Genetic Privacy Notice

Notice of Your Right to Decline Participation in Future Anonymous or Coded Genetic Research

Providence Health & Services is required by Oregon law to provide this notice to you regarding use of your health information or biological samples for genetic research. State laws protect the genetic privacy of individuals and 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 either 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 better treat 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, such as your name, Social Security number 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, making it very difficult 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 your health care provider** by:

- Completing the Genetic Privacy Opt Out form, and
- Giving or mailing the form to your health care provider.

The Genetic Privacy Opt-Out form can be obtained from your health care provider, and the Genetic Privacy Notice can be viewed or printed from this Providence Web site: www.providence.org/geneticprivacy

No matter what you decide now, you can always change your mind later by completing a form and returning it to your health care provider. Your new decision is effective on the date your health care provider receives the Genetic Privacy Opt Out form, and will apply only to health information or biological samples collected **after** your health care provider receives the form.

If you have questions about this Genetic Privacy Notice, please call toll free 1-888-231-4697 or write to:

Privacy Officer  
Providence Health & Services  
PO Box 2987  
Portland, OR 97208