

Research Registry Updates

The Basser Center team wishes you and your family a Happy New Year. Thank you for being a part of the Mariann and Robert MacDonal Cancer Risk Evaluation Center at the University of Pennsylvania's Abramson Cancer Center and the Basser Center for BRCA. The Basser Center for BRCA is the first and only comprehensive center in the world solely devoted to funding research across the globe, educating providers and patients, and advancing care for individuals with BRCA gene mutations.

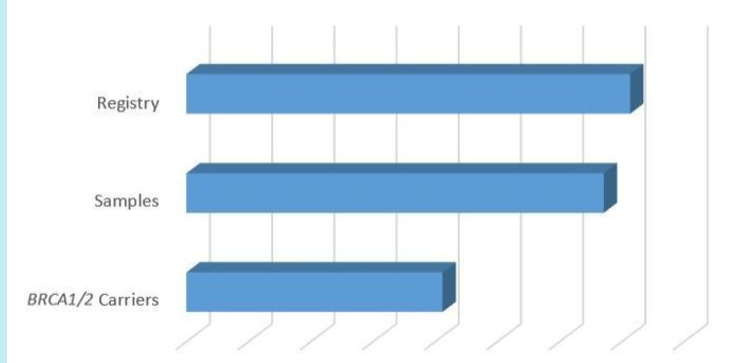
This newsletter proudly shares our exciting achievements and our new initiatives. Your dedication and participation in research has made this progress possible.

Click the button below to view more information about open clinical trials and research opportunities at the Basser Center.

[Open Clinical Trials](#)

Current Research Registry Enrollment Updates

There are currently **7,134** participants enrolled in the Research Registry of which **6,710** have contributed DNA samples. There are **4,117** confirmed *BRCA1* or *BRCA2* mutation carriers and their relatives.



Research Initiatives



Research Registry: Identification and Analysis of Families with Genetic Susceptibility to Cancer

Basser Center Investigators at the Abramson Cancer Center have studied the genetic sources of cancer risk for over 20 years. To support these ongoing studies, we currently have one of the largest collections (also called a registry) of families with known or suspected risk in the world. Participation involves providing personal and family health history, key medical records, and a DNA blood or saliva sample. These samples and clinical data have been used in over 100 studies, and contributed valuable information on genetic risk factors for cancer.

If you contribute a DNA sample and the research laboratory ever discovered information that could significantly affect your cancer risks, this information would be offered to you as part of a genetic counseling session either in person or via telehealth.

There are no costs associated with participation and all arrangements can be made electronically, over the telephone or through the US mail. Travel to the University of Pennsylvania is not necessary for participation. A number of research projects are performed in collaboration with this registry including CIMBA investigators (Consortium of Investigators of Modifiers of *BRCA1/2*), and at other academic sites around the US and the world. Research participants receive a numerical identification number that protects your privacy. Collaborating centers do not have access to personal identifiers.

Clinical Trials

BRCA Vaccine Trial

In 2021, we opened a new research study to test an experimental vaccine to potentially prevent cancer for people with *BRCA1* or *BRCA2* mutations. This study will determine if the vaccine is safe (without significant side effects) and test a new way of administering vaccines. We are also looking to see if the vaccine activates your immune system. Thanks to your participation in our research, both Cohorts (group) A1 and A2 have completed enrollment! Cohort B is currently enrolling.

For more information, contact alexandra.torres@penntmedicine.upenn.edu.

Cohort/Arm	Target Enrollment (n)	Actual Enrollment (n)
Cohort A, Arm 1 <i>(completed enrollment)</i>	8	8
Cohort A, Arm 2 <i>(completed enrollment)</i>	8	8
Cohort B, Arm 1 <i>(now enrolling patients)</i>	14	0
Cohort B, Arm 2 <i>(not open to enrollment)</i>	14	0

Read more about Robert Vonderheide, MD, DPhil, Director of the Abramson Cancer Center, and Susan Domchek, MD, Basser Center Executive Director, in TIME Magazine as they discuss the development of cancer vaccines [here](#).

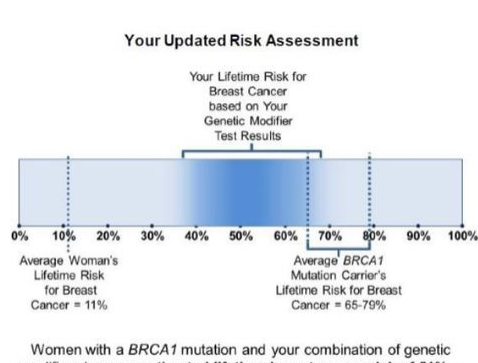
BRCA-P Trial

We recently opened a new research study this month. This study is being conducted to evaluate the reduction in the risk of any breast cancer (invasive or ductal carcinoma in situ [DCIS]) in women with germline *BRCA1* mutation who are treated with denosumab compared to placebo. You may be eligible if you are ages 25-55, with a *BRCA1* mutation and no prior history of breast or ovarian cancer, with no planned preventative breast surgery.

For more information, contact alexandra.torres@penntmedicine.upenn.edu.

Responses to Genetic Risk Modifier Testing Among Women with BRCA1/2 Mutations

Because of the variability in cancer risk estimates among *BRCA1/2* carriers and the risks associated with surgery, a clinical genetic testing panel of genetic risk modifiers may provide more personal risk estimates. It would reduce some of the uncertainty surrounding cancer risk estimates and could help in decision-making regarding prophylactic mastectomy and other less invasive risk management strategies. However, it is unclear how women will ultimately perceive or respond to such novel risk information. The goal of this study is to determine the impact of genetic risk modifier testing on *BRCA1/2* mutation carriers' decision-making about undergoing preventative surgery or pursuing cancer surveillance.



This study has met interim accrual goals. 101 participants from Penn have enrolled; 26 have received results. Total accrual is just over 240 participants across multiple institutions with 44 participants completing the study (6-month follow-up survey completion). Analysis will occur when participants have completed the study measures.

This study is currently closed for enrollment. For more information on this study or to be placed on a list to be contacted if/when the study re-opens, please contact jabrower@penntmedicine.upenn.edu.

Research Registry Annual Follow Up

Annual updates to personal and family history are crucial to keeping our Registry data robust. We will reach out approximately once a year via email (preferred) or mail with a follow up survey.

Please take the time to complete this survey as your updates are important to keeping our Research Registry data current. We are extremely grateful for your contribution to this research! With your help, we can continue making progress in the area of genetics and cancer risk.

Questions or comments? Email us at basserresearch@penntmedicine.upenn.edu. For more information on our research efforts and outreach activities visit our [website](#).

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