

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

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 make this request in writing by completing

a notice to decline form on the bottom of this page. You may complete this form and return to receptionist or mail the completed document to the address provided on the form.

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 our office.

No matter what you decide now, you can always change your mind later. If you change your mind, you will need to communicate your decision to us in writing by sending us a letter addressed to:

The Portland Clinic, LLP,
Attn: Genetic Testing Authorization
800 SW 13th Ave, Portland OR 97205.

If you change your mind, the new decision will apply only to health information or biological samples collected after we have received written notice of your new decision.



NOTICE TO DECLINE to have your health information and biological sample available for anonymous or coded genetic research.

Printed Name

Street Address

City

State

Zip

Date of Birth (MM/DD/YYYY)

Signature

Date

Fact Sheet for Health Care Consumers

Genetic Privacy & Research

Oregon's first genetic privacy laws were passed in 1995 with a goal of trying to help protect your genetic information and prevent possible employment or insurance discrimination to health care consumers like yourself.

In 2005, a few changes were made in Oregon laws about when results of a genetic test, specimens collected (such as blood or tissue), or health care information may be available for certain types of genetic research. You will be asked to make decisions about this starting in 2006.

WHAT IS THE SAME?

- If genetic test results, specimens collected or health care information can be linked to you (for example if it includes your name or address or birth date) the researcher must still get your permission before using this information for genetic research.

WHAT IS NEW?

- If genetic test results, specimens collected or other health care information does not include any information that can be linked to you (or there is only a code and the key to the code is kept separately) the new law allows researchers to access these and ask permission of an independent review board (called an IRB) to use the test results, specimens collected or health care information for what is called "anonymous" or "coded" genetic research.
- The new law requires you to make a decision regarding use of your health information in anonymous or coded genetic research.
- As a result, starting July 1, 2006, the new law requires that your doctor or health care provider give you notice and asks you to complete a form at least once and mark if you **DO NOT** want any of your specimens or health care information available for anonymous or coded genetic research. This is often called an "opt-out" form.

WHY WAS THE CHANGE MADE?

- Many people want to keep their health care information, including their genetic information, private. Many people also recognize that medical and genetic research

can help develop new information that allows both patients and doctors to learn more about diseases, make good health care decisions, and discover new treatments.

- The new law tries to balance the interests of those who want to keep their genetic information private by allowing them to make a decision to "opt-out" while allowing researchers to do genetic research needed to make good health care decisions by you and your health care providers.

WHAT DO I NEED TO DO?

- You will need to make a personal decision on whether your genetic test results, specimens collected or health care information will be available for anonymous or coded genetic research.
- If you **DO NOT** want your results of a genetic test, specimens collected or health care information available for anonymous or coded genetic research you must mark that place on the form provided by your doctor or health care provider.
- If you **DO** want the results of a genetic test, specimens collected, or your health care information available for anonymous or coded genetic research, you don't need to do anything.
- In either case, your health care provider is responsible for providing a notice and form for you to mark. This only needs to happen once, not at every visit.
- If you change your mind in the future, it is **YOUR** responsibility to inform your health care provider and it would only affect results of genetic tests, specimens collected or health care information from that date forward.

WHERE CAN I GET MORE INFORMATION?

Talk to your doctor or health care provider.
The Oregon Genetics Program (971) 673-0271 or
www.oregongenetics.org.

Printable version available from www.oregongenetics.org