

How did your experience as a patient lead to an advocacy role?

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My experience as a patient was initially quite poor. I left the hospital with absolutely no information whatsoever. I was terrified. I felt awful physically and I started to do my own homework. I was lucky enough to have access to the information from the National Blood Clot Alliance, which I found by doing my own work. The more work I did learning about blood clots, learning about pulmonary embolism specifically, which is what had happened to me. I soon learned that there were groups of people that were more negatively impacted by blood clots. African American people, 30% to 60% higher incidence rates than Caucasians, doesn't have to be that way. Women have a much worse outcome going to the hospital than men do because they're often misdiagnosed, as was I. I waited almost nine hours before someone decided to check my lungs. They gave me three gynecological exams instead. I could have died in that period. I also learned that African American women who are pregnant, blood clots are a leading cause of death for these women. It doesn't have to be that way. If there was more education and awareness around them, the incidence rates would be much lower. We know there are populations that are more negatively impacted than others. The more work I did, the angrier I became that the information is not uniform to everybody. That led to my patient advocacy work with the National Blood Clot Alliance. I wanted to make sure that what happened to me never happened to anybody else. I want to work with the National Blood Clot Alliance and make sure that information is universal to everyone. We know that we can reduce incidence levels if we have access to correct information and that'll save lives. That ultimately is what led me to my role with the National Blood Clot Alliance promoting patient advocacy for all in blood clots.