Cancer Health

Connections

A group for patient advocacy was created after an instant connection was made between two women dealing with the same difficult diagnosis.

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When Christine Hodgdon, 41, and Julia Maués, 38, both living with Stage IV metastatic breast cancer, met in 2018, “We just knew we’d be good friends,” says Hodgdon. Adds Maués, “There’s an instant connection with someone dealing with the same difficult diagnosis, a bond. You don’t have to explain the nuances.”

Hodgdon was diagnosed in 2015; her cancer had spread to her lungs. “I thought I would follow a course of chemo, it wouldn’t work and I would die,” she recalls. But she started responding to treatment. She had surgery, chemo, hormone therapy, radiation, “a year of hell.” She did yoga and meditated. Then this self-described type A personality jumped into patient advocacy.

Maués was 29 in 2013 and 25 weeks pregnant at her diagnosis. Her cancer had spread to her bones, liver and brain. She finished the first course of chemo three weeks before her son was born—at term. But the chemo damaged her heart and led to neuropathy so severe she had a hard time holding her baby. For the brain metastasis, she had radiation and, later, brain surgery. “Eventually, I started doing better, the cancer started shrinking and my heart started recovering,” recalls Maués. By 2018, she, too, was ready to fight for fellow patients.

Hodgdon and Maués roomed together at the San Antonio Breast Cancer Symposium (SABCS) in 2018. In 2019, at the American Society of Clinical Oncology (ASCO) annual meeting, they connected with Corrie Painter, PhD, a cancer survivor who is associate director of the patient-driven cancer research program Count Me In at the Broad Institute of MIT and Harvard. Hodgdon invited Painter to tag along to the poster sessions, where researchers stand in front of displays of their abstracts and answer questions. “It was amazing,” recalls Hodgdon. “I was teaching Corrie about my cancer, and she was explaining things to me. I thought, Why don’t we do this at every conference?”

That’s how Guiding Researchers and Advocates to Scientific Partnerships (GRASP) was born. Later that year, at SABCS 2019, the group launched a pilot program to accommodate about 12 patients. The concept was to assemble small groups, run by an experienced patient advocate mentor, of three or four patient advocates, a scientist and, if available, the poster author. The goal was a two-way conversation that would help people with cancer understand the research and school researchers in the lived experience of people with cancer. Demand was so great that they wound up with over 100 people. “We wanted to shift the power dynamic so patients could appreciate their expertise as the ones living with the disease,” says Hodgdon. The mentor’s role is to “make sure the scientist is explaining things clearly and not using a lot of jargon and to make sure the patient advocates share their stories and ask questions.”

GRASP (graspcancer.org) went virtual during the pandemic. It hosted “poster walk-throughs” at the Metastatic Breast Cancer Research Conference in Salt Lake City last September and will run more at the Metastatic Research Society’s annual conference in November, SABCS in December and ASCO in June 2022.

Says Maués, “Patient advocates make research better.”