



Patient advocacy – something we need to do

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by Sharon Pahlka, kidney patient and life coach

“Want to see the cherry blossoms?” That was the subject of the e-mail sent to me and six other kidney patients in January by Northwest Kidney Centers President and CEO Joyce Jacson and Foundation Executive Director Peter Raffa. They were inviting us to join the NKC delegation to Washington D.C.

Northwest Kidney Centers has a goal to expand advocacy with legislators and to include more patients. I took a deep breath when they invited me and said, “Yes.” I didn’t say that I have never been involved in politics before and was having difficulty remembering my sixth-grade civics class. (Fortunately, there are books like *Congress for Dummies*.) Happily, I was only one in a great group. Muff Jacox (and husband Mark and daughter Madison), Bill Peckham, Nancy Spaeth, Irwin Etter, and Bob Jaffe—all kidney patients—generously shared their experiences with me. I got a first-hand look at being an advocate, and I want to share that with you.

The Kidney Care Quality and Improvement Act of 2005 (S 635 and HR 1298) was introduced in Congress on March 16, 2005. To those of us with chronic kidney disease this is critical legislation.

The NKC advocacy team had three messages for our congressional leaders:

1. One in nine people in the U.S. has chronic kidney disease.
2. Medicare payments for dialysis treatments don’t meet the cost of care.
3. Research is vital for patient outcomes to improve.

Most of our legislators were enthusiastic about supporting the Act and pleased to see us, even though they found the “1 in 9” statistic sobering.

Our legislators were especially delighted to talk to 10-year-old Madison who was the first child born to a kidney/pancreas recipient (Muff Jacox). “Madi” came to be known as our secret weapon. She held her listeners with rapt interest. (Thank you Madi!) As we came out of Senator Maria Cantwell’s office, she said: “Mom, I get frustrated sometimes when you can’t do things other Moms do with their kids like riding a bike together or skiing, but I get to do and see things with you that no other kid gets to and I really like that.” A mom never heard better words.

For our part, we learned that as kidney patients we need to be involved in advocacy in order to put a face on the statistics. The six kidney patients talking to our legislators represented 130 years of additional life thanks to the Medicare Program. Who could ignore that? We all shared our stories, which really are quite compelling.

Bill Peckham said to me, "It is a two-way street...we have a duty to let Congress know the value of the [kidney] program and what they are paying for." And Nancy Spaeth added, "The more they hear from us, the more they can learn from us. They want to do what is right for their community."

I learned that doing advocacy work empowered me. It was easier and less scary than I had thought while I was desperately reading *Congress for Dummies*. The senators and representatives wanted to hear from us...especially from those living in their districts. I thought, "Hey, I can do this!" How empowered do you feel when you know you are making a difference in one person's life...in your community...in the world?

What about you? If you want to be involved, write a letter to your senator and representative. Go to local political meetings. Help educate the public. Ask someone to visit your kidney center. NKC has made it easy to be involved. Go to their Web site: <http://www.nwkidney.org>.

Remember what Margaret Mead said:

"Never doubt that a small group of thoughtful citizens can change the world. Indeed, it's the only thing that ever has."

Sharon Pahlka is a life coach specializing in helping those with chronic health challenges live well and meaningfully. She spent 19 years on dialysis, and for the last 12 years has had a kidney transplant. To learn more and read other Coach's Corner articles, visit her Web site: <http://www.lifeisagift.com>.