

## Genetic Information and Research Informed Consent and Right to Decline

Place Patient Label Here

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 <u>anonymous research</u>, 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 <u>coded research</u>, 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 do not want to have your health information and biological sample available for anonymous or coded genetic research, you must tell Samaritan Health Services by checking the box on this form. Your signature is required proof that you received this "Notice of Your right to Decline Participation in Future Anonymous or Coded Genetic Research".

Your decision is effective on the date Samaritan Health Services receives your response and can be made now during this patient registration process or at a later time by sending an e-mail to <a href="mailto:privacy@samhealth.org">privacy@samhealth.org</a> or letter, including your mailing address, to:

Samaritan Health Services Attn: <u>SHS</u> Privacy Officer 3600 NW Samaritan Drive Corvallis, Oregon 97330

If you have any questions or concerns about this notice, please contact the SHS Privacy Officer by phone at (541) 768-6218 or by e-mail at <a href="mailto:privacy@samhealth.org">privacy@samhealth.org</a>.

No matter what you decide now, you can always change your mind later. **If you change your mind,** you will need to fill out a new form and e-mail it or 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 SHS receives the new form.

Opt-Out Statement		
	Checking this box means that I <u>DO NOT</u> give permission to have my health information and biological samples available for anonymous and/or coded genetic research.	
I acknowledge receipt of the "Notice of Your Right to Decline Participation in Future Anonymous or Coded Genetic Research".		
(Printed I	Name of Patient)	
(Signatur	re of patient or personal representative)	(Date)
Description	on of personal representative's authority (if applicable).	