Today, if you were to pull back the curtain on AAKP, you would find much of what you would have expected to see back in 1969 – patients, family members and professionals working together, effectively and efficiently on behalf of fellow patients. Our vision is simple – to change the status quo in kidney care so those suffering with kidney diseases today and those yet to be diagnosed have more, better and advanced choices for care, treatment . . . or a cure. Every person has the right to live their best life, to achieve their aspirations and to feel supported in doing so. That quite simply is why AAKP exists and has thrived and grown over the last 50 years – because we are patients too, but most importantly we are people – we are husbands and wives, daughters and sons, executives, professionals, labor workers, and more – we don’t let kidney disease define us – we in turn define kidney disease. With 50 years of effective patient engagement experience, AAKP is leading the way in elevating the independent patient voice and changing the status quo for kidney disease care. So as we enter into our 50th Anniversary, we’d like to thank you for being a part of AAKP and for supporting our work.

Dedicated to improving the quality of life and long-term outcomes for kidney patients through education, advocacy, patient engagement and the fostering of patient communities – AAKP fights for early detection; increased kidney transplantation and pre-emptive transplantation; full patient choice either at-home or in-center dialysis; protection of the patient/physician relationship; promotion of innovation; and the elimination of barriers for patient access to available treatment options.

As we enter into 2019 – AAKP is proud to celebrate our 50th Anniversary! AAKP was founded on grassroots efforts and although the organization has grown substantially in membership and initiatives – we are still very much grassroots in our efforts to effect change and engage the patient community. This principle has allowed AAKP to set itself apart from other organizations in the kidney space and allows us to have a highly diverse and engaged patient membership; to represent the true and patient membership; to represent the true and independent patient voice; to activate our members when the quality of their care is threatened or to celebrate a policy that promises positive change; and to have the respect of government agencies and national healthcare arenas. AAKP’s concerns are heard at a level that can in fact lead to change. AAKP spearheaded an effort back in 1972 which changed the direction of care for thousands of people, and we intend to continue that level of commitment to kidney patients and the kidney community at-large.

The American Association of Kidney Patients (AAKP) is the oldest and largest fully independent kidney patient organization in the U.S.A. Founded in 1969 by six dialysis patients, with doctor encouragement, our Founders helped create the End-Stage Renal Disease (ESRD) Program, saving more than one million lives since 1973.

The group originally called themselves NAPHT (National Association of Patients on Hemodialysis and Transplantation, which later changed to AAKP). AAKP joined forces with other groups to fight for the enactment of the Medicare End-Stage Renal Disease (ESRD) Program, testifying before congressional committees, seeking public support and creating a newsletter (the forerunner of today’s aakpRENALIFE magazine) to keep everyone informed. It was former AAKP President, Shep Glazer, who dialyzed on the floor of the House Ways and Means Committee to help demonstrate the effects of kidney disease and how, at the time, the life-saving treatment of dialysis should be readily available for all those suffering from this condition and be a bridge to transplantation.

This effort was crowned with success in 1973 when Congress enacted the program that continues to provide Medicare funding for dialysis and kidney transplantation today.

After winning this initial and critical battle for the Medicare ESRD Program, AAKP turned its attention to other important issues – the need to establish a secure national organization to preserve the visibility and influence of patients with Congress and other Federal agencies; to define patient engagement; to ensure patients have a seat at the table when decisions are being made that affect their care, choice and outcomes; and to develop national, educational and supportive programs.

Our Founders wanted to form an organization that would elevate the kidney patient voice in the national healthcare arena, provide patients with educational resources to improve their lives, and give kidney patients and their family members a sense of community. These patients met twice a week in the Kings County hospital ward (NY), and while hooked up to primitive dialysis machines for 12 to 18 hours at a time, they brainstormed, researched and eventually formed AAKP.

AAKP, you would find much of what you would have expected to see back in 1969 – patients, family members, living donors, professionals, 125,000+ Patients, Family Members, Living Donors, Professionals

Celebrating 50 Years of Being the Independent Voice of Kidney Patients

1969

6 Patients

2019

125,000+ Patients, Family Members, Living Donors, Professionals

Please continue to help us grow and speak with an even louder voice:
• Join AAKP at www.aakp.org/join
• Become a National Field Ambassador at www.aakp.org/fellow-patients
• Learn more about our National Board of Directors at www.aakp.org/board-of-directors
• Follow us on social media: Facebook @kidneypatient and Twitter @kidneypatients
(Be sure to share and like!)
• Visit our website at www.aakp.org
• Donate to AAKP to support our programs and advocacy efforts at www.aakp.org/giveyourway
Fifty years ago were the days of letter-writing, telephone calls, and newspapers. My father proudly likes to brag, “I made a phone call that resulted in NIH funding kidney disease research!” Dad organized and joined with others to form an Illinois state kidney program that was one of its first and was noted by the powers that be who pushed for the Social Security Acts of 1972.

As the years went by, my mother joined Dad in his passion for helping kidney patients and after a successful transplant, vowed to help others. They always said it was inspirational to meet other patients, to visit their Congressmen and to pay attention to what goes on in Washington, DC that affects kidney patients. Mom passed away in 2003 and Dad is very frail now, but says he is proud of his daughters for carrying the torch, saying, “It’s better than having a pity party if you get involved.”

Suzanne Ruff is a freelance writer for the Charlotte Observer and author of the non-fiction book The Reluctant Donor. The Reluctant Donor was a Finalist in the MIPA book award and also received the 2015 Illumination book award. She has been published in Chicken Soup for the Soul books. She is a living kidney donor and serves on the executive Board of Directors at AAKP, the Living Donor Council of the National Kidney Foundation and volunteers for the PKD Foundation. Passionate about kidneys, Suzanne speaks, writes and volunteers about all aspects of kidney disease, organ donation and the gift of another day.