

The Benefits of Patient Advocacy: A look into DPC's Patient Ambassador Program

By **Kristy Lukaszewski**, Policy and Communications Director, Dialysis Patient Citizens and Stephen Anderson, Patient Ambassador

Each week, I process Patient Ambassador applications from across the country. Patients have a variety of motivations to join our advocacy network. One common thread among almost all applicants is the desire to help other patients. Stephen Anderson is no exception. I received his application in September of last year. He answered the questions concisely, he had some experience with public speaking, was a patient network representative and like many others, wanted to help other patients. Stephen was quick to jump into action. He spoke with me a few times on the phone about what an ambassador is expected to do, namely to be our representative in the clinic. He joined our monthly conference calls that provide updates on policy, leadership strategies, and ways to engage with your legislators.

When I first joined the patient ambassador program I was nervous. I wasn't sure what my role would be or how I truly could help patients





across the country from my facility in Indiana. I was soon on conference calls with other patients sharing ideas and learning about the complicated relationship ESRD patients can have with the federal government. The primary issue we have focused on in my time as an ambassador is opening Medicare Advantage enrollment to ESRD patients. Even though I'm fortunate to have secondary coverage, I saw many of my fellow patients struggling to afford the 20% Medicare does not cover. When the opportunity to travel to Washington, D.C. came, I quickly and eagerly applied for a chance to attend.

Each year, our advocacy work culminates with an in-person fly-in. DPC will bring anywhere between 20-30 patients from key states and districts to meet with their legislators in Washington, D.C. Decisions are made based on the advocates work throughout the year as well as their congressional districts. Patients who travel to D.C. have dialysis arranged for them and take part in a day long training where they can network with other patients and healthcare professionals while learning about the issues.

Coming to DC was a whirlwind. I had never done anything like this before. I was excited to meet with other patients to share our experiences on dialysis. After learning more about Medicare Advantage and Care Coordination, we worked in groups to prepare for the next day's meetings. I was paired up with a social worker from Wisconsin, so we were set to have eight visits. It was a very busy day, but as we continued, the meetings got easier and easier. The staff really listened to my story and input as a patient.

The patients in our ambassador program work tirelessly throughout the year, sending messages to their legislators, organizing district meetings, and informing patients in their clinic about the issues that can affect their care. *Going to Washington, D.C. was an eye-opening experience for me. To be heard by my legislators was very powerful. To say it was life changing is not an exaggeration. I remember fondly my experience in D.C. and hope to be selected to attend again.*

To join the patient ambassador program, visit <http://www.dialysispatients.org/get-involved/patient-ambassadors>.