

Patient advocates: “Our job is purely about patient safety”

by Heidi Nelson, MD, FACS; and David M. Ota, MD, FACS

In the last issue of the *Bulletin* (*Bull Am Coll Surg*. 2009;95(12):29), we discussed the role of the American College of Surgeons Oncology Group (ACOSOG) in promoting patient safety. We described how ACOSOG is charged with conducting clinical trials that ensure the safe introduction of effective new therapies. We also outlined, in brief, how the complex system of oversights and the team of patient advocates work together to safeguard patients enrolled in clinical trials. In this article, we provide a more in-depth examination of the ACOSOG patient advocates—who they are and what they do to contribute to the scientific effort of ACOSOG.

Who are patient advocates?

Since ACOSOG is sponsored by the National Cancer Institute (NCI), we offer the NCI definition of the patient advocate as a starting point:

A person who helps a patient work with others, who [has] an effect on the patient’s health, including doctors, insurance companies, employers, case managers, and lawyers. A patient advocate helps resolve issues about health care, medical bills, and job discrimination related to

a patient’s medical condition. Cancer advocacy groups try to raise public awareness about important cancer issues, such as the need for cancer support services, education, and research. Such groups work to bring about change that will help cancer patients and their families.

To examine the day-to-day contributions of patient advocates engaged in cancer trials, we invited Bettye Green, RN, the chair of the ACOSOG Patient Advocacy Committee, to offer her insights. We started by asking Ms. Green why, and how, a person decides to become a patient advocate, as well as what is required to become certified or credentialed.

“Just by desire, they decide they want to work with a researcher to find a cure for cancer,” said Ms. Green. “Once they decide to become an advocate, they voice that desire; they seek out and find the opportunities to work with researchers who work on cancer. There is no credentialing yet for patient advocates. There are colleges working on developing programs that would award degrees for advocacy, but they are not available at this time.”

We also enquired about the patient advocates who

work with Ms. Green on the ACOSOG committee and about the role of the committee in promoting the science of ACOSOG.

“The Patient Advocacy Committee of ACOSOG is constituted with rich diversity,” said Ms. Green. “The 13 members of the committee are people from different backgrounds with different experiences and expertise. For example, the ACOSOG Patient Advocacy Committee includes Native Americans, African-Americans, Hispanics, women, men, old and young individuals. Folks are from different parts of the country and have experience in teaching, fundraising, and recruiting. All who serve ACOSOG have some personal connection with cancer so the desire to serve is strong.”

Ms. Green continued, “The job of ACOSOG patient advocates is to represent the patient at all steps along the ACOSOG decision-making process and to promote patient safety. To accomplish this aim, patient advocates are fully integrated into ACOSOG scientific committees and activities.”

Ms. Green explained that the process starts with the advocate reviewing the study

idea or concept. They critically address the first key question, which is: will patients find the idea appealing enough to enroll into the trial?

If the answer is “yes,” the next step in the process is the Peer Review Committee. While the scientists are critically appraising the study methods and endpoints for what they need to learn from the study, the patient advocates on the committee are considering the

logistics of the proposed methods. Will the study methods be something a patient can reasonably achieve?

Once a study is approved, the patient advocates work on the dissemination phase. “You need to reach out to patients in a culturally sensitive manner...and you have to reach out into the community,” explained Ms. Green. “The ACOSOG advocates train local advocates to reach communi-

ties to spread the word about trials, and they keep their eye on the accrual goal target.”

And finally, in order to put safety first during the conduct of the trial, patient advocates are part of the ACOSOG Data Monitoring Committee. “We are the patient at the ACOSOG table,” Ms. Green added.

***Dr. Nelson**, of Rochester, MN, and **Dr. Ota**, of Durham, NC, are ACOSOG Co-Chairs.*