



By **Mike Guffey**, DPC Board Treasurer

After the January Education call, I had a couple of people thank me for my participation and say they could tell I feel passionately about my need to advocate on behalf of ESRD patients. For those of you who were not able to attend the call, let me explain my passion for you.

Like many of you, I crashed into dialysis with no prior planning or education. I got up one morning hoping to take in some sun and warm up on vacation and by noon was hospitalized in the ICU with a diagnosis of End Stage Renal Disease. (No matter how many times they tell you not to worry, that is just a governmental label, End Stage does not sound comforting or reassuring to me.)

My journey living (and working) with the disease led me quickly to the DPC website and soon after that to applying for a position on the DPC Board. To my amazement, I was

accepted onto the Board and soon found myself at my first fly-in with no idea what to expect.

Why advocate? To put a human face with an issue. At my first fly in, I learned how important it is to personalize an issue. I could sit with my Senator (or even better his aide) and explain how a proposed bill was either going to improve or worsen my life. It really was not about the facts, although DPC had me prepared with handouts to leave behind with all sorts of facts and figures. It was about the fact that I could explain to them that I was their constituent (a voter they needed to keep their position), and I was willing to come visit them to explain my concerns as well as those of an additional 3,000 dialysis patients and potential voters. (And, I warned them on that first visit, I am persistent. I have been on the DPC Board since 2011, and DPC's representative to Kidney Care Partners



since 2016, and have missed one fly-in when I received my transplant).

Why advocate? It is easy to do. Advocacy does not just mean the Washington fly-in. It means contacting your legislators throughout the year as bills are introduced or being spoken about. It can be a written letter or a telephone call. It can be in person in Washington, D.C. or at an event in your community. It can be as simple as calling into one of their Town Hall calls or going to a Town Hall meeting. Go to their website or the DPC website and sign up for their email list to open the communication channels.

Why advocate? It is rewarding. On the call, I told the story of how after my first fly-in, I was walking through the terminal at Reagan National Airport and noticed an older man walking alongside of me. I was thinking to myself that I felt so much younger and more enthusiastic than that guy before I realized I was walking past a jewelry store with mirrors down its front. Then, I realized that I might not look rejuvenated, but I sure felt it.

Why advocate? We need and deserve their attention. If you and I don't advocate on behalf of ESRD patients, some other group will be there. If we are not communicating to our Senators and Representatives about our needs, somebody else will be about theirs. An available Congressman in an airport is like a homing beacon. Everybody wants a few minutes of his time and a little attention.

One warning about advocacy. It is generally not an overnight process. I often see people on their first fly-in, or their first

visit to the State Capital thinking they are going to go home with the satisfaction of seeing their issue addressed on the spot, with a commitment from their Congressman to do anything in their power to ensure the bill is passed or blocked as you requested.

That usually only happens on TV or at the movies. Not much in DC happens overnight. Medicare Advantage was a discussion topic for several fly-ins before it suddenly received a groundswell of attention and was passed last year, and speeding up the implementation timeframe will still be a topic this year. I spent three years with one Senate aide encouraging him to come visit a local dialysis clinic before he finally took me up on the offer. That was a rewarding experience for everyone involved, including the aide, the clinic patients, the clinic staff, and me.

So again...

Why advocate? If you are able to advocate and not feeling like doing it for yourself, please remember there are others who are physically or financially unable to undertake the effort and are depending on the rest of us to be their voices. If not for me, then for rest of us.

Thank you for giving me this chance to advocate to you. ●

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