

NURSE CANCER SURVIVOR BRINGS PATIENT PERSPECTIVE TO RESEARCH PLAN

Medical professionals are the ones who most often make decisions about clinical research studies. Patients are the “subjects.” But an independent non-profit funded by Congress in 2010 set out to change that. They put their focus in their name: The *Patient-Centered* Outcomes Research Institute or PCORI.

In Atlanta, one organization that has received three tiers of awards from PCORI is putting the focus on cancer survivors. They are involving men and women of various ages, with different cancer diagnoses and ethnic backgrounds, to have a say in what research would most impact their lives.

One person on the PCORI team is both a nurse and a 21-year breast cancer survivor, Cecilia Hammond, MSN, RN. Her cancer journey started in 1996 when she was diagnosed with advanced stage breast cancer that required her to go through surgery, chemotherapy, radiation therapy and even a clinical trial where she had a bone marrow transplant. And she was only in her mid-30s.

One of the fortunate breast cancer survivors to have no recurrence, Cecilia admits that no matter how many years out you are from your cancer diagnosis, the fear of it coming back still remains. In fact, she still visits her oncologist every year.

Cecilia became involved with the Georgia Center for Oncology Research and Education when she was working on her Master’s Degree in Nursing from Benedictine University in Illinois in 2013. Her capstone project involved investigating the role of the Nurse Navigators in Georgia in referring patients to Cancer Clinical Trials, something to which she could relate both personally and professionally.

Soon after, Nancy Paris, Georgia CORE President, asked her to join Georgia CORE’s Advisory Board, bringing both her professional and personal strengths, among them being her ability to reflect the survivors’ perspective. When Georgia CORE was notified that it would receive a PCORI award, Paris asked Lanell Bellury, PhD, RN, AOCNS, OCN, Associate Professor at Georgia Baptist College of Nursing at Mercer University, herself an expert in cancer survivorship, to co-lead the project with Angie Patterson, Vice President of Georgia CORE and a 17-year cancer survivor. It was a natural fit to ask Cecilia to join the PCORI team.

“PCORI brings a totally different approach to research. Patients are truly at the center of the decision-making process. They are intimately involved in working with the team, looking at the evidence, and determining which research questions would have the greatest impact on their lives,” she says.

Survivors have had a voice in all aspects of the PCORI team’s work: assembling a statewide team; formulating its governance; establishing a strategic plan for developing research questions; gathering evidence; designing the study; and

developing a communications plan. Their ultimate goal is to develop a community-led funding proposal for survivor-centered research. Currently, the team has narrowed the potential project down to three research questions, and is now working to determine which would be most impactful to interventions and outcomes for cancer survivors.

As the Senior Medical Science Liaison at Genomic Health, Cecilia works in oncology every day of her professional life. Her job brings her in contact with medical and pharmaceutical professionals and cancer thought leaders, working to advance clinical research in the field. But, the PCORI process is different. “Survivors are the critical piece in this project, as they should be, since they are the ones who can benefit the most from this effort. It’s very empowering to all the survivors on the committee and I am honored to be a part of the process.”

Caregivers also play an important role on the Georgia CORE PCORI team as well as nurses, cancer navigators, social workers, and physicians. “We’ve assembled a statewide group of diverse stakeholders for this initiative. Facilitating collaboration is the cornerstone of Georgia CORE, and PCORI is a great example of bringing people together to find ways to improve the cancer survivorship experience for Georgia’s 410,740 survivors,” says Georgia CORE Vice President Angie Patterson, who co-chairs the PCORI project and is a cancer survivor.

In addition to volunteering with Georgia CORE, Cecilia participates in the Susan G. Komen Race for the Cure, The Avon 3-Day Breast Cancer Walk, and the 26.2 with Donna Breast Cancer Marathon. She is a member of the American Society of Clinical Oncology, Oncology Nursing Society, and Sigma Theta Tau (National Nurse Honor Society).