse to have my health information and biological samples available for anonymous and/or coded genetic research.

(Printed Name of Patient)

Date: _____

(Signature of patient or personal representative)

Description of personal representative's authority (if applicable): _____

The following information is needed to process this form. If there is already information in the upper right hand corner of this form indicating your correct information, you do not need to complete the following; however, please correct any incorrect information.

Patient Date of Birth

Patient Medical Record Number