

Who's Your Advocate?

I don't think we oncologists fully appreciate just how fortunate we are to have advocacy groups in our field. Most other fields of medicine would love to have the added level of support and promotion that cancer advocacy groups provide for our patients as well as for our cause. For the past three years, I have been privileged to serve as chair of the Kidney Cancer Association (KCA) Medical Steering Committee, during which time I have had a behind-the-scenes look at the effect advocacy can have on a field. Supported by a strong endowment grown over 34 years, the KCA can apply the resources it raises directly toward patient care and research.

For patients with a diagnosis of kidney cancer, the KCA provides a credible source of information, resources, and support to which we confidently direct them. If you look for a moment at the "Patients" section of the KCA website (www.kidneycancer.org), you will find a link to numerous resources, including a "Just Diagnosed Toolkit." This toolkit contains important information about kidney cancer for patients written in understandable terms. In this era of disinformation, it is so helpful to point patients to trusted online resources. For patients with financial concerns, resources are available to help defray some of the unanticipated uncovered costs associated with cancer care. Most importantly, patients can find a community to connect with so that they are not alone in their journey, even though every patient with cancer is unique.

What makes kidney cancer particularly challenging is its wide range of histologic subtypes, nearly 20 in number. Histologic subtypes make up the landscape of various cancers. Although clear cell carcinoma is the predominant form of renal cell carcinoma, the remaining 30% of the cancers are essentially orphan diseases. With little investment from industry because of their low incidence, the KCA, alone or in partnership with other advocacy groups, is funding research and infrastructure to support investigators and studies directed at these rare conditions.

I have been fortunate to have received grants from several advocacy groups, including the Prostate Cancer Foundation (PCF), the American Cancer Society, and the KCA, that have helped me during my research career. These grants, both large and small, have supported specific projects and have also given me the confidence and credibility to obtain other funding, build new collaborations with colleagues, and create data that fills the gaps outside large phase 3 clinical trials. In addition, just as

these organizations create community for patients, they create community for us as well.

Advocacy research conferences have filled a special need in my career. Early in my career, small, disease-focused advocacy meetings—like the International Kidney Cancer Symposium and the annual PCF Scientific Retreat—offered me an opportunity to meet and discuss my ideas and experiences with young and older colleagues. These more casual and intimate interactions helped me form friendships and identify role models that have lasted my whole career. Now that I am older, the meetings take on a different purpose. Like a high school or college reunion, they allow me to catch up with old friends and interact with young oncologists who are just starting out in our field. The meetings break up the grind of daily patient care, provide interactive updates in clinical care, and rekindle my enthusiasm for treating patients and doing research. As more and more community oncologists subspecialize in fields like genitourinary oncology, the conferences create a unique opportunity for colleagues in academic medicine and those in community practice to come together.

At Duke, we recently hosted a dinner meeting with some of our local community-based genitourinary oncologists, and I was surprised to hear about some of their challenges. Despite practicing in large health systems, they still feel isolated in their daily practice, with limited opportunities to discuss cases with colleagues because of their growing clinical burden. It dawned on me how important these advocacy conferences could be for them as well. The American Society of Clinical Oncology Annual Meeting is an amazing resource of people and data, but it has grown so large that many people find it overwhelming.

In the coming year, consider attending a cancer advocacy group meeting in a field of your interest. I bet you will be surprised by the people you meet and the information you absorb in a smaller setting. And while you are there, offer your thanks to the organizers. They will appreciate the encouragement, just as all of us do.

Sincerely,



Daniel J. George, MD

