



RENALIFE

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**Speak to Be Heard -
Becoming My Own Best Advocate**

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Speak to Be Heard

Becoming My Own Best Advocate

By Suzanne Ruff

Advocacy is defined as “giving aid to a cause.” How exactly does someone do that? Of course, there is the money aspect of giving aid. That’s important and necessary. But, as a writer, I know that everyone has a story. Your story with kidney disease can make a difference. Your story can affect how laws are written, healthcare is determined, and what your elected official learns from you about kidney disease.

I can trace my family’s battle with kidney disease to the 1940’s when my grandmother died, three months after doctors told her there was nothing they could do about her failing kidneys. She suffered and died from polycystic kidney disease (PKD). There is no cure - almost 70 years later. The only treatment is dialysis or a kidney transplant. Although my grandmother died of kidney disease before I was born, in addition to being named after her, my grandmother’s kidney disease has defined my life.

Five of my grandmother’s six children died of the same disease, including my mother. Counting my cousins who have succumbed to kidney disease there are 10 family members gone. One aunt died because not enough dialysis machines were available. Two uncles had to find someone to help them pay for their dialysis treatments before Medicare paid for dialysis. Within my family there has been six kidney transplants (and two living kidney donors) to six different people. Both of my sisters battle the disease now. Three cousins are on

the waiting list for a transplant, one cousin died on the waiting list, and one cousin is on dialysis now, with another one soon to follow once he decides the best dialysis option. There were not options in the 1940’s.

The fact that Medicare covers the cost of dialysis is partly because, in 1971, a group of patients traveled to Washington where dialysis was performed on the floor of Congress. One man named Shep Glazer, a dialysis patient who helped organize patients into a group known as NAPH (the beginning of AAKP) was there. These are his words: *“I am 43 years old, married for 20 years, with two children ages 14 and 10. I was a salesman until a couple of months ago until it became necessary for me to supplement my income to pay for the dialysis supplies. I tried to sell a non-competitive line, was found out, and was fired. Gentlemen, what should I do? End it all and die? Sell my house for which I worked so hard, and go on welfare? Should I go into the hospital under my hospitalization policy, then I cannot work? Please tell me. If your kidneys failed tomorrow, wouldn’t you want the opportunity to live? Wouldn’t you want to see your children grow up?”* (U.S. Congress, House, Committee on Ways and Means, 1971b)(Origins of the Medicare Kidney Disease Entitlement: The Social Security Amendments of 1972 Richard A. Rettig)

You don’t have to go to DC to advocate, though.

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Excellent training through the AAKP organization by Amber Roseboom, a national media consultant, can give you a voice from home using Social Media.

Sadly, though as I write this, one of my sisters is a patient in the hospital with complications from polycystic kidney disease. Her kidneys failed when she was 39-years-old. This is her 22nd or 23rd hospitalization in the last three years.

My frustration levels soar. Feelings of helplessness are replaced by anger, which is replaced by determination. Anger doesn't solve problems, but determination does. Determination becomes advocacy.

The first time my husband and I went to Capitol Hill in Washington DC to advocate, I wondered, "Am I capable? Will I be able to tell a member of Congress my family's story?"

My fears were unfounded because of the excellent preparation given once we arrived in Washington, DC. The day before we went to the Hill, organizations such as the American Association of Kidney Patients (AAKP), the Polycystic Kidney Foundation (PKD Foundation) and the National Kidney Foundation (NKF) joined forces and provided professionals to train and prepare us. On my first visit, there were about 77 of us, representing 21 states.

One of the experts involved in training us was the President of the AAKP, Paul T. Conway. A Washington insider, Conway's vast knowledge, experience, and background of how things work on Capitol Hill, along with his organized presentation, professional speaking skills, and playful sense of humor, helped us relax as we learned.

Each of us was reminded constantly that our stories were important and needed to be heard. Conway's infamous comment, repeated often, helped everyone sit up a little straighter and believe his or her story could make a difference: "Remember, they work for you." It quelled my worries.

Educating us in "Washington speak" so we understood how a bill works its way through Congress, who sponsored the bill and the present status of the bill. It was a refresher course of what we learned in school. We would be well informed for when we would meet with our Senator or House representative.

A rehearsal was done with volunteers. In one training session, retired Rep. Stokes, D-Ohio, "play-acted" with us about what to expect and how to tell our stories. The adage "practice makes perfect" is true. The more you tell your story, the better you become at it. Streamlining the issues, emphasizing my experiences, and catapulting my frustration in a professional manner gave me a voice. Apprehension melted away because of the training (and inspiration) we received.

There is tension, anger and shouting about gridlock in Congress along with repeated mutterings of, "Nothing gets done!" But, no one will hear our stories if we don't try. No one will learn of the issues we face if we don't try. No one will listen to our pleas if we don't try. 🌸



Suzanne Ruff is a member of the AAKP Board of Directors. Suzanne is a family member and a living donor from Mooresville, NC. Suzanne is the Author of "The Reluctant Donor", and received the Midwest Publisher's award for her book. She is a self-employed Free Lance writer. Suzanne is a member of PKD Foundation and the National Kidney Foundation and has experience in fundraising, public policy, patient experience, marketing and public relations

If you would like to join AAKP in its advocacy efforts in Washington, DC, contact AAKP's Communications & Marketing Director Jerome Bailey. He can be reached at jbailey@aakp.org.