Spotlight on Lieukin Gore

How Cancer Patients Can Share, Be Heard And Give Back

(NAPSA)—If you or someone you care about has ever been diagnosed with cancer, there is an online resource that may benefit you.

Where To Turn

People with any type of cancer can share their thoughts and concerns with others with similar experiences in the Cancer Experience Registry. It was launched by the Cancer Support Community (CSC), an international nonprofit organization that wants to ensure that everyone affected by cancer is empowered by knowledge, strengthened by action and sustained by community.

CSC's Cancer Experience Registry is a research study for people living with cancer to talk about the issues they confront, listen to what others have to say and give back to the larger cancer community.

"We know that cancer patients at every stage of their journey have many concerns and that people can feel isolated or alone," said Joanne Buzaglo, Vice President of Research and Training at CSC and a two-time cancer survivor. "Our Cancer Experience Registry provides patients with an opportunity to have their voices heard—and also to 'pay it forward' in a sense, to share what they have learned from their experience with other people who are facing these same kinds of issues."

What You Get And Can Give

Anyone who has been diagnosed with cancer at any time can join. The process involves filling out a detailed survey to help identify the most important social and emotional issues for each individual. The data will be used to develop new programs, educational tools, policy initiatives and research projects aimed at improving the quality of care and outcomes for everyone impacted by cancer.

"The Cancer Experience Registry connects patients who are going through active treatment



People who have or have had cancer have a new place to go for information and to express their opinions.

and those who are survivors in a way that allows us to make a difference in our own lives while we are helping others at the same time. By collecting and sharing this information, we are also identifying the gaps that exist today, not just in cancer care, but also in communication," said Kay Johnson, a chronic myeloid leukemia survivor.

As the registry grows beyond its current level of over 6,000 members, CSC plans to add new programs for patients who share specific cancer diagnoses or concerns. The Registry also produces a monthly newsletter that addresses the full range of issues, from side effects to financial worries to diet and nutrition. It provides updates on the data from Registry participants and lets readers submit and respond to questions.

"The Cancer Experience Registry is a very rich and important resource for cancer patients," said Kim Thiboldeaux, President and CEO of CSC, "but what makes it so special is that the insights we are gaining from the Registry come directly from the people who are living with cancer and help us identify and deepen our understanding of the often-overlooked needs of cancer patients."

Where To Learn More

For more information or to join, visit www.CancerExperienceReg istry.org or call (888) 793-9355.