Grasping Science Together

Words by
Julia Maues and Christine Hodgdon

Most of us diagnosed with breast cancer never planned on entering the cancer world. We had a life and career very distant from cancer. But we won the bad lottery. We were the one in eight. We didn’t ask for it, but cancer became part of our lives. Then it stayed in our lives and even though we didn’t plan on it, we became experts in living with cancer.

In contrast, there are people who one day choose to pursue a career in cancer.

Doctors, nurses, researchers, who dedicate their lives to studying cancer or caring for the people living with it. We have been living with metastatic breast cancer since 2013 (Julia) and 2015 (Christine) and after harrowing experiences of facing our own mortality, we emerged with a renewed sense that this “bonus time” should be spent helping and supporting other patients.

One of the major barriers we identified over the years of our advocacy, was the disconnect between patients and researchers. We are all working towards the same goal to find treatments that can extend the lives of people living with cancer, but rarely do researchers ever have a chance to meet patients and vice versa.

The need to break down these institutional silos inspired GRASP (Guiding Researchers and Advocates to Scientific Partnerships), a patient-led program piloted at the 2019 San Antonio Breast Cancer Symposium (SABCS) in December 2019. The program consisted of a walk-through of scientific posters by small groups of one or two novice patient advocates, an experienced patient advocate mentor and a scientist or clinician. We wanted the program to represent a level playing field where each individual was an expert in their own right - clinicians are experts in treating patients with cancer, researchers are experts in the biology of cancer, and patients are experts in living with cancer. Together, patients and professionals are experts in cancer and that’s why patient advocates should have a voice in cancer research and policy. We know what it feels like, we know our priorities and we should have a seat at the table.

At the SABCS conference, GRASP participants met with their small groups on the morning of the poster sessions and after short introductions, headed to their assigned posters to talk with presenters and learn about research findings. Posters chosen for GRASP walk-throughs were honored with an “Amanda” emblem that featured the portrait of Amanda de Fiebre, a young woman and dear friend who lost her life to metastatic breast cancer this past August 2019.

Amanda had attended SABCS for the past three years and loved the poster sessions. She was not afraid to talk to researchers, tell her story, ask questions, and educate scientists about the realities of living with cancer. Amanda’s family kept her memory alive with the Amanda de Fiebre Legacy Travel Grant which sent advocates to San Antonio who otherwise would not have been able to attend. We hoped to instill within GRASP advocates Amanda’s fearless and persistent spirit to advocate more effectively and voraciously for themselves and their communities.

What was originally planned as a small pilot program, grew to an inaugural event of 120 participants. During the GRASP poster sessions, scientists, patient advocates, and clinicians gathered together sharing stories, laughing and learning. The poster presenters were thrilled to meet people who understand the realities and hardships of a cancer diagnosis, either as patients living with cancer, or as the family and friends who supported a loved one through a cancer diagnosis, or just loved one to cancer. Scientists and clinicians who participated were invigorated by the experience and eager to return to work and make progress towards providing better lives to those affected by cancer.

One researcher said, “Patient advocates humanize the science. The best research questions come from patients. They allow researchers to prioritize what needs to be done.” To which one patient responded, “I was reminded that they (the clinicians and researchers) are just human like us.”
Participant Perspective

WORDS BY
Jasmine Souers

As an African American patient advocate diagnosed at the age of 26, I’m always looking for ways to make the journey easier for the young black women diagnosed after me. Having the opportunity to not only attend the San Antonio Breast Cancer Symposium (SABCS), but participate in GRASP was absolutely amazing. When I co-founded For the Breast of Us, a breast cancer community for women of color, I knew we’d need the support of non-women of color if we really wanted to elevate the issues in our communities. Because let’s face it, mainstream media tends to turn a blind eye to the challenges people of color face.

My partner, Marissa, and I created an Accomplice Guide in an effort to help non-women of color support our fight against breast cancer health disparities, but GRASP founders Julia and Christine not only pledged to make sure their advocacy efforts included women of color, they gave nearly a dozen black women the chance to meet and learn from some of the brightest minds in breast oncology – something many of us wouldn’t have been able to do otherwise.

I was really nervous about the poster tour segment of the conference. SABCS was really my introduction into the research advocacy aspect of breast cancer and it was a lot of information to take in during the week, but the poster tour was incredible. It wasn’t overwhelming at all. It was informative, engaging and it seemed to be helpful for both the researchers and the participants.

It was eye-opening to see the needs researchers were focusing on and the different ways they were trying to address the unique issues of different breast cancer patient populations.

It was clear we were in a safe learning environment. The small groups gave us an opportunity to have conversations about research without the fear of appearing unintelligent. It also helped that everyone on the team knew everyone else’s role so it leveled expectations. I appreciated the opportunity to give researchers ideas about how their research could be expanded to help under-served breast cancer communities and to also affirm some ideas I, myself, had about ways to help women affected by breast cancer.

As soon as I returned home, I started referring women of color in the For the Breast of Us Facebook group to Julia and Christine because more women need to have the experience I had. More women need to be exposed to breast cancer research in an approachable way. And more women of color need the opportunity to use their experiences to help inform research as well. It was an honor to be in the first class of GRASP participants.

Editor’s Note: Learn more about GRASP at thestormriders.org/grasp.
The two of us are white women. We are living with metastatic breast cancer and engaged in advocacy to allow people with cancer to live longer and better lives. In this role, we get our voices heard by writing articles, speaking on panels, participating in advisory boards, or reviewing grants.

We have always seen ourselves as allies to people of color and thought it was unacceptable that certain population groups experience disparities in cancer outcomes. But we decided that “not being ok” with something this terrible wasn’t enough! We had to act.

Inspired by the work of Maimah Karmo from The Tigerlily Foundation and Jasmine Souers and Marissa Thomas from For the Breast of Us, all early stage breast cancer survivors who always include the metastatic experience, we decided to make an inclusion pledge.

WE PLEDGE TO NOT PARTICIPATE IN ANY ADVOCACY INITIATIVE - PANELS, ADVISORY BOARDS, PLANNING COMMITTEES, PROGRAMS, ETC - THAT DON’T INCLUDE THE EXPERIENCE OF PEOPLE OF COLOR.

Now it’s your turn.
What’s your #InclusionPledge?