Hereditary Melanoma

A Patient's Guide

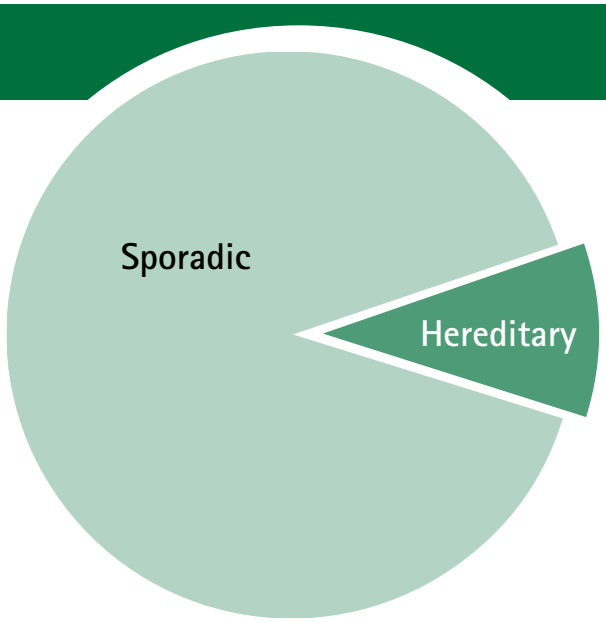
to risk assessment

Hereditary Cancer Testing: Is it Right for You?

This workbook is designed to help you decide if hereditary cancer testing is right for you and should be completed with a trained healthcare provider.

Introduction

Most cancer occurs by chance (also called sporadic). In some families we see more cancer than we would expect by chance alone. Determining which of these families have cancer related to an inherited gene mutation is important, as the cancer risks in hereditary cancer families are much higher than the general population.



Notes:

Personal and Family History

Check all that apply:

- ❑ Melanoma
- ❑ Pancreatic cancer
- ❑ More than one melanoma in the same individual
- ❑ Both melanoma and pancreatic cancer
- ❑ A personal and family history of melanoma and multiple atypical moles
- ❑ Relative with a *p16* gene mutation
- ❑ Other: _____

Hereditary melanoma is an inherited condition that causes an increased risk for melanoma, and in some families, an increased risk for pancreatic cancer. The most common known cause of hereditary melanoma is a mutation in the *p16* gene. These mutations can be inherited from either your mother or father.

Cancer Risks for *p16* Mutation Carriers

Having a *p16* mutation increases the risk of certain cancers. If you have already had a cancer diagnosis, you have an increased risk of developing another cancer.

	p16 Mutation Risk	General Population Risk
Melanoma by age 80	Up to 76%*	<2%
Pancreatic cancer by age 75	Up to 17%	<1%

*Based on U.S. data

Managing Hereditary Melanoma

INCREASED SURVEILLANCE

- Clinical skin exams every 6 to 12 months beginning at age 10. More frequent exams may be necessary during puberty or pregnancy if moles are rapidly changing.
- Skin self-exam performed every month beginning in childhood.
- Color photographs of the entire surface of the skin and close-ups of atypical moles may be useful in comparing moles over time in both clinical and self-exams.

SURGICAL MANAGEMENT

- Biopsy and/or removal of suspicious moles.

LIFESTYLE MODIFICATIONS

- Limit or reduce exposure to the sun or ultraviolet radiation (for example: tanning beds). Do not get sunburned.
- Wear protective clothing, such as wide-brimmed hats, sunglasses, and long-sleeved shirts when going outside.
- Apply sunscreen with a Sun Protection Factor (SPF) of 15 or higher at regular intervals when outside to prevent sunburns.

Pancreatic cancer surveillance may be considered in some individuals. Please speak to your healthcare provider.

THE ABC'S OF MELANOMA

Potential signs of melanoma—look for moles with one or more of the following characteristics:

Asymmetry: A mole with a different shape on one side of the mole compared to the other.

Border irregularity: A mole with jagged or notched edges.

Color variation: Moles with various shades of black and brown (or even pink, white or blue). Normal moles are generally one color (ranging from tan to black).

Diameter: Any mole larger than the head of a pencil eraser.

Evolution: Moles that have changed in appearance or the development of a new mole.

Testing Options

There are two types of tests to look for *p16* mutations:

❑ **Comprehensive MELARIS®:**
Full sequence analysis of the *p16* gene.

❑ **Single Site MELARIS®:**
Mutation-specific analysis for individuals with a known *p16* mutation in the family

Possible Test Results

Positive Result → **Increased Cancer Risk**
Medical management based on recommendations for mutation carriers

Negative Result

- A mutation has been previously identified in the family (Single Site Analysis) → **Slightly Increased Cancer Risk**
  Medical management based on other genetic, environmental, and lifestyle risk factors
- No mutation has been previously identified in the family (Comprehensive Analysis) → **Cancer Risk Not Fully Defined**
  Medical management based on personal/family history of cancer, environmental, and lifestyle risk factors

Uncertain Variant → **Cancer Risk Not Fully Defined**
Medical management based on personal/family history of cancer, environmental, and lifestyle risk factors

Notes

It's a Family Affair

- *p16* mutations are passed on in a family.
  - If you have a mutation in this gene, your parents, your children, and your brothers and sisters have up to a 50% chance that they have the same mutation.
  - Other relatives may be at-risk to carry the same mutation.
- Testing is the only way to accurately identify mutation carriers.
- It is important to share test results with family members.

Benefits and Limitations of Testing

Benefits

- Personalized risk assessment
- Appropriate medical management to help reduce cancer risk
- Important information for family members
- Reduces anxiety and stress

Limitations

- Like all medical tests, testing does not detect all causes of hereditary cancer
- A negative result is most helpful when there is a known mutation in the family
- Some genetic variants are of unknown clinical significance

Individuals may differ in their viewpoints and reactions to hereditary cancer testing.

Notes:

Health Care Coverage and Testing

- Insurance coverage for genetic testing of at-risk patients is excellent, with the majority of patients covered for testing. Although each case is unique, the average patient pays coinsurance of less than $100.*

Privacy

- Federal laws (HIPAA and GINA) and laws in most states prohibit discrimination regarding eligibility, benefits, or premiums based on genetic information. Additionally it is Myriad policy that test results are disclosed only to the ordering healthcare professional or designee, unless the patient consents otherwise.

Next Steps:

❑ Pursue testing

❑ Schedule follow-up appointment for results disclosure

Date: _____ Time: _____

❑ Decline testing—Medical management based on personal and family history of cancer

❑ Undecided

Who to contact with questions: _____

*Test prices may be confirmed by calling Myriad Customer Service at 1-800-469-7423. Unmet deductibles are always the responsibility of the patient.

Additional Resources

Melanoma Center

An on-line resource developed by physicians that provides melanoma information.
www.melanomacenter.org/index.html

American Academy of Dermatology

Provides information on melanoma risk factors, detection, treatment, and diagnosis, as well as assistance in finding a dermatologist in your area.
www.skincarephysicians.com
1-847-330-0230

National Cancer Institute

Provides information on melanoma-related clinical trials, treatment, and prevention.
www.cancer.gov

Myriad Genetic Laboratories, Inc.

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