



Oregon Health & Science University
Hospitals and Clinics
Health Information Services/
Medical Correspondence
3181 SW Sam Jackson Park Rd,
Mail Code: OP17A
Portland, OR 97239-3098
(503) 494-8521, Fax (503) 494-6970

ACCOUNT NO.
MED. REC. NO.
NAME
BIRTHDATE

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Patient Identification

HOW TO OPT-OUT OF PARTICIPATION IN FUTURE TISSUE AND GENETIC RESEARCH

NOTICE OF YOUR RIGHT TO DECLINE TO PARTICIPATE IN FUTURE RESEARCH, INCLUDING ANONYMOUS OR CODED GENETIC RESEARCH

OHSU is a research institution. One of our missions is to provide breakthroughs for better health. Research is an important part of our mission because it helps us learn ways to prevent or better treat diseases such as diabetes and cancer. Oregon and federal laws protect your rights to privacy when it comes to research. You have the right to decide whether to allow us to store and use your biological samples (such as tissue, blood, or body fluids) in future research and to use your biological samples and health information in future anonymous or coded genetic research.

How are biological samples used in research?

At times you may need to have a procedure, treatment or tests done as part of your care at OHSU. We may need to take biological samples from you as part of the procedure, treatment or tests. If we have any leftover samples after using your biological samples for your care, you can choose to allow OHSU to store them for use in future research. For example, if you have surgery and we send your tissue to the lab for tests, you could agree to have any extra tissue stored and used later for research.

If you allow us to store your biological samples, you are also letting us use them for research and for anonymous or coded genetic research, along with your health information. The samples may be used by OHSU and others outside of OHSU who we work with. This may include companies that do research to develop products such as drugs and diagnostic tests. Your biological samples and health information may be used to make a discovery that could be profitable to OHSU or another company. You will not be financially compensated if this happens. However, you will not be responsible or liable for any use made of your biological samples or health information.

What is anonymous or coded genetic research?

We can also use these biological samples and health information in anonymous or coded genetic research, if you choose. For example, researchers could run genetic tests on your remaining samples to study the role our genes play in illness. We may learn why some people get sick and others don't, or what can prevent disease before it happens. Researchers may be able to use what they learn to develop new tests, find new ways to treat and diagnose disease, and make new products and medicines. For more information go to www.healthoregon.org/genetics

Your genetic information is personal. We follow the law to protect your privacy. If you agree to make your biological samples and health information available for future anonymous or coded genetic research, OHSU will use and disclose your samples in a way that is either anonymous or coded, to protect your identity.

- Anonymous research: Your identity cannot be linked to your samples or health information.
- Coded research: Your identity is kept separate from your samples or health information.





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Is research at OHSU safe and ethical?

Yes. Federal law requires research institutions like OHSU to have an Institutional Review Board to review research before it begins. They make sure that all research at OHSU is safe and ethical by federal and state standards. The State of Oregon also has laws to protect the genetic privacy of individuals. These laws give you the right to refuse to have your biological samples or health information used for anonymous or coded genetic research. You can also choose to not allow use of your extra biological samples for any other future research. Your decision either way will not change the care you get from your health care provider or OHSU.

How do I participate or opt-out of future research?

If you agree to allow your biological samples to be stored and used in future research and your biological samples and health information to be used in future anonymous or coded genetic research, you do not have to do anything. If you make this choice, your biological samples may be stored and used in future research, and your biological samples and health information may be used in anonymous or coded genetic research without further notice to you.

If you do NOT want to have your biological samples stored and used for future research or your biological samples and health information used in future anonymous or coded genetic research, please answer the questions below and give this form to your OHSU provider, or send to:

OHSU Health Information Services
3181 S.W. Sam Jackson Park Rd. Mail Code OP-17A
Portland, OR 97239-3098.

Your decision to not participate will be effective the date your provider receives this form. If you change your mind later, write to your provider or send in a new form. The changes will apply to any health information and samples that we collect after we get your new written notice.

By checking the box and signing below, I am NOT allowing the use of my biological samples or health information, as follows:

- ☐ I do NOT want my extra biological samples stored and used for future research.
- ☐ I do NOT want my health information and extra biological samples to be used for anonymous or coded genetic research.

Printed Name of Patient: _____

Address: _____

City, State, ZIP: _____

Date of Birth: _____

Printed Name of Legally Authorized Representative (if applicable): _____

Signature of Patient or Legally Authorized Representative _____

Date: _____

If you have questions or want more information about anything in this notice, please call
503-494-8020 Option 1 or visit Oregon Health Authority Genetics and Privacy page
<https://www.oregon.gov/oha/ph/diseasesconditions/geneticconditions/pages/research.aspx>