

The Patient Voice in Medical Research

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AACR Scientist-Survivor Program 2022



 [Click here for Barbara's voice](#)

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Survivorship Story

My History/Journey. In the last 12 years, I have experienced cancer diagnoses, treatments, and recovery for three different cancer sites: *bladder, breast, and appendix*.

I have been treated at four different hospitals and had most types of cancer treatments/interventions: radical surgery, investigative surgery, chemotherapy, radiation, and am on an anti-estrogen medication regimen.

My survivorship plan includes regular (constant) screenings, scans, blood tests, and follow up appointments with clinicians.

Unsurprisingly, genetic testing showed that I have an inherited gene mutation--*BRCA2*.



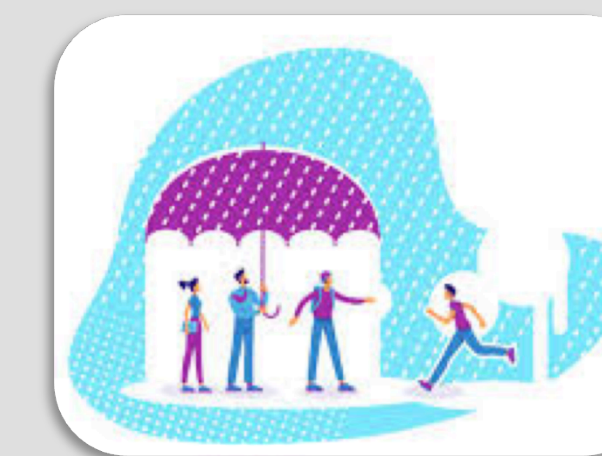
As a single middle-aged woman, I needed the support of family, friends, and community in order to recover from the many challenges I faced.

I also found a sense of purpose and motivation to carry on by supporting other cancer patients and survivors and learning as much as I can about survivorship strategies.

Advocacy/Self-Help Activities

I have participated in various self-help and advocacy activities related to cancer, including:

- A weekly, in-person cancer support group.

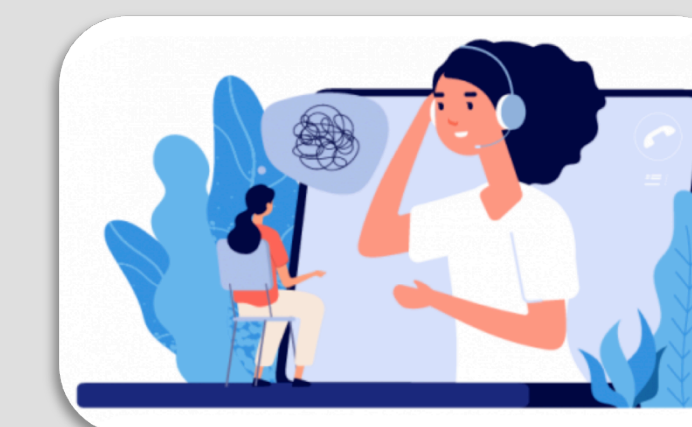


- Site specific support groups, in-person and online, once/month for breast cancer and bladder cancer.



- Fundraising events such as walks, sporting events: United for Her, Living Beyond Breast Cancer, Bladder Cancer Advocacy Network.

- Peer-to-Peer telephone support program.



- Friends of Hospital group.

- Finally, the one that really stuck—serving as a Patient Peer Reviewer and on the Peer Editorial Board, for the Patient Centered Outcomes Research Institute (PCORI).

“Nothing about us without us.”



Patient Centered Outcomes Research Institute PCORI

PCORI is a federally-funded organization designed to encourage medical research that is focused on the patients, both in terms of outcomes and input. PCORI provides research funding for studies that include patient engagement at all levels, in the planning, implementation, analysis, conclusions, and reporting of results.

Patients are not only included as stakeholders in research projects that receive PCORI funding, but are also recruited to serve on National Advisory Panels, as PCORI ambassadors, as members of grant review panels, and as **Patient Peer Reviewers**.

As a peer reviewer, I check that the final research report of PCORI funded research projects includes patients at all stages of the research and that their input was valued and respected. I ascertain whether the report contents, especially the findings, are understandable to patients. I also consider whether the research conducted was something that patients would be concerned about and find relevant.

Investigators have reported that the comments of the patient peer reviewers are the **most valuable comments they receive**.

My advocacy plans are to encourage more cancer researchers to embrace patient engagement and to make it easier for cancer patients to engage in research as “citizen scientists.”

My PCORI profile: [Video](#)