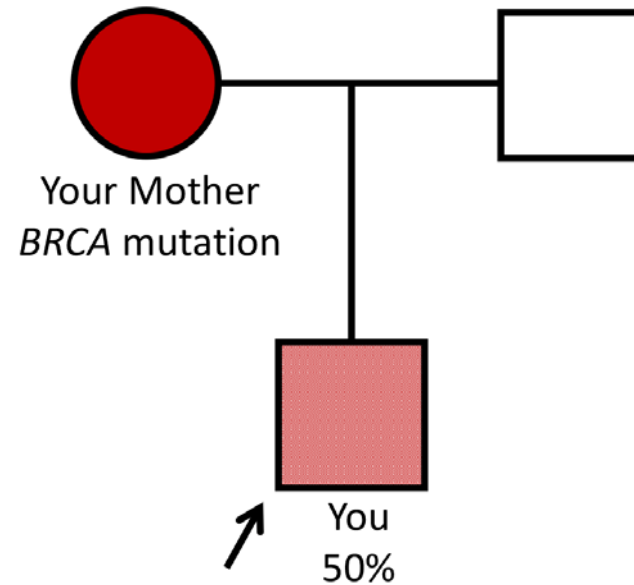


Supplement to Journal of Cancer Education

**The Genetic Education for Men (GEM) Trial: Development of Web-Based Education for
Untested Men in *BRCA1/2*-Positive Families**

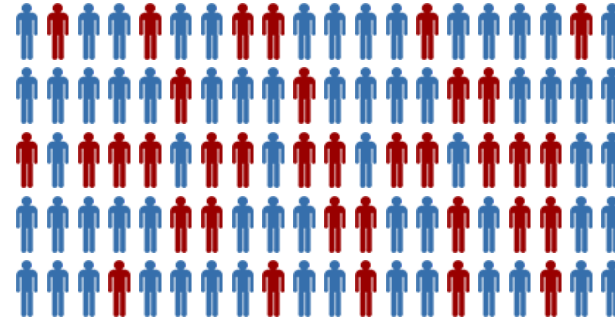
What Is My Risk For Carrying The *BRCA2* Mutation In My Family?

- Because your mother has a *BRCA2* mutation, you have a 50% (or 1 in 2) chance of having the same mutation.
 - Genetic testing can determine for certain whether you have inherited this mutation.
- Getting tested may also provide information about your children's risk.
 - If you test positive for the *BRCA2* mutation in your family, your children have a **50% (or 1 in 2)** chance of having inherited the same mutation.
 - If you test negative for the *BRCA2* mutation in your family, this also means that your children **have not** inherited the mutation.
 - If you are not tested, then your children's chance of inheriting the mutation remains unknown.

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Prostate Cancer Risk In *BRCA2* Carriers

- Having a *BRCA2* mutation is the single strongest risk factor for the development of prostate cancer.
- Men with a *BRCA2* mutation may have up to a 30-40% chance of developing prostate cancer in their lifetime compared to about a 10% chance for men without a mutation.
 - We do not know how race and ethnicity affect the chance of prostate cancer in men with a *BRCA2* mutation.
 - Men with a *BRCA2* mutation tend to develop prostate cancer before age 65, which is earlier than average.

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The risk for prostate cancer in a *BRCA2* mutation carrier is 30-40 in 100.

[Click to See General Population Carrier Risk](#)

Can Prostate Cancer Be Prevented?

- Two drugs (Finasteride and Dutasteride) have been shown to reduce the chance of developing prostate cancer by 20-25%.
- These drugs:
 - Have not been tested in *BRCA2* mutation carriers
 - Mainly reduce the likelihood of developing **low-risk prostate cancer**
 - Have significant side effects
 - Have not been approved by the Food and Drug Administration (FDA) for prostate cancer prevention
 - Are not currently recommended by any medical organizations for prostate cancer prevention
- If you have questions about prostate cancer **chemoprevention**, you should speak with your doctor.

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Would Knowing My *BRCA2* Mutation Status Impact My Prostate Cancer Treatment Options?

- There are no specific treatment guidelines for *BRCA2* mutation carriers.
- Given the aggressive nature of prostate cancer in *BRCA2* mutation carriers, doctors may recommend:
 - More aggressive follow-up of suspicious screening results
 - More aggressive prostate cancer treatment
 - This means that men with a *BRCA2* mutation who develop prostate cancer would be more likely to be treated with surgery or radiation, rather than **active surveillance**.
 - New treatments specifically targeted to *BRCA2* mutation carriers

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Prostate Cancer In *BRCA2* Carriers

- In the general population, prostate cancer is usually slow-growing.
 - For men without a *BRCA* mutation, **active surveillance** may be an option for early stage prostate cancer.
 - Active surveillance means that the prostate cancer is closely monitored, but is not treated unless it progresses.
- Prostate cancer in men with a *BRCA2* mutation:
 - Grows faster
 - Is more likely to spread to other parts of the body
 - Is much more likely to be fatal.
- Prostate cancer treatment is recommended for *BRCA2* carriers.



Source: FotoSearch | Photographer: gajdamak

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Benefits & Harms Of Prostate Cancer Screening

Benefits Of Prostate Cancer Screening (PSA + DRE)

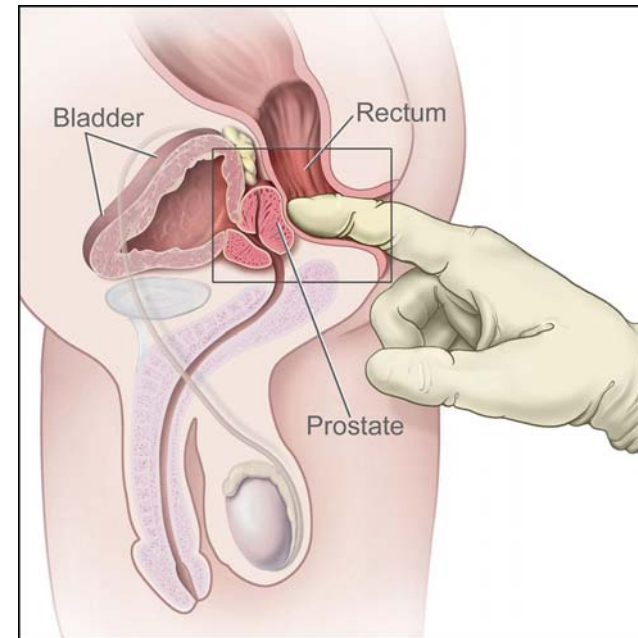
- May detect prostate cancer when it is very small and before symptoms are present.
- May help to identify a fast-growing cancer at an early stage when treatment may stop the cancer from spreading.
- May be especially beneficial for men who are more likely to develop prostate cancer.

Harms of Prostate Cancer Screening

- Not clear whether early detection and treatment lead to a reduced chance of dying from prostate cancer.
- Tests may be normal even when prostate cancer is present.
- Tests are often abnormal even when no cancer is present, leading to more prostate biopsies.
- Prostate biopsies may detect slow-growing prostate cancers that would never have caused harm, leading to overtreatment and side effects such as:
 - Difficulty obtaining or maintaining an erection
 - Loss of bladder control (urinary incontinence)
 - Bowel problems after radiotherapy treatment

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Digital Rectal Examination



Supplementary Figure A6: Benefits and Harms of Prostate Cancer Screening

Cancer Risks For My Children

- Getting tested for the *BRCA2* mutation in your family could provide information about your untested children's chance of inheriting a mutation.
- If you test positive, your untested children have a 50% chance of inheriting the same mutation.
- If you test negative, your untested children are not at risk for inheriting your familial mutation.
- If you choose not to be tested, the chance that your children have inherited the same mutation will remain unknown.

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Is Genetic Counseling And Testing Available To Me Through This Study?

By reviewing this website, you have received information that is comparable to the information you would receive in genetic counseling. As a result, you have several options for proceeding at this point:

- You can proceed directly to *BRCA* genetic testing coordinated through the study.
 - Testing is optional and is not required as part of this study.
 - If you are interested in genetic testing, pre-test genetic counseling is not required as part of the study unless you choose to bill your insurance for testing and they require pre-test genetic counseling.
 - We can help you determine what is required by your insurance provider.
 - If you prefer to have pre-test genetic counseling prior to deciding about testing:
 - We can provide free genetic counseling over the phone by a board-certified genetic counselor.
 - Or we can refer you to a genetic counselor in your area where you can obtain in-person genetic counseling.
 - The cost of genetic counseling provided outside the study or in-person is not covered by the study.
 - If you choose to have testing through the study, post-test genetic counseling is required, and is provided free of charge over the phone by a board-certified genetic counselor.

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What Information Is Covered In Pre-Test Genetic Counseling That Is Not Covered In This Web-Based Program?

Pre-test genetic counseling typically includes:

- A comprehensive review and assessment of your family history, including your maternal and paternal sides (i.e., not just the side of the family with the *BRCA* mutation).
- A discussion about genetic testing options for hereditary cancer based on your family history, which in rare cases may include testing beyond the *BRCA* mutation identified in your family.
- An opportunity for you to discuss the pros and cons of genetic testing based on your values and preferences.
- Supportive counseling to address emotional concerns related to inherited cancer risk.

Some of these issues are also addressed during post-test genetic counseling.

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Is Genetic Testing Right For You? *The Choice Is Yours.*

The quotes below provide different examples of what men have said about *BRCA* genetic testing.

Some men who believe that getting tested is helpful have said the following:

- "I wanted to know if I carried this gene mutation so I could take steps to prepare for or potentially head off a cancer diagnosis."
- "I have four daughters. I am not as concerned about myself as I am about passing a mutation onto my daughters, and what it would mean for them. I am getting tested so that my wife and I know if they need to be tested."
- "I am so happy I went through with testing. I mean, rather than just going through life happily and all of a sudden you are fifty and boom, you have cancer. So I'm glad that we are on top of it, and we are doing the necessary screenings so if anything does develop, we can catch it quickly."

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Some men who have wondered whether getting tested is helpful have said the following:

- "For me, the downside of genetic testing was finding out that I have a mutation, and now I'm constantly worrying about my increased chance of cancer."
- "I'm not sure that testing is right for me. I don't have any children to worry about, and I do not believe that it would impact my medical care one way or another."
- "Since finding out I carry a mutation, my doctors have given me conflicting recommendations for cancer screening. I am unsure whose advice to follow."

Pros And Cons Of Getting Tested

Pros Of Getting Tested If the statements below are important to you, you might think about getting tested for the <i>BRCA2</i> mutation in your family.	Is this important to you?	
	YES	NO
Getting tested will provide definitive information about whether I have inherited the <i>BRCA2</i> mutation in my family.	<input checked="" type="radio"/>	<input type="radio"/>
Getting tested will determine if my chances of developing some specific cancers are increased or about average.	<input checked="" type="radio"/>	<input type="radio"/>
Getting tested will provide information about my children's chances of having inherited the familial <i>BRCA</i> mutation.	<input type="radio"/>	<input checked="" type="radio"/>
Getting tested may eliminate the need for my children to undergo genetic testing in the future.	<input type="radio"/>	<input checked="" type="radio"/>
Getting tested may help guide decisions about my cancer screening and possibly cancer treatment.	<input checked="" type="radio"/>	<input type="radio"/>
Getting tested may eliminate the need for me to undergo some cancer screening tests.	<input checked="" type="radio"/>	<input type="radio"/>
Getting tested may relieve my uncertainty and worry.	<input checked="" type="radio"/>	<input type="radio"/>
Other Pro of Testing: <input type="text"/>	<input type="radio"/>	<input checked="" type="radio"/>
Other Pro of Testing: <input type="text"/>	<input type="radio"/>	<input type="radio"/>
Cons Of Getting Tested If the statements below are important to you, you might think about not getting tested for the <i>BRCA2</i> mutation in your family.	Is this important to you?	
	YES	NO
Even after getting tested, there may still be uncertainty about my chance of developing cancer.	<input type="radio"/>	<input type="radio"/>
Even after getting tested, there may still be uncertainty about what cancer screening tests I should obtain.	<input type="radio"/>	<input type="radio"/>
There are no proven ways for me to reduce the chance of being diagnosed with cancers that are associated with <i>BRCA</i> mutations.	<input type="radio"/>	<input type="radio"/>
Getting tested may lead to additional medical consults but no changes in my cancer risk management.	<input checked="" type="radio"/>	<input type="radio"/>
Getting tested may cause me to be anxious or worry about my chance of developing cancer.	<input type="radio"/>	<input checked="" type="radio"/>
Getting tested may cause me to be anxious or worry about my children's chance of having inherited the mutation.	<input type="radio"/>	<input type="radio"/>
Getting tested may raise concerns about genetic discrimination not addressed by current laws.	<input type="radio"/>	<input type="radio"/>
Other Con of Testing: <input type="text"/>	<input checked="" type="radio"/>	<input type="radio"/>
Other Con of Testing: <input type="text"/>	<input type="radio"/>	<input type="radio"/>

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Supplementary Figure A11: Pros and Cons of Genetic Testing