Pre-Test Genetic Counseling Visual Aids

[These materials were shown to members of *p16* families in the University of Utah BRIGHT Project prior to obtaining informed consent for genetic testing.
Post-test genetic counseling visual aids shown to members of these families may be found in a separate file in these supplementary materials.
Please refer to the Bright Project Genetic Counseling Protocol Summary, also in these supplementary materials, for more information.]

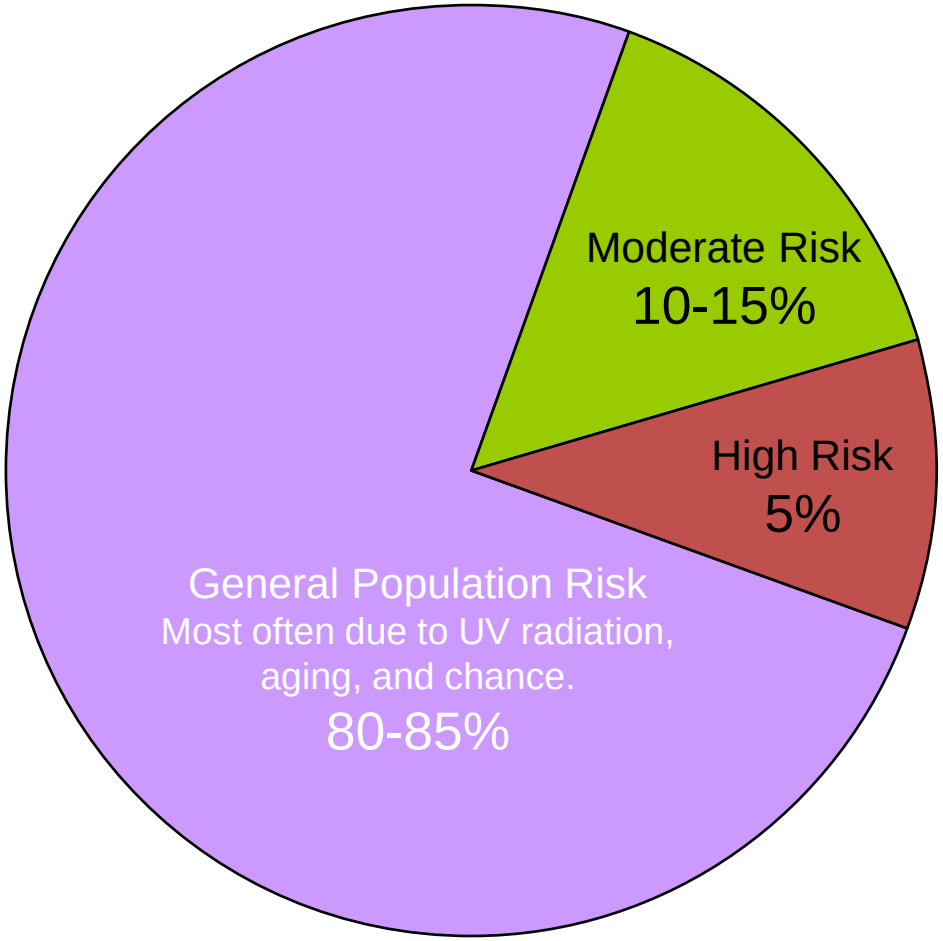
Family Tree

The patient's personal family tree will be drawn out on this slide. The genetic counselor will review the family history for accuracy and to determine the patient's experience with melanoma in the family.

Melanoma

- Melanoma is a deadly form of skin cancer.
- Melanoma starts in cells that give your skin its color. These cells are called melanocytes.
- About 1 in 100 (1%) of Caucasians with no family history of melanoma will get this disease at some point during their lives.

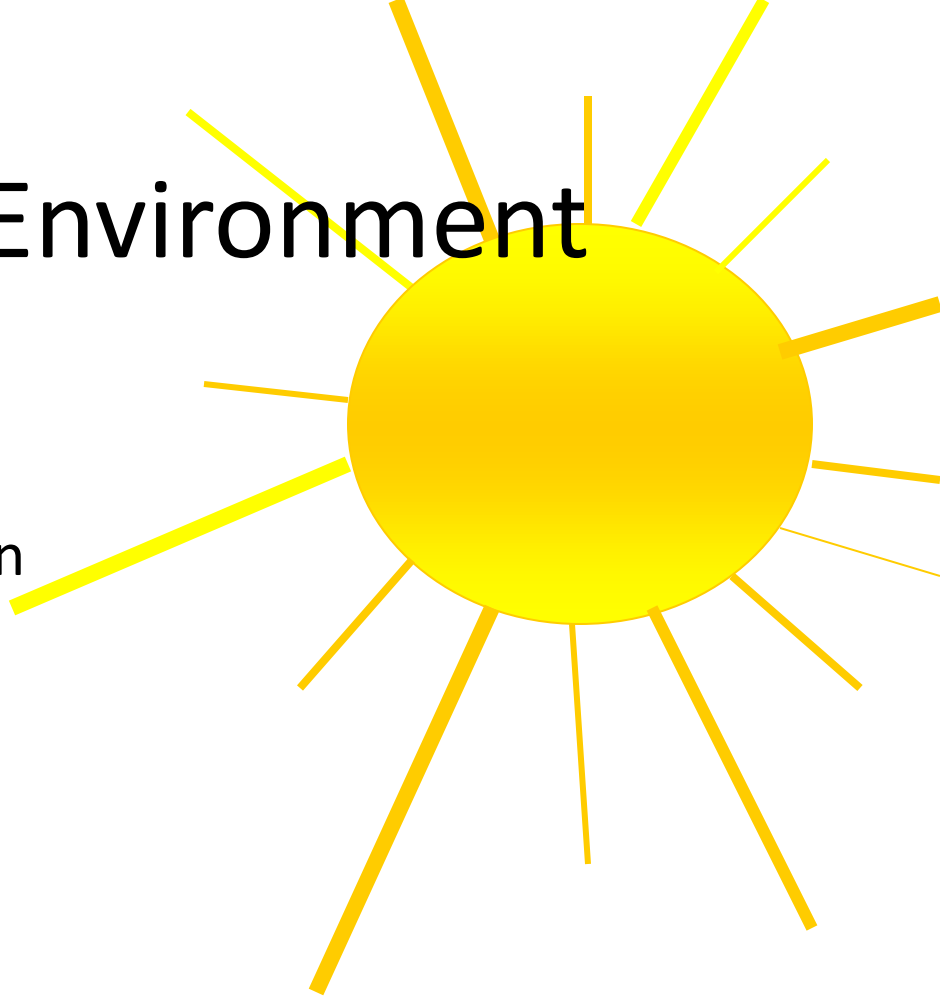
Levels of Melanoma Risk



Melanoma Risk Factors

- Environment
- Genes that determine physical features
- High-risk genes that don’t determine physical features

Risk Factor: Environment

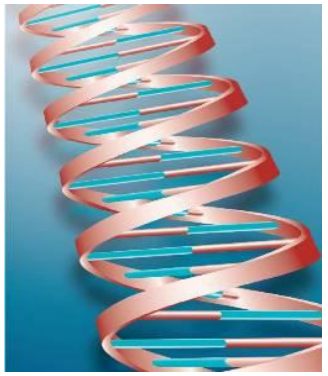


- Ultraviolet radiation (UV)
  - The **sun** is the most common source of UV radiation.
  - **Tanning beds** are also an intense source of UV radiation.
  - A safe amount of sun exposure has **not been determined**.
  - A **blistering** sun burn doubles your risk for developing melanoma.

Risk Factors: Genes that Determine Physical Features

- Genes control our hair color, skin color, and the number and type of moles we get.
- People who have fair skin, red or blond hair, or many moles have a higher risk of getting melanoma.
- These genes can double or triple your risk of getting melanoma.

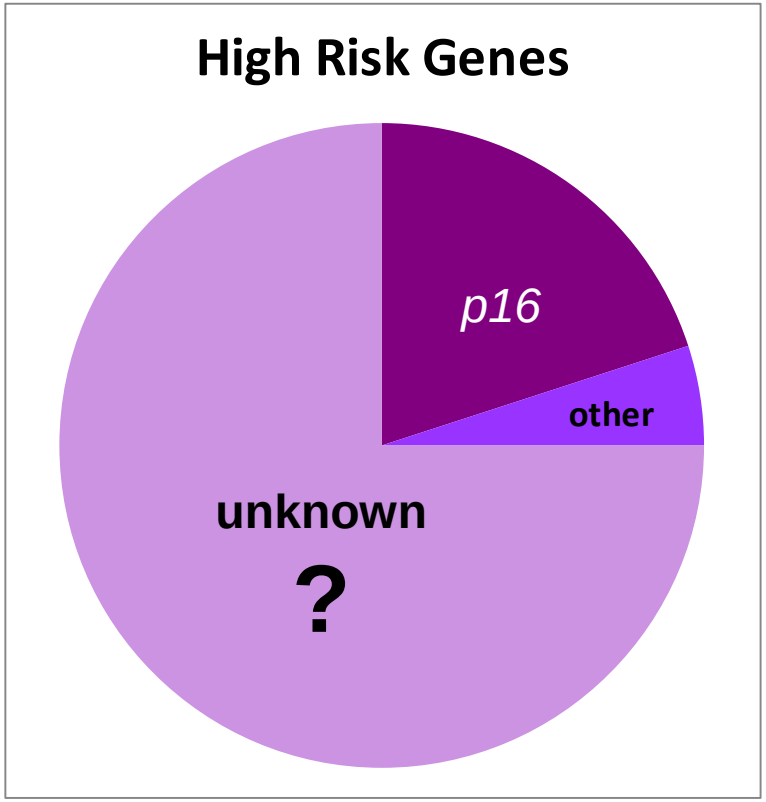
Risk Factors: High-Risk Genes



- Not all genes affect appearance.
- Some genes control processes that go on inside your body, such as how cells grow and divide.
- Some genes control how cells repair damage caused by UV light.
- If these genes are not working properly, there is a higher risk for getting melanoma, even if your skin and hair are dark.

Risk Factors: High Risk Genes

- Mutations in a gene called *p16* cause a high risk for melanoma.
- About 20% of families with a high risk for melanoma have a mutation in the *p16* gene.
- Through our research, we found that your family **has a *p16* mutation.**



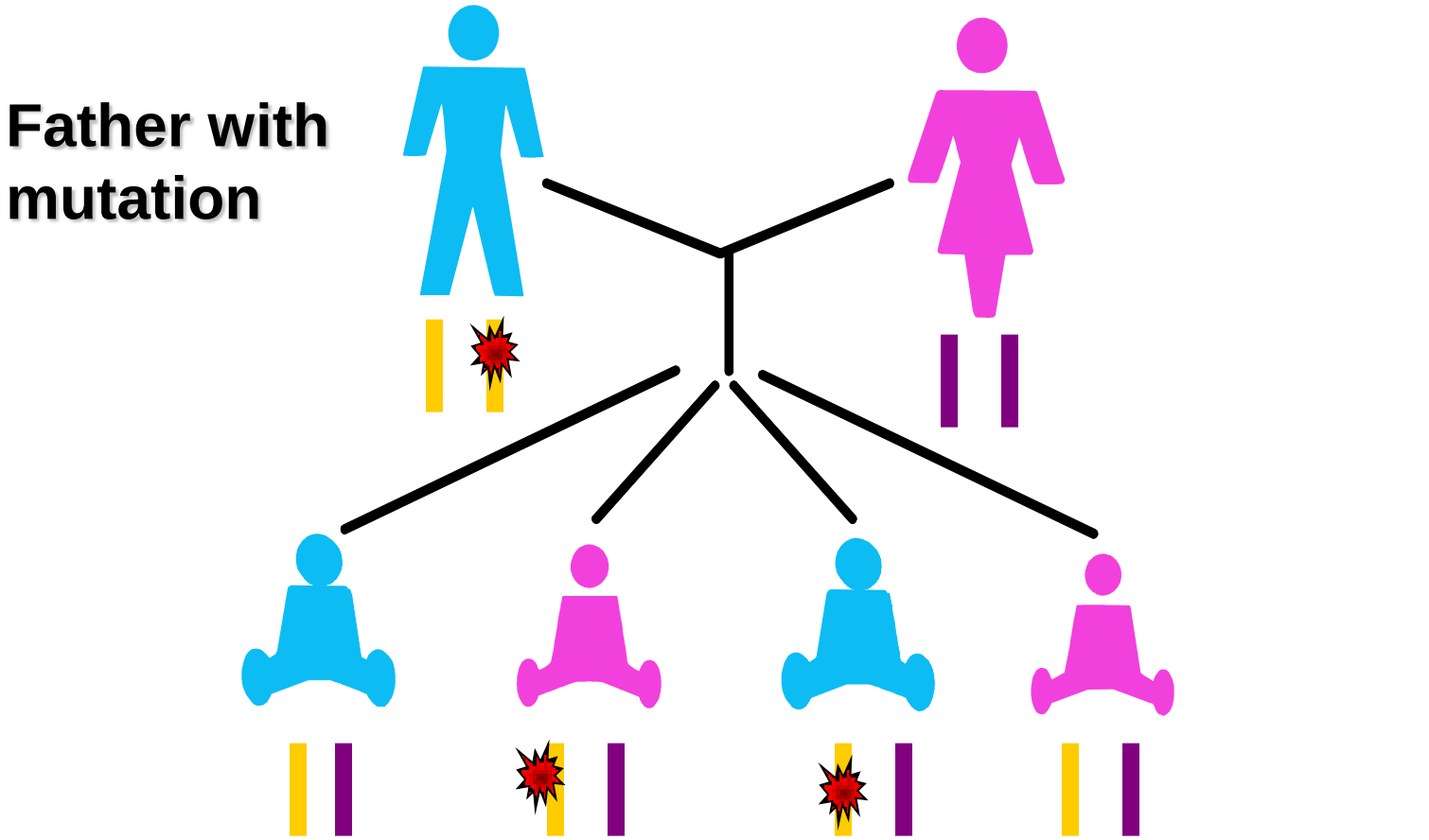
What is your cancer risk?

- These risk factors can interact to increase your risk of developing melanoma.
- Currently, we are unable to give you a comprehensive risk assessment number that takes into account all of your personal risk factors.
- However, we can give you a general risk assessment based on your family history.

Approximate Lifetime Cancer Risk

Type of Cancer	General Population Risk of Melanoma with No Family History	Your Risk as a Member of a High Risk Family
Melanoma	1 in 100	30 in 100 to 70 in 100
Pancreas	1 in 100	17 in 100

Inheritance of *p16* Gene Mutations



Each child has a 50% chance of inheriting the gene mutation

Possible Results of Genetic Testing

POSITIVE (mutation found)

- High risk for melanoma and pancreatic cancer
- Screening and steps to limit UV radiation
- Each child has a 50% risk of inheriting the familial mutation

Negative (no mutation found)

- Still at a moderate risk for melanoma (2 in 100)
- Screening and steps to limit UV radiation
- Since you do not have the mutation, you cannot pass it on to your children

Laws to Protect Against Genetic Discrimination

- Genetic Discrimination is when a person or family with a genetic mutation is treated differently.
- Federal and state laws protect you from health insurers and employers using your genetic information against you.
- Current laws do not protect you when it comes to life and disability insurance.
- The **G**enetic **I**nformation **N**on-discrimination **A**ct **(GINA)** was signed into law in 2008. For more information about GINA: http://www.genome.gov/24519851

Management Recommendations

- All members of families with melanoma should:
  - Regularly check their skin
  - Take steps to lower UV exposure
- Recommended screening includes:
  - Monthly skin self-exams
  - Annual total body skin exams with your dermatologist
- Individuals testing positive for a *p16* mutation should also begin screening for pancreatic cancer at age 50.