

My Journey to Advocacy

BY SEIJA OLIVIER, BSN, RN



In a very real sense my healthcare career began as a patient in 1999, when I was diagnosed with cancer at the age of 33. I had no experience with healthcare issues and—like many Americans—I assumed that because I had health insurance, I would be fine. I was wrong.

The words “You have cancer” were terrifying enough. I had two young children and wanted to see them grow up. But being told that I might have to pay out-of-pocket if my insurance did not cover the cost of my treatment was devastating. How would I afford my treatment?

The moment the inequality in care really hit me was when I lost my health insurance. Was my life not worth saving? The harsh reality was that without health insurance, I could no longer pay for my oral anticancer medications *and* pay my bills. In the end, I stopped taking the adjuvant oral medication, potentially sacrificing my long-term survival for my short-term needs.

I was diagnosed with cancer for the second time in September 2013. And I could

not help but wonder—if I had been able to afford my medications and taken them as prescribed, would I have had a recurrence? Nobody should have to make those difficult and possibly life-threatening choices.

Making a Difference

I knew then that I needed to somehow work to create change in the way cancer patients are treated in this country. With my experience as a cancer patient as a powerful motivator, I enrolled in nursing school in 2000 to learn more about how we care for oncology patients.

I have since moved into a practice manager position, which allows me the ability to effect change at our program’s policy level. However, I have found that developing better education sessions or more efficient processes in our office was not enough to meet all the needs of our cancer patients. Instead, I had to work for change at the national and state legislative level.


First Steps

I started by becoming involved with organizations that advocate for cancer patients on issues related to access and quality care. The Association of Community Cancer Centers (ACCC) was a great place to get started on my advocacy journey. For example, ACCC hosts an annual Hill Day where members visit with their representatives to talk about issues important to our cancer patients and cancer programs. Not only are these visits important in shaping the future of oncology care in this country, they are so easy to do! ACCC staff takes care of every detail—from providing information

about pending legislation to scheduling appointment times with key legislators to preparing talking points and “leave-behind” materials. ACCC staff makes it simple to take your first steps as an advocate—whether by email, phone, or in person.

At the same time, I was working on advocacy issues, such as oral parity legislation, on the state and local level. The Michigan Society of Hematology and Oncology (MSHO) is a strong, state-based professional organization, which currently represents more than 93 percent of practicing hematologists and medical oncologists in Michigan. MSHO’s mission is to promote exemplary care through advocacy, education, and research. Through MSHO, I have had opportunities to advocate and speak out on issues affecting cancer patients and cancer programs at the state level.

That said, I must confess that I still get nervous when I first begin to talk. Yet even as I struggle with my anxiety about public speaking, I realize that my voice truly makes a difference—nervous or not.

In 2014 I was honored with a grassroots advocacy award at the ACCC 40th Annual Meeting. Sitting next to the other award recipients, I was reminded that it is not our “perfect words” that get the world to change, but our tenacity. It’s that we show up over and over again. That’s how we create change. So I invite you to join me in creating change for our cancer patients—one conversation or one letter at a time. 

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