PUBLIC HEALTH DIVISION
Screenwise
Kate Brown, Governor

Oregon Health Authority

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Portland, OR 97232
Voice: (971) 673-0273
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www.healthoregon.org/screenwise

NAME
ADDRESS1
ADDRESS2
CITY, ST ZIP

DATE

Regarding: Lynch Syndrome (LS) Survey and Resources

Dear «FirstName» «LastName»,

Please help ScreenWise, an Oregon Health Authority program, by taking the enclosed survey. Your answers will help us to improve the information that we share with Oregon health care providers. We are hopeful that it will also help save lives.

Please complete the survey by **Friday, November 9, 2018**. If you do so, you will receive a $15 Amazon gift card as a thank you for your prompt reply.

There are three ways to take this survey:

1. By mail: Please return your survey in the postage paid envelope enclosed.
2. Online: www.surveymonkey.com/r/hpeswls
3. By phone: Call ScreenWise at 971-673-0273 to schedule a time to complete the survey with a ScreenWise staff member.

You received this letter because according to Oregon State Cancer Registry data from 2009-2014, you have seen patients with any of the following:

- Colorectal or endometrial cancer diagnosed before age 50
- Two or more LS-related cancers diagnosed at any age
    - These are LS-related cancers: colorectal, endometrial, gastric, ovarian, pancreatic, ureter and renal pelvis, biliary tract, brain (usually glioblastoma), small intestine, keratoacanthomas, sebaceous adenoma and sebaceous carcinomas.

These patients may be at high-risk of having LS. They meet National Comprehensive Cancer Network guidelines for a formal cancer genetic risk assessment for LS by a genetic specialist. We have also sent an informational packet to these patients about LS. Some patients may want to discuss this information with you.

(**Continued on back**)

Oregon Health Authority

Lynch Syndrome
Health Care Provider Survey

Thank you for taking our survey!

Please return the finished survey by **Friday, Nov. 9, 2018.**

OHA 9295B (09/2018)

Lynch Syndrome Healthcare Provider Survey

Why did I get this survey?

ScreenWise, an Oregon Health Authority program, created this survey. Your answers will help us to tailor education materials for health care providers who diagnose and care for patients with hereditary cancer.

How can I complete the survey?

1. By mail: Please return your survey in the postage paid envelope enclosed.
2. Online: **www.surveymonkey.com/r/hpeswls**
3. By phone: Call ScreenWise at 971-673-0273 to schedule a time to complete the survey with a ScreenWise staff member.

How long will it take?

The survey will take about 5 minutes. Some people take more time, others less.

When do I need to return it?

Please return the finished survey by **Friday, Nov. 9, 2018**. If you do so, you will receive an electronic $15 Amazon gift card as a thank you for your prompt reply. Please provide your email address below if you are completing the survey and would like to receive the gift card.

Email:

When do I get to see the findings of this project?

We will put a summary of the results for this project on the Hereditary Cancer Awareness Project webpage at **http://www.healthoregon.org/genetics** by **Feb. 28, 2019**.

1. Please indicate your practice specialty. (*Check all that apply*)

- ☐ Colorectal surgery
- ☐ Family medicine
- ☐ Gastroenterology
- ☐ General surgery
- ☐ General practice
- ☐ Internal medicine
- ☐ Medical genetics
- ☐ Obstetrics and gynecology
- ☐ Gynecologic oncologist
- ☐ Oncology
- ☐ Other(s) (*please name*):

2. What medical credential(s) do you have? (*Check all that apply*)

- ☐ DO
- ☐ MD
- ☐ ND
- ☐ NP
- ☐ PA
- ☐ Other (*please name*):

3. Indicate whether you agree or disagree with the following statements

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
a. I learned something new in the packet about Lynch syndrome.					
b. I will change my clinical practice based on the information I learned from the packet.					
c. I believe this information will be useful for other health care providers.					

4. What was the most helpful information in the packet?

5. What other information would have been helpful?

6. What feedback or comments do you have for us?

That is all of our survey questions. Thanks so much for your help!

If you have any questions, please contact Summer Lee Cox, ScreenWise genetics coordinator, at 971-673-0273 or **Summer.L.Cox@dhsoha.state.or.us.**

ScreenWise website: **http://www.healthoregon.org/screenwise**
More information about hereditary cancer: **http://www.healthoregon.org/genetics**

Please return the finished survey by **Friday, Nov. 9, 2018.**

Background information about LS and board-certified cancer genetic specialists in Oregon is enclosed. When appropriate, please consider referring your patients to genetic counseling for cancer genetic risk assessment.

We will put a summary of the results for this project on the Hereditary Cancer Awareness Project webpage at http://www.healthoregon.org/genetics by **February 28, 2019**.

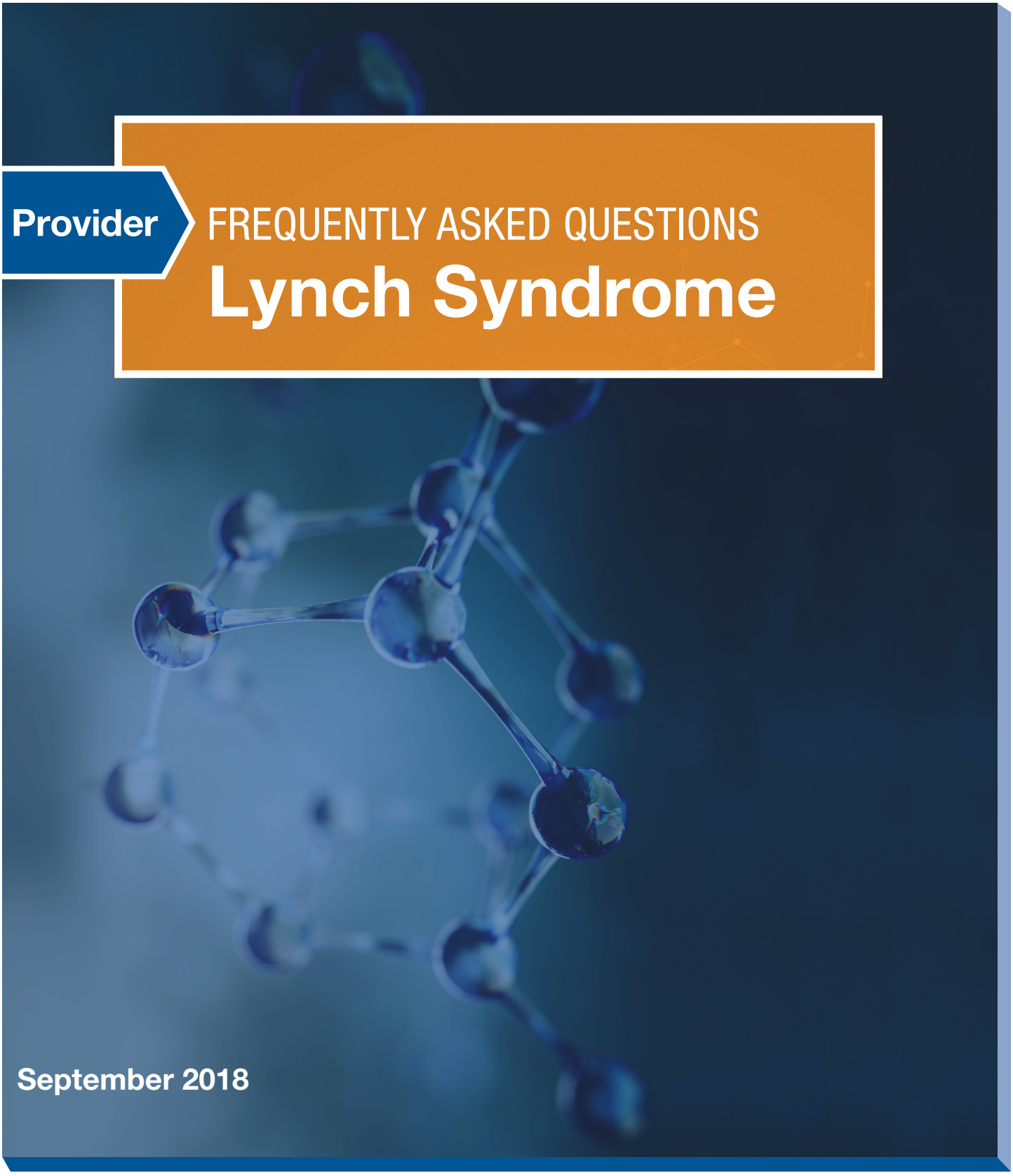
Thank you for taking the time to help us learn more about the use of and communication about LS genetic services in Oregon. Please let us know if you have questions or comments about this project.

Sincerely,

Summer Lee Cox, MPH
ScreenWise genetics coordinator
971-673-0273
summer.l.cox@dhsoha.state.or.us

Jasmin Griggs, BA
ScreenWise genetics program analyst

ScreenWise website: http://www.healthoregon.org/screenwise
Genetic conditions website: http://www.healthoregon.org/genetics



Provider

FREQUENTLY ASKED QUESTIONS

Lynch Syndrome

September 2018

PUBLIC HEALTH
ScreenWise

Oregon Health Authority

Table of Contents

How do I gauge patients' personal and family history of cancer and help save lives?

There are three key parts to collecting cancer family history:

1 Who had cancer?

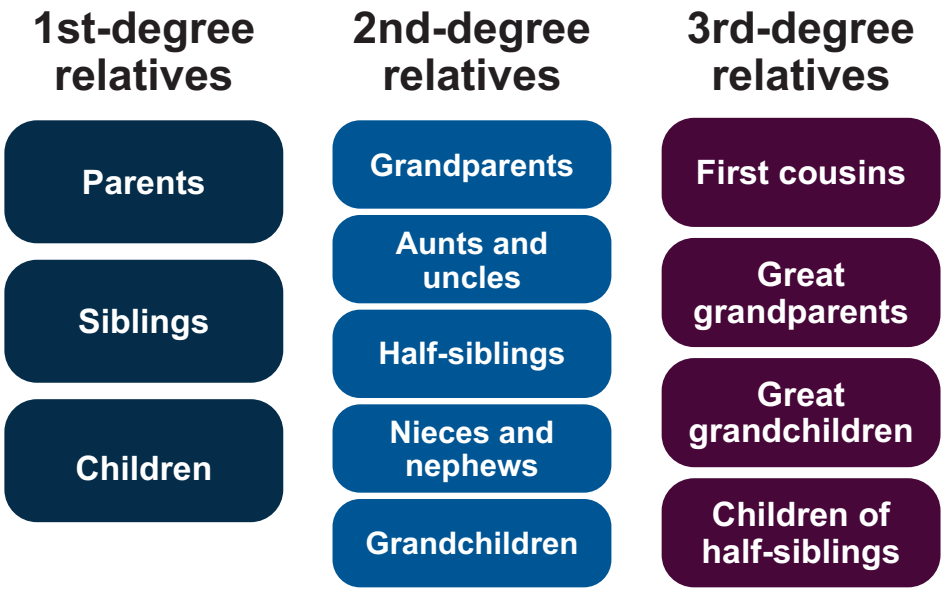
- » Relationship (e.g., patient, full or half-sibling, aunt, etc.)
- » Lineage (maternal or paternal side)
- » Multiple generations (three generations are best)

2 What was the location of the primary cancer?

- » Get as much information as possible about the cancer

3 What was the age of the relative at diagnosis?

- » In general, screening should start at or before the age of earliest onset of a particular cancer in the family



NOTE: Without intervention, people with Lynch syndrome (LS) are at higher risk of developing early and aggressive cancers than people in the general population.

Other helpful family history information to get for patient and relatives includes:

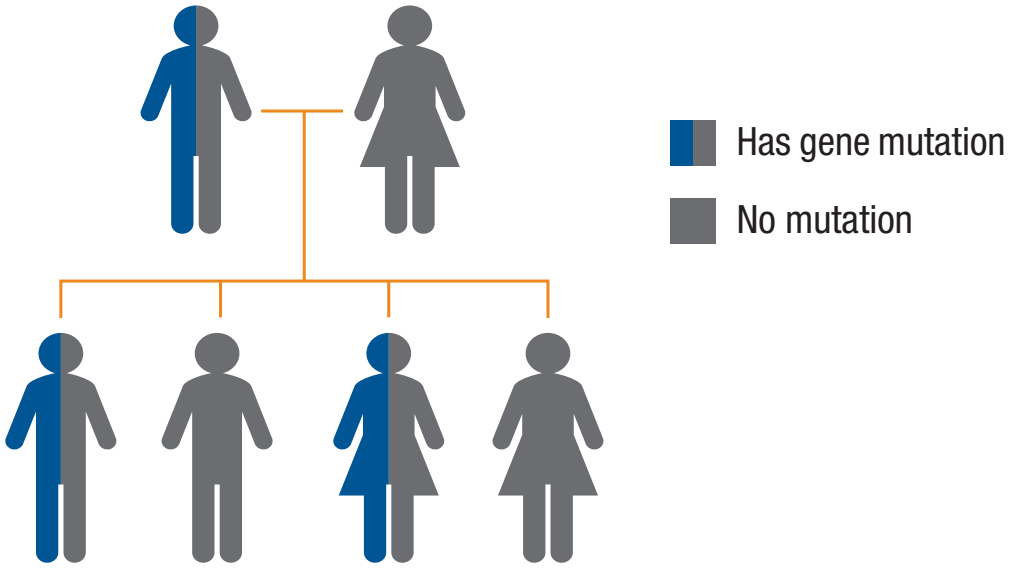
- Date and place of birth
- Age at time of death
- Cause of death
- Ethnicity (some genetic diseases are more common in certain ethnic groups)
- Presence of chronic diseases and major medical conditions
- Information about habits, such as exercise, smoking, alcohol consumption and diet

NOTE: **Be sure to ask your patients to update this information regularly.**

How are hereditary cancer syndromes inherited?

Hereditary cancer syndromes generally follow an autosomal dominant inheritance pattern. This is where an affected individual has:

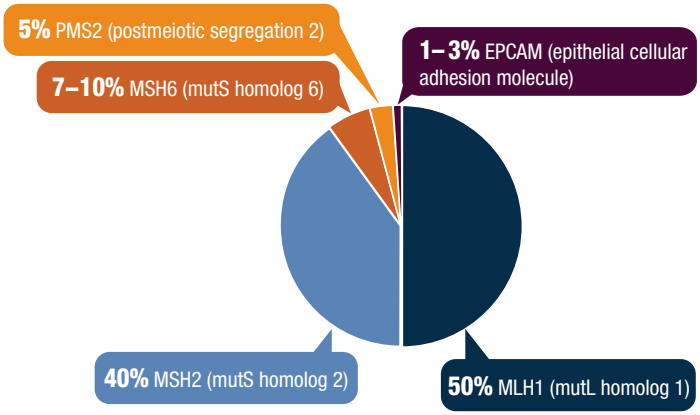
- One copy of a normal gene on a pair of autosomal chromosomes
- One copy of a gene with a harmful mutation
  - » The harmful mutation can be passed from mother or father. All first-degree relatives of someone with a harmful mutation have a 50 percent chance of also having it. Having the harmful mutation increases the risk of developing certain cancers.



Mutations that commonly cause LS

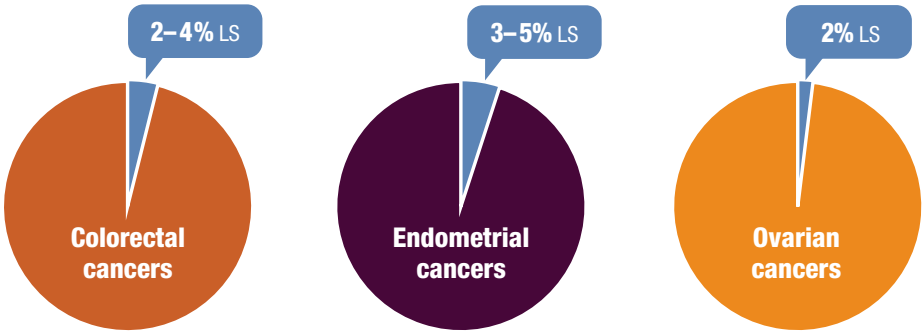
Most LS-related cancers are due to mutations in four DNA mismatch repair genes (MLH1, MSH2, MSH6, and PMS2) or the EPCAM gene, which can interfere with MSH2. When working normally, DNA mismatch repair genes find and fix DNA mistakes and damage. A harmful mutation in any DNA mismatch-repair gene or EPCAM will significantly increase patients' lifetime risks for developing LS-related cancers. The proportion of LS-related cancers due to mutations in these five genes are as follows:

CHART 1 **Common genes involved in LS-related cancers** (1)



How common are these harmful mutations?

Estimates suggest that one in every 300 people may have Lynch syndrome — though most people with LS remain undiagnosed. Think about the time frame in which you see 300 patients. Make sure you have a system to identify people likely to have LS.

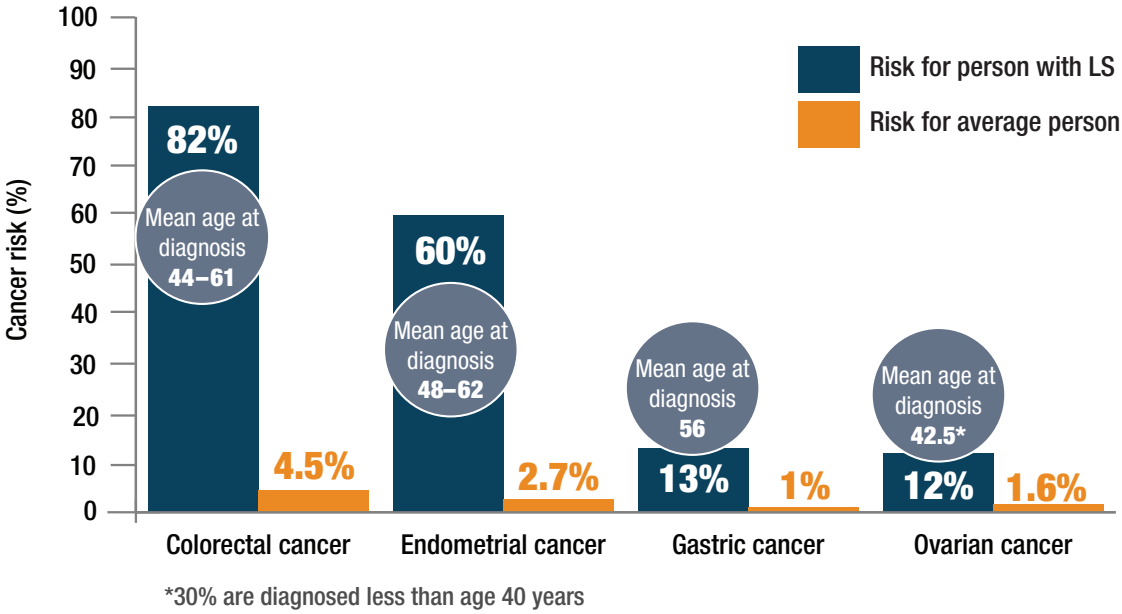


Lynch syndrome (LS) accounts for about 2–4 percent of all colorectal cancers, 3–5 percent of all endometrial cancers and about 2 percent of all ovarian cancers (2).

Lynch syndrome causes an increased risk for many cancers

The highest risks are for colorectal, endometrial, gastric and ovarian cancers. The following chart shows the maximum lifetime risk for individuals with LS compared to that of an individual at general population risk (1).

CHART 2 **Maximum lifetime risk for individuals with Lynch syndrome compared to lifetime risk for individuals at average risk** (1)



*30% are diagnosed less than age 40 years

NOTE: People with LS are at risk for developing other LS-related conditions at a rate substantially higher than the general population.

People with LS often (1)**:**

- Develop multiple primary cancers
- Develop cancers at a younger age
- Have cancers that are aggressive

LS-related cancers include (2)**:**

- Colorectal
- Endometrial
- Gastric
- Ovarian
- Pancreas
- Ureter and renal pelvis
- Brain (usually glioblastoma)
- Small intestinal cancers

LS-related conditions can also include (2)**:**

- Sebaceous adenoma
- Sebaceous carcinomas
- Keratoacanthomas, as seen in Muir-Torre syndrome

How can I take action?

You can identify your patients who have an increased risk for hereditary cancers and help them understand their risk for developing hereditary cancers and ways to prevent or catch cancer early, by:

- Making referrals to genetic counseling and working with board-certified genetic specialists
- Creating and implementing personalized cancer surveillance and risk reduction plans for your patients
- Helping your high-risk patients get enhanced screening according to guidelines
- Encouraging your patients to practice risk reduction through lifestyle behaviors, such as those listed in the "How can patients lower their risks?" section
- Encouraging your patients to be aware of changes in how parts of their body normally function or feel. Have them let you know if they are experiencing signs of cancer or unintentional changes in their body

For patients at risk of hereditary cancers it's important to be aware of changes in how parts of their body normally function or feel. Many signs of endometrial and ovarian cancer can be vague and non-specific. So, it is especially important for patients at risk to be aware of body changes.

Signs of endometrial cancer include:

- Unusual vaginal bleeding, spotting, or other discharge
- Abnormal Pap test results
- Difficulty or pain when urinating
- Pelvic pain or pain during sex

Signs of ovarian cancer include:

- Bloating
- Difficulty eating or feeling full quickly
- Pelvic or abdominal pain
- Urinary symptoms (urgency or frequency)

Ask your patients to look for any of the above. Have them talk with you if they have any condition that does not improve. Especially, if they do not see an improvement by eating healthier, exercising more, using OTC medications, and getting more rest.

A board-certified genetic specialist is trained to talk with people about genetic and non-genetic risk and can:

- Ensure patients make fully informed choices
- Help identify if genetic testing may be a good choice for the patients and their family
- Ensure the right tests are ordered and the results interpreted correctly
- Identify what types of cancer tests and screenings are right for the patient and how often to get them
- Identify activities that may help lower the patient's chance of developing a new cancer

Genetic counseling can help people make fully informed health care decisions and life choices

Any of the following meet criteria for referral to genetic counseling (2)

- Colorectal cancer and more than 10 adenomas
- Colorectal or endometrial cancer diagnosed before age 50
- Two or more LS-related cancers diagnosed at any age
- Colorectal or endometrial cancer with an absence of microsatellite instability (MSI) or immunohistochemistry (IHC) proteins
- Colorectal or endometrial cancer diagnosed at any age and a LS-related cancer diagnosed in two first- or second-degree relatives at any age
- A known mutation in the family
- PREMM$_{1,2,6}$ score of 5 percent or more, with or without cancer
- One or more first-degree relatives diagnosed with colorectal or endometrial cancer before age 50
- One or more first-degree relatives diagnosed with colorectal or endometrial cancer and another LS-related cancer
- Two or more first- or second-degree relatives diagnosed with a LS-related cancer, with at least one diagnosed before age 50
- Three or more first- or second-degree relatives with a LS-related cancer
- One or more first-degree relatives diagnosed with polyposis

Does health insurance pay for genetic counseling and testing?

Most health insurance plans cover cancer genetic counseling and testing for people with signs of Lynch syndrome. Board-certified genetic specialists are experts that can help patients figure out the payment and deal with insurance issues. They can check what patients' insurance covers. They know how to help get patients the right care that is affordable, no matter what their insurance is.

What if patients don't have health insurance to pay for genetic counseling and testing?

Board-certified genetic specialists are experts at helping patients get and pay for the care they need. In addition, many testing labs help people who are uninsured or who have high-deductible plans. There are also organizations that can help your patients cover the cost of genetic counseling and testing if they are uninsured or their insurance does not cover it. For example, Patient Advocate Foundation has information, resources and assistance. They help support health care access and solve insurance issues (**http://www.patientadvocate.org**).

NOTE: Almost all Oregon health insurance plans cover cancer genetic counseling and testing for people with signs of Lynch syndrome.*

Oregon Health Plan:

- Covers cancer genetic counseling and testing for people with signs of LS.
- Services are covered according to the National Comprehensive Cancer Network Guidelines.

* Your patients' health insurance companies may require in-network providers. They may also have other rules about how to access qualifying care. Please remind your patients to check with their insurance companies to find out what their plans cover and if specific requirements must be met.

Where are the board-certified cancer genetic specialists?

These clinics currently offer cancer genetic counseling by board-certified genetic specialists.

Location	Institution	Genetic counseling providers	Phone number	Consultation type
Eastern Oregon (Boise, Idaho)	Saint Alphonsus "St. Al's" Cancer Care Center	St. Al's and Huntsman Cancer Institute	208-367-3131	Face-to-face (at St. Al's) Telephone (Huntsman Cancer Institute)
Eugene/ Springfield	Willamette Valley Cancer Institute and Research Center (currently for established patients only)	Compass Oncology, Genetic Risk Evaluation and Testing (GREAT) program	503-297-7403	Live video screen
Medford	Asante Rogue Regional Medical Center's Infusion Services	OHSU, Knight Cancer Institute, Genetic Counseling and Risk Assessment	541-789-5006	Live video screen
Portland metropolitan area	Compass Oncology (Compass)	Compass, Genetic Risk Evaluation and Testing (GREAT) program	503-297-7403	Face-to-face
Portland metropolitan area	Kaiser Permanente Northwest (KPNW — Kaiser members only)	KPNW, Department of Medical Genetics	503-331-6593 or 1-800-813-2000 Ext. 16-6593	Face-to-face Telephone
Portland metropolitan area	Legacy Health, Good Samaritan Medical Center, Comprehensive Cancer Center	Legacy Genetic Services	503-413-6534 or 1-800-220-4937 Ext. 6534	Face-to-face

Location	Institution	Genetic counseling providers	Phone number	Consultation type
Portland metropolitan area	OHSU, Knight Cancer Institute (OHSU KCI)	OHSU KCI, Genetic Counseling and Risk Assessment	503-494-9300	Face-to-face
Portland metropolitan area	Providence Health and Services, Oregon and Southwest Washington (Providence)	Providence, Genetic Risk Clinic	503-215-7901	Face-to-face
Salem	Kaiser Permanente Northwest (KPNW — Kaiser members only)	KPNW, Department of Medical Genetics	503-331-6593 or 1-800-813-2000 Ext. 16-6593	Face-to-face Telephone
Salem	Salem Health Hospitals and Clinics	Cancer Risk Assessment and Genetic Counseling	503-814-3214	Face-to-face

NOTE: **Visit the National Society of Genetic Counselors website at www.nsgc.org to:**

- Get more information about genetic counseling
- Find a genetic counselor near you

How can patients lower their risks?

Studies have shown that people can take action to catch cancer early. They can also lower their chances of getting cancer. These things are possible, even if they don't get genetic testing.

Lowering patient risks

Earlier and more screenings

Patients with LS may benefit from starting colon cancer screening at age 20–25 years or 2–5 years prior to the age of the earliest colon cancer diagnosis in the family, whichever is earliest.

There is no standard or routine screening test for endometrial, ovarian or stomach cancer. However, the NCCN provides evidence-based Lynch syndrome management guidelines. (www.nccn.org) (2)

Exercise

As an adult, it is healthiest to exercise in either of the following amounts each week, if possible:

- Moderate energy — 150 minutes or more
- A lot of energy — 75 minutes or more
  - » In general, a patient using moderate energy can talk, but not sing. A patient using a lot of energy will not be able to say more than a few words without stopping for a breath. (3)

Weight control

A patient's healthiest waist size will measure between 40 percent and 50 percent of their height. For example, if a patient is 5-feet (60 inches) tall, their waist size is healthiest if it measures less than 30 inches and more than 24 inches. (2,3,4,5)

NOTE: **For more information about being and staying healthy,** visit the Oregon Health Authority, Public Health Division Healthy People and Families page at **http://oregon.gov/oha/ph/HealthyPeopleFamilies**.

Limit alcohol consumption

As an adult, it is healthiest to consume less than one drink per day. (2,6)

Don't use tobacco

It is healthiest to not use tobacco products. A patient who uses tobacco can call the Quit for Life® Program. There is telephone and web-based counseling to help the patient quit using tobacco and nicotine products. The phone line is open 24 hours a day, seven days a week. (3,7)

English
1-800-QUIT-NOW
1-800-784-8669
quitnow.net/oregon
quitnow.net/oregonsp

Spanish
1-855-DEJELO-YA
1-855-335356-92
quitnow.net/oregonsp

TTY:
1-877-777-6534

Risk reduction (prophylactic) medication

Data suggests that aspirin may decrease the risk of colon cancer in LS. However, the optimal dose and duration of aspirin therapy are uncertain. (2) Risk reduction agents for other cancers may be an option. (2)

Risk reduction (prophylactic) surgery

Some preventive surgeries may be an option for some patients with LS. (2)

Genetic privacy and anti-discrimination laws

State

Oregon Genetic Privacy Laws (OGPLs)
These state laws make it:

- Illegal for an employer to obtain or use your genetic information to discriminate against you as an employee or prospective employee
- Illegal for health insurance companies to use your genetic information to price or decline individual policies
- Required for health care providers to give clients an opportunity to request that their biological sample(s) and health information not be used for anonymous or coded genetic research.

Federal

Genetic Information Nondiscrimination Act (GINA)
This federal law makes it illegal for the following to discriminate against an individual based on that person's genetic information, including family history:

- Health insurance companies
- Group health plans
- Employers of more than 15 employees

The Americans with Disabilities Act (ADA)
This federal law makes it illegal to discriminate in employment, public services, accommodations and communications against a person:

- Who is regarded as having a disability based on genetic information relating to illness, disease or other disorders
- With symptomatic genetic disabilities
- With a genetic predisposition

The Affordable Care Act (ACA)
This federal law establishes "guaranteed issue," meaning:

- Issuers offering insurance in either the group or individual market must provide coverage for all individuals who request it.
- Issuers of health insurance are prohibited from discriminating against patients with genetic diseases by refusing coverage because of pre-existing conditions.
- Certain health insurers may only vary premiums based on a few specified factors such as age or geographic area, thereby prohibiting the adjustment of premiums because of medical conditions, including genetic diseases.

Health Insurance Portability and Accountability Act (HIPAA)

This federal law is not specific to genetics; rather the law has sweeping regulations governing all personal health information. This law:

- Applies to employer-based and commercially issued group health insurance, and:
  - » Prohibits group health plans from using any health status-related factor, including genetic information, as a basis for denying or limiting eligibility for coverage or for increasing premiums
  - » Limits exclusions for preexisting conditions in group health plans to 12 months and prohibits such exclusions if the individual has been covered previously for that condition for 12 months or more
  - » States explicitly that genetic information, in the absence of a current diagnosis of illness, shall not be considered a preexisting condition.
- Protects medical records and other personal health information maintained by health care providers, hospitals, health plans, health insurers and health care clearinghouses, it also:
  - » Limits the nonconsensual use and release of private health information
  - » Gives patients the right to access their medical records and to know who else has accessed them
  - » Restricts most disclosure of health information to the minimum needed for the intended purpose of establishing criminal and civil sanctions for improper use or disclosure
  - » Establishes requirements for access to records by researchers and others.

Where can I learn more about LS?

The Jackson Laboratory
Provides free genetics-related course offerings with continuing medical education (CME) and continuing nursing education (CNE) credits for providers. Topics include hereditary cancer syndromes, family history collection, precision medicine and more. To learn more, go to https://learn.education.jax.org/browse/hpe.

The Jackson Laboratory Clinical and Continuing Education Program developed an Identifying and Managing Lynch Syndrome course. There are two distinct modules:

- Designed for practicing primary care providers as well as students and residents, 0.25 CMEs. The course expires Apr. 23, 2020. Go here to sign up: https://learn.education.jax.org/browse/hpe/cme/cancer/courses/lynchcme
- Designed for nurses or advanced practice nurses, 0.5 CNEs. The course expires Dec. 21, 2019. Go here to sign up: https://learn.education.jax.org/browse/hpe/cne/courses/lynchcne

National Cancer Institute (NCI)
Provides a comprehensive and evidence-based source of cancer information in their Physician Data Queries (PDQs). The Genetics of Colorectal Cancer (PDQ®)–Health Professional Version is at https://www.cancer.gov/types/colorectal/hp/colorectal-genetics-pdq

National Comprehensive Cancer Network (NCCN)
Develops resources that present valuable information to numerous stakeholders in the health care delivery system. Their evidence based Genetic/Familial High-Risk Assessment: Colorectal guidelines can be key in making appropriate referrals to cancer genetic services. Check for the current version at www.nccn.org; registration is free and required.

NCCN Guidelines® Insights – Genetic/Familial High-Risk Assessment: Colorectal, Version 3.2017. This free activity is designed to meet the educational needs of physicians, nurses, and pharmacists involved in the management of patients with cancer. Course expires Dec. 10, 2018. Go here to sign up: https://education.nccn.org/node/81998.

Lynch Syndrome Screening Network

Mission

- Promote universal Lynch Syndrome screening on all newly diagnosed colorectal and endometrial cancers.
- Facilitate the ability of institutions to implement appropriate screening by sharing resources, protocols and data through network collaboration.
- Investigate universal screening for other Lynch Syndrome related malignancies.

Benefits

Member institutions can attend LSSN meetings and have access to the network listserv, networking opportunities, and aggregate database information. Those that participate in the database have open access to their own data for internal purposes.

Who can join?

LSSN is open to institutions (hospitals, clinics, and academic medical centers) or organizations (federal/state agencies, professional societies, patient support/advocacy groups, laboratories or companies) that are interested in promoting the goal of routine screening for Lynch Syndrome on newly diagnosed colon and/or endometrial cancers.

Becoming a member

Institutions that meet the criteria listed on the website are eligible for full or affiliate membership. Because membership is at the organizational level, only one person from each institution should complete an application where they will indicate the primary and secondary contact persons for that institution.

If they are interested in the use of routine tumor testing to identify people with Lynch syndrome, organizations can partner with LSSN to promote or participate in this research. Designation as a partner of the LSSN does not mean that the LSSN endorses any product or service provided or sold by that partner. Individuals are not eligible to become partners, although each organization designates one or two representatives as primary contacts.

For more information, visit https://www.lynchscreening.net.

Endnotes

1. Kohlmann W, Gruber SB. Lynch Syndrome. 2004 Feb 5 [Updated 2018 Apr 12]. In: Adam MP, Ardinger HH, Pagon RA, et al., editors. GeneReviews® [Internet]. Seattle (WA): University of Washington, Seattle; 1993-2018 [cited 2018 May 2]. Available from: https://www.ncbi.nlm.nih.gov/books/NBK1211.

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3. American Cancer Society. ACS Guidelines on Nutrition and Physical Activity for Cancer Prevention [Internet] [cited 2018 Apr 5]. Available from: https://www.cancer.org/healthy/eat-healthy-get-active/acs-guidelines-nutrition-physical-activity-cancer-prevention.html.

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5. Health-Calc. Waist to height ratio [Internet] [cited 2018 Feb 21]. Available from: https://www.health-calc.com/body-composition/waist-to-height-ratio.

6. National Cancer Institute. Colorectal Cancer Prevention (PDQ®)-Patient Version. February 8, 2017. https://www.cancer.gov/types/colorectal/patient/colorectal-prevention-pdq. July 14, 2017.

7. American Cancer Society. Colorectal Cancer Risk Factors. July 6, 2007. https://www.cancer.org/cancer/colon-rectal-cancer/causes-risks-prevention/risk-factors.html. Accessed July 14, 2017.

You can get this document in other languages, large print, braille or a format you prefer. Contact Screenwise at 971-673-0581 or email ScreenWise.info@dhsoha.state.or.us. We accept all relay calls or you can dial 711.

Oregon Health Authority

PUBLIC HEALTH DIVISION
ScreenWise
800 NE Oregon St., Suite 370
Portland, OR 97232 | 971-673-0581
ScreenWise.info@dhsoha.state.or.us
www.healthoregon.org/genetics

OHA 9295A (09/2018)

Hereditary Cancer Awareness Project Fact Sheet

Purpose:

1. Survey – To find out more from Oregon cancer survivors and clinicians:
    a. Their understanding of Hereditary Breast and Ovarian Cancer (HBOC) syndrome or Lynch Syndrome (LS)
    b. Their use of, or referrals to, resources
2. Educate – To inform Oregon cancer survivors and clinicians about HBOC or LS:
    a. Raise knowledge of resources
    b. Encourage life-saving conversations

Process: A letter, survey and other material sent to specific persons:

- Cancer survivors who fit cancer genetic services referral guidelines.
- Reporting clinicians of cancer survivors (when known).

Survey candidates: ScreenWise used the Oregon State Cancer Registry (OSCaR) to find certain cancer survivors and reporting clinicians. We looked for cancer survivors who may have been offered cancer genetic services to gage if they have HBOC syndrome or LS. This does not mean the person has HBOC or LS. However, it does mean that some people with that cancer diagnosis might have HBOC or LS.

To learn more about HBOC or LS, the person may want to talk with their doctor or a board-certified genetics specialist. For example, they may want to talk to their certified genetic counselor (CGC) or a geneticist (MD or PhD). These specialists can explain the risk of HBOC related cancers to the person and their family.

Post survey: By Sept. 28, 2018, we will put a summary of the results for this project on the Hereditary Cancer Awareness Project webpage. You will be able to go to http://www.healthoregon.org/genetics, for the results. This summary will not include any personal information.

Data source: The Oregon State Cancer Registry. For more information about OSCaR, go to http://healthoregon.org/oscar.

Administered by: The Oregon Health Authority's ScreenWise Program. Go to http://www.healthoregon.org/screenwise for more information about ScreenWise.

Funded by: Centers for Disease Control and Prevention (CDC), Division of Cancer Prevention and Control, cooperative agreement number DP005353-04.

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