## GENETIC TESTING: WHAT DOES IT *REALLY* TELL YOU?

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## Definitions:

- DNA: The material found in our cells the "instructions" for our body
  - **DNA** is found in all living things
  - **Chromosomes** are "units" of DNA that are visible under the microscope
  - **Genes** are segments of DNA on chromosomes
  - **Mutations** are changes in genes that affect the function of that gene



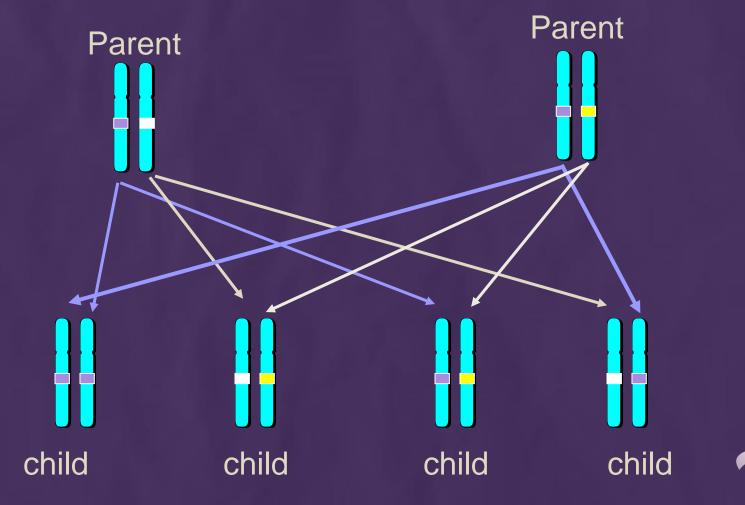
#### **Disease-Associated Mutations**

A *mutation* is a *change* in the normal structure of a gene that *alters the function* of the gene



All cancer arises from gene mutations, but not all cancer is inherited!

### Children get half of their genes from each parent



## Hereditary Cancer Syndromes are Suspected When:

- Early age at diagnosis
- Cancer in 2 or more close relatives (on same side of family)



- More than one primary tumor
- Group of tumors seen in specific cancer syndrome (e.g., breast and ovary; colon and uterus)
- Cancer in more than one generation



## HEREDITARY CANCER RISK ASSESSMENT

### Who Needs Genetic Assessment?

- Individuals with cancer diagnosed at a younger than average age
- Individuals with more than one kind of cancer
- Individuals with cancer who have a family history of related cancers
- Individuals with a known mutation in a family member



### How Can Genetic Testing be Helpful?

- Most syndromes have risks for more than one type of cancer
- Knowing you have a mutation may impact your treatment decisions
- If you have a mutation, you may need screening that is different than other people



## What Should You Ask *Before* Testing?

- What impact will the test have on my treatment if I have a mutation?
- If I have a mutation, do I have risks for other cancers? What type?
- What is the chance that I have a mutation?



## What Should You Ask *Before* Testing?

- Does this test always give a *yes* or *no* answer?
- What does it mean if I do *not* have a mutation?
  - Could I still have an inherited cancer?
  - Do I have risks for other cancers?
  - What does it mean for my family members?



## What Should You Ask If You *Have* a Mutation?

- Does this change my treatment options?
- Who in my family needs this information?
- What resources are available for this syndrome?
- What other screening should I have?



# What Should You Ask if You *Don't* Have a Mutation?

- What does this mean for my treatment?
- What are the chances that my cancer is still inherited?
- Is there other genetic testing I need?
- Is there research I can participate in?



## COMMON QUESTIONS ABOUT GENETIC TESTING

#### SHOULD EVERYONE WITH CANCER HAVE GENETIC TESTING?

Most cancer is <u>not</u> inherited. Genetic testing is for people who have cancer at a much younger than average age, or who have family history of cancer.

#### IF MY GENETIC TEST IS NEGATIVE, DOES IT MEAN MY CANCER IS DEFINITELY NOT INHERITED?

We don't know how to test for all hereditary cancer syndromes. If your test is negative, we need to look at your family history to interpret the test results. Also, there may be other or further tests that could be useful.

#### IF I HAVE GENETIC TESTING, WILL I BE ABLE TO GET HEALTH INSURANCE?

Genetic information can't be used as a pre-existing condition for people who do not have cancer for health insurance or employment.

*Current laws do not apply to long-term care or life insurance.* 

## WHY DID MY DOCTOR DO A GENETIC TEST ON MY TUMOR?

Tumors are tested for genetic changes because this information can help us treat your cancer. The genetic changes in your tumor don't usually mean anything about the genes in your other organs. Examples would be Her2 or KRAS testing. IF THERE IS A KNOWN MUTATION IN MY FAMILY AND I DIDN'T INHERIT IT, CAN I STILL GET CANCER?

Yes. You are still at the same risk as the general population, so you should continue to follow all screening recommendations and live a healthy lifestyle. CAN INHERITED BREAST OR OVARIAN CANCER COME FROM THE FATHER'S SIDE OF THE FAMILY?

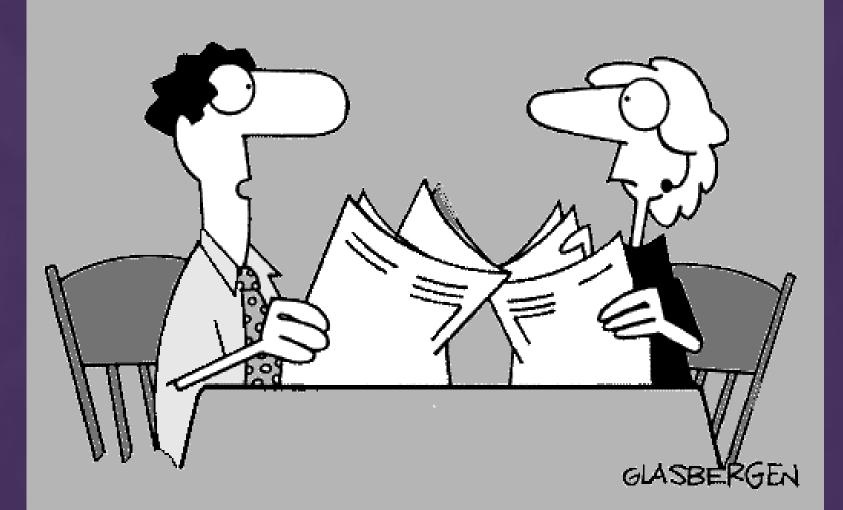
Yes. Most cancer syndrome genes can come from either side of the family, so it is important to tell your doctor about cancer history on both sides. IF I DON'T HAVE ANY FAMILY HISTORY OF CANCER, DOES IT MEAN THAT MY CANCER ISN'T INHERITED?

Not necessarily. Sometimes families are too small or there are not enough family members of the right gender to make that conclusion. Occasionally, a person will be the first to develop the genetic change, an event that happens at conception.

#### ISSUES TO CONSIDER

- Understand the reason for testing, and the associated risks, benefits, and limitations of the test
- Understand what test results mean before testing, positive, negative or uncertain variant
- GET A COPY OF YOUR RESULTS





"Scientists have isolated the gene that makes scientists want to isolate genes."

