Are there risks to genetic testing?

Genetic test results may become known to other people or organizations, particularly those that have legal access to patient medical records, such as health insurance companies and employers that provide health coverage.

In the U.S., the Genetic Information Nondiscrimination Act (GINA) provides some protection from discrimination based on genetic information. Health insurers are prohibited from using genetic information to determine eligibility or prices. Employers are barred from using genetic information in hiring decisions. But the federal law does not cover members of the military, and it does not apply to life insurance, disability insurance, or long-term care insurance. Oregon has an additional genetic privacy law, but neither the federal nor state laws can guarantee protection from discrimination in all circumstances.

All of the privacy concerns raised by genetic testing must be considered and managed in order for the public to benefit fully from new scientific studies of cancer genetics.

For information about heritable cancers and genetic testing, please visit **healthyoregonproject.com** or email **healthyoregonproject@ohsu.edu**

Federal protections for genetic testing: **ginahelp.org**

State protections for genetic testing: **oregonlegislature.gov/lpro/publications/gen**

OHSU

Who are we?
We are a team of geneticists, community outreach specialists, scientists and genetic counselors at OHSU.

IRB #18473
Investigators: Paul Spellman, Ph.D. and Jackie Shannon, Ph.D, R.D., M.P.H.I.

OHSU KNIGHT CANCER INSTITUTE

SPIT SPOT

HEALTHY OREGON PROJECT (HOP)

OHSU

Why are we conducting this study?

The goal of the Healthy Oregon Project (HOP) is to learn how a person's genetics, environment and behavior can affect their risk for long-term diseases and conditions, including cancer. To do this, HOP will assemble a group of people living in Oregon (and beyond) and invite them to share information about themselves with our researchers. HOP is a partnership between many different health and research groups in Oregon.

What are we asking participants to do?

- Consent to participate in this study by using our mobile app for Android or iPhone.
- Submit an optional DNA sample by swishing with Scope® mouthwash for 60 seconds.
- Complete optional surveys about your health and habits to aid us in early detection research and allow us to follow your health for as long as you choose to participate in the study.
- Choose your results. We will return genetic results to you that will identify whether you may have an inherited genetic abnormality that may put you at a higher risk of developing cancer in the future. You may choose not to receive these results and only have them used for research, or not to submit a sample at all. Whatever you choose to do — fill out surveys or submit DNA — it is your choice, and entirely optional.
- Allow this study to:
  - » Use your samples to analyze your data for research on cancer and other genetic diseases.
  - » Share your de-identified samples and data with other approved researchers for other health studies.
  - » Contact you with other research opportunities and studies that you may be interested in.

What is genetic testing?

Genetic testing uses laboratory methods to look at your genes, which are the DNA instructions you inherit from your parents. This information helps identify increased risk of health conditions, and helps you choose possible prevention measures (such as imaging and, in rare cases, surgical procedures) that may decrease risk of developing cancer.

Why test?

About 5–10% of cancers are inherited, meaning they can be passed down by family members. With the advent of genetic testing, it's possible to look at a person's DNA and determine whether there is an elevated risk for heritable cancers. With this information, you can take action earlier to prevent or identify cancer at its earliest stages, when it is most curable.

What common heritable cancer syndromes can be detected?

Hereditary breast and ovarian cancer (HBOC). Families with HBOC have an increased risk for breast, ovarian, prostate, and pancreatic cancers. The genes associated with HBOC are BRCA1 and BRCA2.

Lynch syndrome. Families with Lynch syndrome have an increased risk for colorectal, uterine, stomach, and ovarian cancers. The genes associated with Lynch syndrome are MLH1, MSH2, MSH6, PMS2 and EPCAM.

Familial adenomatous polyposis (FAP) and attenuated FAP (AFAP). Families with FAP or AFAP have an increased risk for colorectal, small bowel, pancreatic and thyroid cancers. The gene associated with FAP and AFAP is APC.