What are some significant ways advocates can help advance cancer research?

Advocates can help during the design stage of a trial, identifying questions for researchers that are meaningful to patients. We can share the patient experience, which is important in trial design, but also in activation and recruitment. Advocates can describe what it is like to undergo a particular therapy or to live with a certain disease or side effect. We can also suggest ways to communicate effectively with patients. Since researchers have such an in-depth understanding of the science, sometimes they overlook when the person they are speaking to is not getting the full picture.

How can principal investigators and study teams utilize the advocacy community to build awareness and understanding of trials?

Advocates are great at making connections, so one way we can help is by introducing researchers to individuals at organizations that focus on specific cancer types and serve specific patient communities. PIs and study teams should consider the ECOG-ACRIN Cancer Research Advocates Committee a valuable resource for this. I would also encourage researchers to simply remain open to advocate feedback. Communication between physicians and patients can sometimes be a challenge. We can help with this, and translate information into lay language so patients can feel informed when making decisions.

What projects or initiatives is the Cancer Research Advocates Committee focused on right now?

We’re focused on a couple of things. One of them is shared research – or community-based participatory research – and applying that framework to our efforts. It involves a patient population identifying problems within their own group, and then working on solutions together with the researchers.

We’re also investigating how to better incorporate the community voice into our committee discussions. Attendance at the Group Meetings is limited among community oncology professionals and advocates, so we’re trying to identify other ways to gather community input, especially from the NCI Community Oncology Research Program (NCORP) sites.

What else would you like EA members to know about advocacy or the Cancer Research Advocates Committee?

We are a resource for them, and we want to help make their research as good as it can be. Our committee is really varied: we have different races, ethnicities, genders – and of course different cancers – represented. We include advocates from all the major cancers that are part of ECOG-ACRIN’s research agenda. We can do things as simple as send a letter of support for a trial when it goes to a steering committee, or find a patient willing to attend a call and provide input. These are not huge things, but they can have a big impact.