



## Genetic Privacy Notice



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

The Children's Clinic of Klamath is required by Oregon law to provide this notice to you regarding the use of your health information or biological samples for genetic research (OAR 333-025-0100-333-025-0165). State law protects the genetic privacy of individuals and gives 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. The 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 **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, signing and returning the form as directed by your clinic representative.

#### GENETIC PRIVACY OPT OUT STATEMENT

I have read and understand the above Genetic Privacy Notice and I **DO NOT** want to have my or my child's health information and biological samples available for anonymous or coded genetic research.

Patient Name: \_\_\_\_\_ Date of Birth: \_\_\_\_\_

Patient or personal representative printed name: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Relationship to patient: \_\_\_\_\_

If you want to allow your health information and biological sample to be available for anonymous or coded genetic research and make this choice, your health information or biological sample may be used for anonymous or coded genetic research without further notice to you.

No matter what you decide now, you can always change your mind later by completing this 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 Genetic Testing, please call the Oregon Genetics Program at 971-673-0271.

This form will be retained in your medical chart throughout your relationship with The Children's Clinic of Klamath.

Sincerely,

The Children's Clinic of Klamath