Men's Stories About Hereditary Cancer





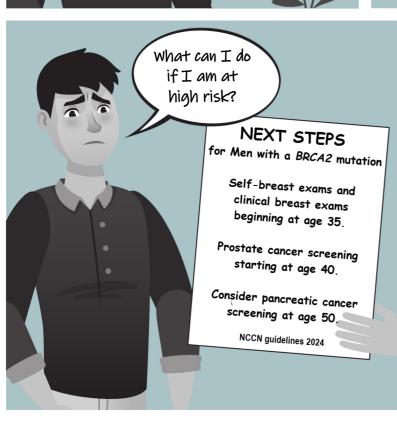


How BRCA gene mutations affect men

We dedicate this work to Dr. Emily A. Rauscher. Emily was our friend and colleague who inspired this work.









Steps You Can Take to Learn Your Cancer Risks

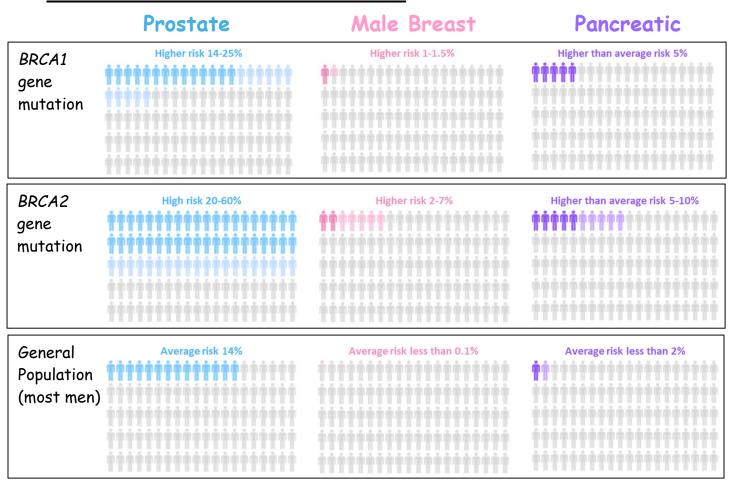
Speak to a doctor or a genetic counselor

- You can find a genetic counselor or cancer genetics clinic:
 - o https://findageneticcounselor.nsqc.org
 - o Clinics.acmq.net
- Genetic counselors can answer your questions, gather your personal and family history of cancer, talk about your risks, help you decide about testing, and help you understand your results.

Learn about insurance coverage for genetic testing

- Options for covering the cost of genetic testing include:
 - o Labs can bill your health insurance
 - You can pay about \$250 without billing your insurance
 - Labs may offer free or reduced-cost testing
- When there is a gene mutation in the family most testing costs are usually covered by insurance.

Learn About Cancer Risks for Men



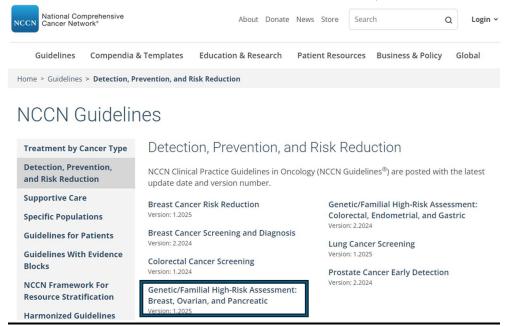
Steps You Can Take to Manage Your Risks

Learn about cancer screenings that help find cancer early

- Your doctor can screen for prostate cancer with a physical exam and a blood test (i.e., PSA screening).
- For a clinical breast exam or self-breast exam the doctor or the patient will feel the breasts and check for lumps.
- Pancreatic cancer can be found early by taking pictures of the pancreas (without using any radiation or X-rays).

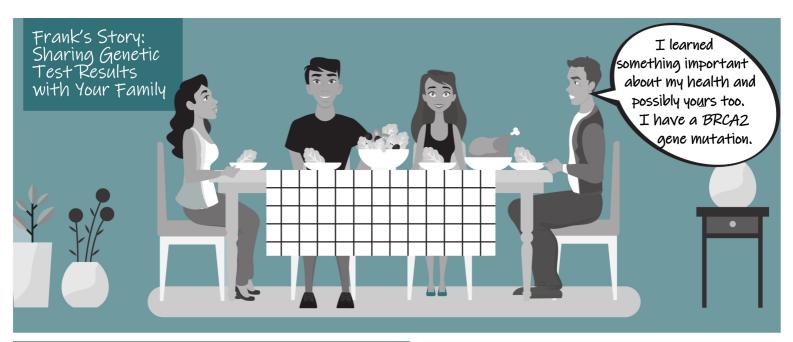
Stay up to date on risk management guidelines

- Medical management guidelines may change as we learn more.
- FORCE has medical management information organized by gene: https://www.facingourrisk.org/info/hereditary-cancer-and-genetic-testing/hereditary-cancer-genes-and-risk/genes-by-name
- Get the latest NCCN medical management guidelines:
 - o Go to https://www.nccn.org/ to create a free username and password
 - o Login and select the "Guidelines" tab in the top menu.
 - Click "Detection, Prevention, and Risk Reduction" (see screenshot below).



Make a plan

- There may be other risks to consider.
- Talk to your doctor or genetic counselor about what medical care may be best for you.

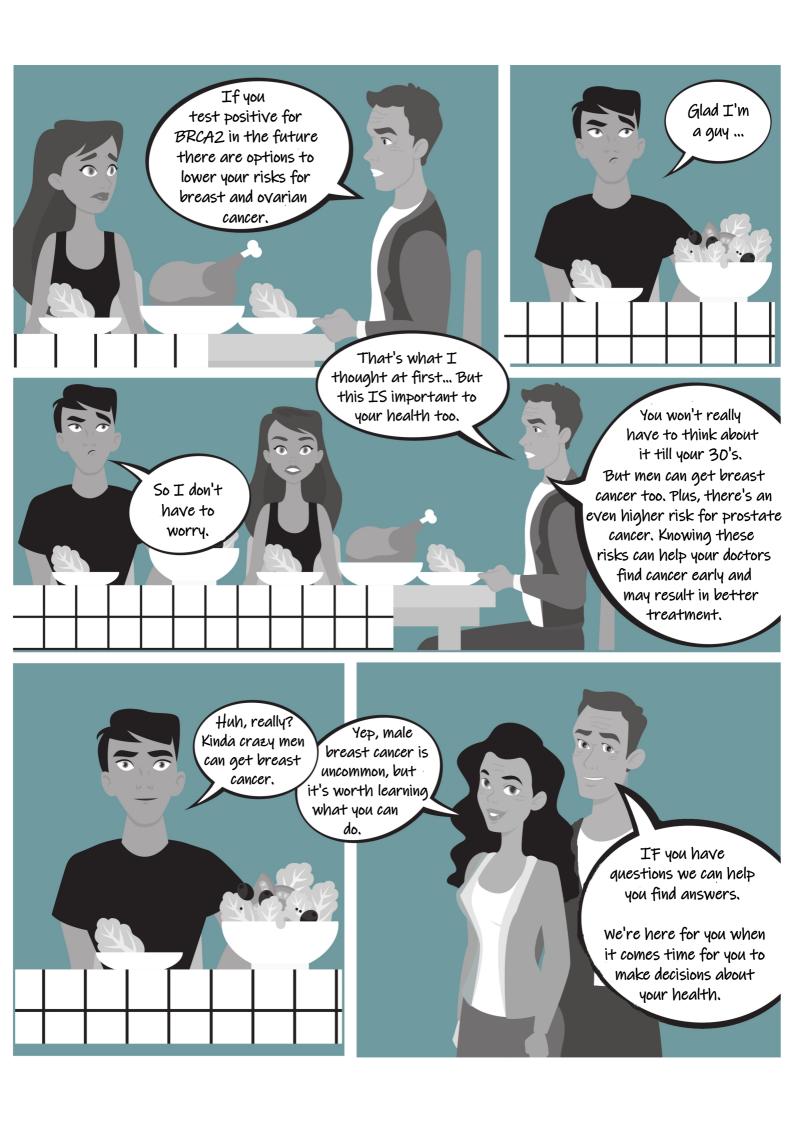




If you share this genetic risk with me, it is important to find out because it can affect your healthcare decisions. But there's still a 50% chance you may not have it.





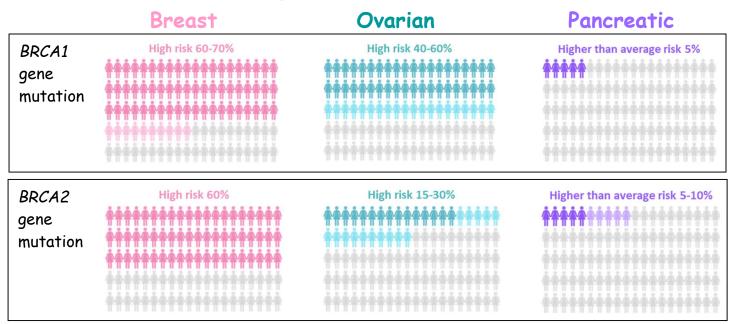


Steps You Can Take: After Testing

Share genetic information with family members

- Get ready for the conversation.
 - o Collect your genetic test results.
 - o List your family members.
 - o Decide when and where to talk with them.
 - o Practice what you will say.
- Consider how a family member might react.
 - Finding out about an inherited gene mutation in the family can result in different emotions.
 - o Family members may react positively, negatively, or lack any interest.
 - o Affirm their emotions & try not to take their reactions personally.
- Follow up with family members.
 - o Family members may need time and space to process this information.
 - Give them time, but follow up with them to see if they have any questions or need help finding a healthcare provider who can help them.

Learn cancer risks & options for women with BRCA mutations



Ways for women to prevent cancer or find cancer early

- Some women choose to have their breasts removed, and other women choose to have breast MRIs and mammograms.
- Most have surgery to remove their ovaries after they are done having children.
- Pancreatic cancer can be found early by taking pictures of the pancreas (without using any X-rays or radiation).





BRCA Brotherhood

private group

Welcome! Our purpose is to allow men who have the BRCA gene mutation or who have a family member with the gene mutation to discuss the various issues, problems and concerns that we face.

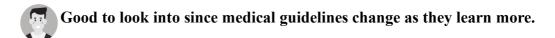


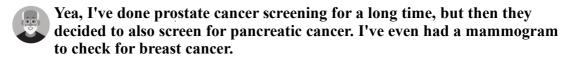
I have a BRCA1 mutation, but can't find much out there for men





Doesn't seem that important for us men - but I want all the right info







Guess I should talk to my doctor about it - thanks



Other Steps You Can Take

Explore these non-profit organizations:

- FORCE https://www.facingourrisk.org
 Seeks to improve the lives of people affected by hereditary cancer through education, research, support, and public policy initiatives.
- Imerman Angels https://imermanangels.org
 Provides support to cancer patients, survivors, previvors, and caregivers through personalized, one-on-one support.
- HIS Breast Cancer https://www.hisbreastcancer.org
 Strives to raise awareness and early cancer detection for all men and to help those who are at high risk due to genetics and other risk factors gain access to regular cancer screenings.

Join a social support group:

- FORCE's Men's Virtual Support Group https://www.facingourrisk.org/support/calendar
- BRCA Brotherhood Private Facebook Group

Sign up for ICARE





- ICARE is a registry open to any adult interested in participating in research.
- Visit https://redcap.link/ICAREconsent or scan the QR code to enroll directly online or contact the team at ICARE@vumc.org or (615) 875-2444.
- By participating in ICARE you can:
 - Be a part of new discoveries, get care updates personalized to you, and find out about studies you may be eligible for.
 - Receive educational newsletters about inherited cancer twice per year.
 https://inheritedcancer.net/newsletters/
 - Follow us on your favorite social media platform @inheritedcancer
 (Facebook, Twitter, Instagram, LinkedIn, or YouTube) to stay updated.

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