GIFTS Unwrapped

The Annual GIFTS Study Newsletter

Volume 1 | Spring 2025

Welcome to the first edition of GIFTS Unwrapped! In this annual newsletter, we will share:

- Updates on GIFTS progress and findings
- How your contributions to this study are helping us learn more about prostate cancer risk, progression and care
- Other prostate cancer news and upcoming events

We hope you find it valuable. If you have any questions about this newsletter or your participation in the study, please contact us using the contact information below.

A Letter from GIFTS Principal Investigators

Greetings!

We're excited to launch GIFTS Unwrapped and celebrate our first year of patient recruitment for our new phase of the GIFTS Study!

When GIFTS started in 2018, we recruited people in Western Washington who had prostate cancer that spread outside the prostate (metastatic prostate cancer). At the time, our goals were to learn who received genetic testing and to offer free genetic testing to people who hadn't received it. Genetic testing can help guide treatment decisions for patients with metastatic prostate cancer and inform patients if their family is at risk for prostate cancer.

During that phase of GIFTS, we learned that only 10% of people with metastatic prostate cancer had received genetic testing before participating in the study. As a result of our study, this increased to 41% of people with metastatic prostate cancer receiving genetic testing.

In 2024, we expanded our study across the whole state of Washington and included people with any stage of prostate cancer and their male family members. In this new phase, we focused on recruiting people from populations that have traditionally been underrepresented in prostate cancer research. Again, we offered free genetic testing to people who hadn't received it. Engaging a more varied population allows us to help even more people impacted by the disease.

The other piece that makes this phase unique is that we will be following participants long term. Our goal is to learn how they use their genetic test results and if there are any changes to their prostate cancer or treatment over time. With this information, we hope to better understand an individual's risk of prostate cancer and personalize screening practices based on genetic risk.

We look forward to interacting with you more over the coming years, including next year when we'll send out the first follow-up questionnaire. **Your participation is what makes this research possible.** Thank you — we are so grateful.

If you have any questions, comments or feedback for our team, please reach out anytime.

Sincerely,

Burcu F. Darst, PhD Heather H. Cheng, MD, PhD

Do you have new contact info?

If you have changed your name, address, phone number or e-mail address, please e-mail us your updates.

GIFTS Contact Information

Email: GIFTSstudy@fredhutch.org
Phone: (206) 667-4738 | (833) 338-1383 toll free
Website: FredHutch.org/GIFTS

Mailing address:

Fred Hutch Cancer Center
PO Box 19024, Mailstop: M1-B208
Seattle, WA 98109

Take Action

✅ **Stay Active for Better Health**
Regular exercise may improve the quality of life for people with prostate cancer and can significantly lower the risk of dying from prostate cancer. There are also many other health benefits, like reducing the risk of heart disease and improving mental health. If you're already exercising, keep it up! If you'd like to start or add to your routine, talk with your doctor about the safest way to do so. To watch **exercise videos made for people with prostate cancer,** scan the QR code or visit: shorturl.at/H2GH9

✅ **Know and Share Your Family History**
Many people don't realize a close relative had cancer until they're diagnosed themselves. **Talking with your family about your cancer history** could help them decide to start screenings earlier — catching cancer at a treatable stage.

✅ **Help Us Advance Research**
You can still **invite your first-degree male relatives (fathers, brothers, sons) to participate in GIFTS**. If you have interested relatives, please email us their name, address and relationship to you at **GIFTSstudy@fredhutch.org**

Meet the Principal Investigators

Heather H. Cheng, MD, PhD

Director, Prostate Cancer Genetics Clinic and Genitourinary Cancer Risk Management Clinic, Fred Hutch Cancer Center
Professor, Clinical Research Division, Fred Hutch Cancer Center
Dr. Cheng is a medical oncologist who treats patients with prostate cancer or who are at risk for prostate cancer. She studies the inherited genetics of prostate cancer risk and the genomics of prostate cancer (how genes in a tumor behave). Dr. Cheng is passionate about using genetics to guide the care of prostate cancer patients and their family members who may be at risk for prostate cancer. Her goal is to help make sure all patients with prostate cancer have access to genetic testing and reduce the risk of cancer in their family members. Outside of work, Dr. Cheng loves exploring the beauty of Washington state and the Pacific Northwest with her family, going to Mariners games (and learning about rules and stats from her tween son), and reading as many books as she can.

Burcu F. Darst, PhD

Assistant Professor, Public Health Sciences Division, Fred Hutch Cancer Center
Dr. Darst is a genetic epidemiologist whose research focuses on identifying inherited genetic risk factors that make people more likely to develop prostate cancer and progress to lethal disease. Her research led to the development of a polygenic risk score (see "Cancer Genetics 101" below) that can identify people with high risk of developing prostate cancer, which may inform prevention, screening and treatment strategies in the future. Dr. Darst works closely with care providers, including Dr. Cheng, to ensure that patients can benefit from and use genetic findings from her research. Outside of work, Dr. Darst loves spending time outdoors — hiking, running, backpacking, cross-country skiing and gardening. Right now, she has two very small kids, so she just daydreams about these hobbies and enjoying them with her kids when they're a little older.

Other GIFTS team members

These key team members will be featured in future newsletters!

- Heather O'Brien (Study Manager)
- Angela Carvajal (Study Coordinator)
- Lauren Brown, MS, GCG (Genetic Counselor)
- Diana Quintero-Perez (Research Interviewer)
- Sajida Hassan, PhD (Research Scientist)
- Hiba Khan, MD, MPH (Investigator)
- Daniel Lin, MD (Investigator)
- Manoj Menon, MD, MPH (Investigator)
- Yaw Nyame, MD, MS, MBA (Investigator)
- Colin Pritchard, MD, PhD (Investigator)

Cancer Genetics 101

By Louisa Goss, MS (Research Associate)

What is genetic testing?

Genetic testing uses a saliva or blood sample to look for changes (also called variants) in a person's genes that are inherited from a parent and may increase the risk of diseases such as cancer.

What is the link between cancer and genetics?

Cancer is a genetic disease. It is caused by changes in genes that control the way cells grow and multiply. Each cell has a copy of your genes (long strands called DNA), which act like an instruction manual to make proteins. Proteins are often referred to as the "work engines" of the body and are responsible for repairing and growing cells, coordinating bodily functions and transporting/storing nutrients. Scientists have found hundreds of genetic changes (variants) that stop genes and proteins from working properly and help cancer form, grow and spread. Genetic changes can occur because of random mistakes, changes from environmental carcinogens (like tobacco smoke), or because they are inherited from one of our parents.

Does having a genetic variant cause cancer?

Inheriting a cancer-related genetic change can increase your risk of cancer but doesn't mean you will definitely get cancer. Some genetic changes contribute to a higher risk of developing cancers (a change in a gene called *BRCA2* impacts ability to repair damaged DNA), but cancer risk can also be influenced by combinations of many genetic changes (hundreds or even thousands of changes) that each contribute a very small amount of cancer risk. Even if someone has a cancer-related genetic variant, a healthy lifestyle and environmental factors play an important role in cancer prevention.

How was my saliva sample used for genetic testing?

Your saliva sample was used to determine if you have a known inherited risk factor using the University of Washington's BROCA panel. If your results indicate that you have a variant in one of ~80 tested genes, it's considered a "positive" result. A positive result can inform testing recommendations for your family members and can sometimes inform treatment decisions. Our study's genetic counselor reaches out to all GIFTS participants with a positive result to discuss these options and is also available to meet with participants with negative results.

What is a polygenic risk score?

We measure the combined risk of the genetic changes that contribute a small amount of cancer risk using what we call a polygenic risk score ("poly" meaning many and "genic" involving genes). Although polygenic risk scores can be very predictive of developing cancer, they are harder to interpret than individual variants. Because of this, we are currently only using polygenic risk scores for research and not returning results to patients. One goal of GIFTS is to understand how polygenic risk scores could be provided to prostate cancer patients in the future.

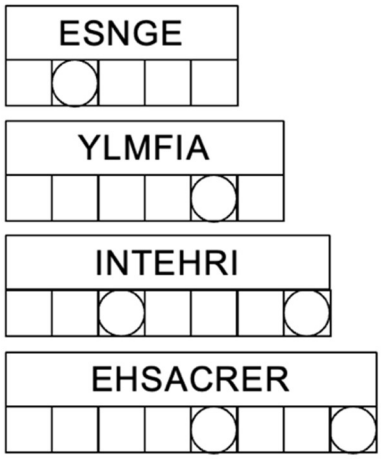
We hope that the GIFTS Study will give us new insights into the effectiveness and impact of genetic testing in all populations.

Glossary

DNA: Deoxyribonucleic acid (DNA) carries instructions that tell our bodies how to develop and function.
Genetic variant: A change in DNA that was inherited from a parent or acquired in a person's lifetime.
Polygenic risk score: Many genetic variants combined in a single score that represents a person's unique genetic risk of a condition, such as prostate cancer.

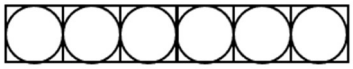
JUMBLE

Unscramble each of these jumbles:



Now arrange the circled letters above to form the surprise answer in the following statement:

ALL YOUR EFFORTS CONTRIBUTE TO IMPROVING THE



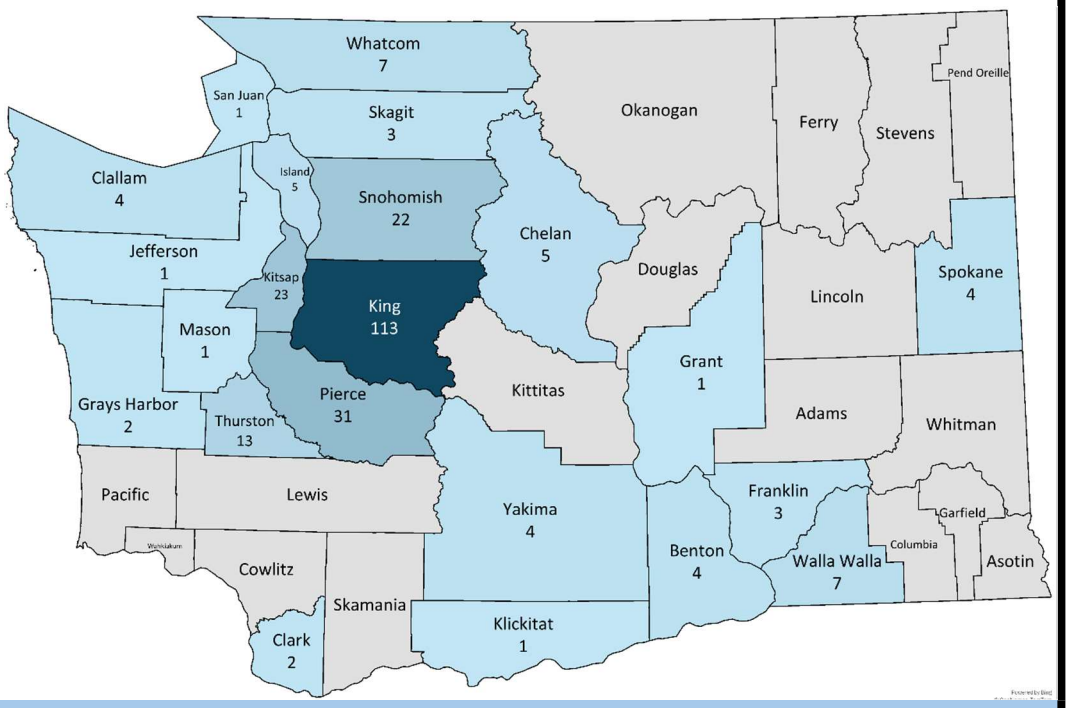
OF PROSTATE CANCER PATIENTS!

GIFTS Participants as of April 2025

We have enrolled 280 participants into GIFTS, including:
241 prostate cancer patients and 39 family members (23 of whom live outside of Washington state). Of these participants, we have identified 15 people who inherited variants in prostate cancer risk genes such as *CHEK2*, *ATM* and *BRCA1*.

We hope this information will be useful to the patients and their family members. In the coming year, we will continue enrolling patients and their family members to represent the entire state of Washington.

Number of Participants by Washington County



Seattle Area Events

IPCR Symposium
May 10, 2025
8 a.m. –3 p.m.
Seattle

Institute for Prostate Cancer Research Symposium

Breakthroughs in Prostate Cancer Research
This event is free and will be held in-person at Fred Hutch.
Sessions will feature advances in treatments for newly diagnosed and advanced prostate cancer, discussions on optimizing prevention and early detection, and strategies for personalized, genetically tailored care.
Join us for this unique chance to hear the latest advances in prostate cancer research from experts behind the progress.

Have questions? Contact **PPCR_SPOREadmin@fredhutch.org**
Register online or scan the QR code:
ppcrspore.formstack.com/forms/ipcr2025

BACPAC Symposium
October 4, 2025
Seattle and Virtual

3rd Annual BACPAC Prostate Cancer Community Research Symposium

This event is free and will be held in-person at Fred Hutch and virtually via Zoom with Yaw A. Nyame, MD, MS, MBA.
An education event for patients with prostate cancer and their caregivers, this symposium is a collaboration of Fred Hutch Cancer Center, University of Washington Medical Center and the Black and African-descent Collaborative for Prostate Cancer Action (BACPAC).

Sign-up to be notified when registration opens:
surveymonkey.com/r/2025BACPACInterestForm

JUMBLE answers: Genes, Family, Inherit, Research, HEALTH