

## **CANCER SURVIVORS ARE CRITICAL PART OF GEORGIA RESEARCH PLANNING TEAM**

When companies are researching a new service or product, they get detailed input from consumers to understand their perspective. Fairly recently, interest in the patient perspective has become important to healthcare researchers. Once regarded as “subjects” who had research performed *on* them, patients are now contributing across the spectrum of clinical research development, including in the design and planning of research protocols, selection of outcomes and endpoints, development of recruitment and retention strategies, and dissemination of research results.

The Georgia Center for Oncology Research and Education (Georgia CORE) has engaged a collaborative team of health care professionals, researchers and 9 cancer survivors to design research relevant and meaningful to the person who would ultimately benefit most: the survivor. Funded by the Patient Centered Outcomes Research Institute, (PCORI), the community-based organization has been working since 2015, building a team that is developing a comparative effectiveness research study that would merit significant research funding.

“We feel that the unique perspectives afforded by patients’ lived experiences can inform researchers’ approaches and help identify knowledge gaps. By sharing their experiences of the daily burden of cancer survivorship and their perspectives regarding unmet needs, our survivor partners have been critical in determining the types of research questions most important to them,” says co-lead Lanell Bellury, PhD, RN, AOCN, Georgia Baptist College of Nursing of Mercer University.

Three-time cancer survivor Lynn Durham, Associate Vice President and Chief of Staff at Georgia Tech, sees cancer as a teacher, from whom she’s learned gratitude, patience and humility. She volunteers with Georgia CORE and the PCORI team to help inspire others who are facing cancer. Bobbie Menneg, a survivor and support group leader, is concerned about cancer patients being given nothing more than a book to read or a pat on the back when their cancer treatment regimen is complete.

Angie Patterson also knows, from personal experience, that the cancer journey is not over when you are labeled a “survivor.” Her battle with breast cancer changed her career path, and now, as, Vice President of the Georgia Center for Oncology, Research and Education, she co-leads the PCORI project. “As cancer survivors, we are transforming the research development process. We are not directed by sponsors and investigators, but rather driven by the needs of cancer survivors and their caregivers,” she says. “Cancer makes you step back and look at your life. As survivors, advocacy helps us move forward. We have made a conscious choice to take responsibility for improving survivorship for those who share this difficult journey. Together, we will make a difference.”

### ***The Patient-Center Outcomes Research Institute (PCORI)***

*PCORI is an independent, non-profit organization authorized by Congress in 2010 to fund comparative effectiveness research. The focus is “patient centered,” meaning that the research will provide patients, caregivers, and clinicians with the evidence needed to make better-informed health and healthcare*

*decisions. Patients are partners in research, not just “subjects.” The purpose of “pipeline to proposal” awards are to enable individuals and groups that are not typically involved in clinical research to develop the means to advance community-led funding proposals.*

### ***Georgia CORE***

*Georgia CORE is a public-private partnership that connects cancer care providers, leaders, organizations, and advocates throughout the state. Led by a Board of Directors of cancer experts from academic institutions, hospitals and cancer centers, collaboration orchestrated by Georgia CORE improves access to personalized cancer care and support for patients, survivors, and caregivers. It created GeorgiaCancerInfo.org, the only statewide online information center of its kind, where details can be found on oncologists, clinical trials and treatment centers throughout the state.*

