

**Name:** Suzanne Ruff, AS

**Project Role:** Stakeholder Co-Investigator

**Affiliation:** Patient/Caregiver

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**Personal Statement:** Kidney Disease has defined my life. I am from a family that – for five generations – has been devastated by polycystic kidney disease (PKD). Ten relatives have died with the word ‘kidney’ on their death certificate, including my mother. My sisters have the disease. I am the only one of my parent’s children that did not inherit PKD. We have twenty-one (21) family members who had or have PKD. Six different family members have received kidney transplants. One cousin died while waiting for a kidney transplant. Three cousins are now faced with failing kidneys. I am a living kidney donor. I serve on the Living Donor Council Executive Committee of the National Kidney Foundation (since its inception in 2010). I am a Board of Director on the AAKP (American Association of Kidney Patients). I am also a volunteer and active member of The Polycystic Kidney Foundation since it was formed in 1982. Finding a cure and better care, treatment and options for kidney patients is my passion. I care also about educating living donors, long-term studies on living donors and resources for future potential living donors.

**Hobbies/Interests:** Swimming; Reading; Gardening; Cooking

**Why this project is important to me:** One of my aunts gave up her place on the waiting list for a dialysis machine in the 1960’s. One of my uncles donated his dialysis machine to his county back in the 1970’s (after his transplant) and worked diligently to bring attention to the plight of kidney patients in his state. My father brought kidney patients together forming the first “Friends Chapter” of the PKD Foundation in 1982 and worked tirelessly for thirty years as a volunteer for other kidney organizations. He’s 91-years-old now and says he won’t leave this earth until cures are found for kidney diseases. Amazing people! My beloved niece and godchild, along with others in our family, will face kidney failure in the future. I’d like her to know that I tried to emulate those selfless people who went before us. It is my hope that this project will greatly enhance future kidney patients with better and better treatments, always with the hope that cures will be found.