

VOICES OF PKD

Polycystic kidney disease (PKD) is one of the most common, life-threatening genetic diseases affecting thousands in America and millions worldwide. There is no treatment or cure for PKD. Read on to learn more about those affected by PKD and their experiences.



**Gayle Sellars -
St. John, Indiana**

Gayle Sellars passed away in March of 2013, leaving behind a strong legacy of advocacy and passion for finding treatments and a cure for polycystic kidney disease (PKD).

Gayle first found out about PKD when her mother, Marilyn Zubo, was diagnosed with autosomal dominant PKD (ADPKD) while Gayle was 19. Gayle found out she too had PKD when she was 24 years old. "Gayle was always a very smart, determined and forceful person," Marilyn said.

"She was a champion for our family and for those who live with the challenges of PKD everyday."

Marilyn had a transplant 10 years ago and is in good health. But, Gayle knew life would be better for her mother if she didn't have to worry about insurance and the cost of anti-rejection drugs. Gayle's passion inspired her to attend United on the Hill for the first time in 2009 and she attended every year after, fighting hard to inform representatives of the impact PKD has not only on the individual, but the family as well. It was very important to Gayle to find a cure for PKD, not only for herself, but for her mother, daughters, brothers, nieces, nephews and for all those who suffer from this disease.



**Dale Filsell -
San Antonio, Texas**

I was diagnosed with PKD in 2005 after an MRI on my back. Once I found out PKD was genetic, my mom and sister were tested and diagnosed as well. My grandmother died from PKD, although no one knew the exact kidney complication at the

time. My Uncle Victor died two years later, awaiting a kidney transplant after undergoing a radical nephrectomy and subsequent dialysis. After 21 years in the military, I am now on my ninth assignment, working at Lackland-Kelly Air Force Base in San Antonio. I support the PKD Foundation because we need an organization to fight for PKD and bring as much exposure to this disease as possible. I support the Foundation's continued fight on Capitol Hill to get research funding so we can discover treatments and a cure for this disease.



**Carol Mainolfi -
Lutherville, Maryland**

I have PKD, as does my teenage son. I spent several years on dialysis and recently received a kidney transplant through the paired

exchange program at the University of Maryland Medical Center after a failed transplant in November 2011. I believe my story and experiences can help others by educating them on the choices and resources that are available to them while dealing with the illness, including the financial options as well. I am attending United on the Hill this year because I feel that it is important to reach out to our senators and representatives so that they may better understand the issues faced by generations of PKD families.



**Jana Cox -
Alabaster, Alabama**

I volunteer for the PKD Foundation not only for my daughter who has autosomal recessive PKD (ARPKD), but all of the children out there that have this terrible disease.

A relatively rare form of PKD, ARPKD affects approximately 1 in 20,000 children, and often causes death in the first month of life. It is my hope that one day there will be a cure for ARPKD so that no other child will have to experience what my child has had to endure. If my efforts in volunteering can help make a positive change in the future of one child and their family, my time will have been well spent.



**Christina Prieto -
San Antonio, Texas**

I volunteer because I live with PKD. I think it's important to always have an understanding of the changes that are happening in our PKD community. I got involved after experiencing a ruptured cyst and realizing that I (just like my father)

may too be on dialysis some day. I hope that my younger sisters can see that you can live a perfectly normal life with PKD.





**John Jennings -
Attleboro, Massachusetts**

I am a National Guardsman and Army veteran and had just finished two deployments in Saudi Arabia when I was diagnosed with PKD in 1995. At the time, my only symptom was high blood pressure. Eleven years later, those symptoms began to worsen. I was slated to deploy to Afghanistan with the National Guard, but I couldn't go due to low kidney function. In 2011, I went on the kidney transplant list and began preparing for dialysis. On November 7, I received a kidney transplant, avoiding dialysis by a week and-a-half. Currently, dialysis and kidney transplantation are the only treatment options for PKD. Our hope is that while research continues on PKD, that we can help get the word out about all the people in dire need of transplants. We hope that by sharing our story and our time that we can help many other families.



**Nicole Harr -
Overland Park, Kansas**

Eight years ago, I joined the PKD Foundation's fight to end PKD by becoming a volunteer. I was looking for a way to raise money for research and I found the most amazing people in Kansas City and across the country that are looking for the same thing - a day without worry that PKD will impact our children and every future generation. I volunteer for my children, Emily and Hunter. I am willing to accept what having PKD may mean to me in the future, but I am not willing to accept the effects of this disease for my children.



**Karyn Waxman -
Germantown, Tennessee**

I can honestly say that the satisfaction I receive staying actively engaged as a volunteer in the PKD Foundation's mission to find treatments and a cure for PKD far outweighs the work element by a long shot. Whether it's rolling up my sleeves to organize a fundraising event, networking to raise PKD awareness, or simply empathizing with a fellow patient, I know that my participation is meaningful, purposeful and appreciated. The overall experience is empowering and optimistic...a feeling I greatly prefer to the fear and dread that accompanied my PKD diagnosis 13 years ago. Whatever I can do for my ailing kidneys ultimately helps my heart.



**Eric Myszka -
Chicago, Illinois**

I recently lost my mother to a long hard fight with PKD and the lack of public awareness of the disease always amazed me. I decided to volunteer with the goal to build awareness and provide support to those who are currently fighting the disease in the Chicago area. There is a lot of potential in Chicago to help the Foundation find treatments and a cure for PKD.



**Kari Lusby -
Roseville, California**

My family began our PKD journey in March 2013 after our son, Honor, was diagnosed with ADPKD. Honor had been experiencing severe back pain, and after multiple doctor visits and tests, we were surprised and devastated by the news that our precious four-year-old had PKD. Honor is the first in our family to have PKD so we want to learn everything we can about the disease and how to fight it. Approximately 10 percent of the people diagnosed with PKD have no family history of the disease, with PKD developing as a spontaneous (new) mutation. Once they have it, they have a 50 percent chance of passing it on to each of their children. We are determined to end PKD for our son, Honor, for all of the wonderful families we have met battling the disease and for millions of others worldwide.

How to Connect

- ▶ Visit pkdcure.org.
- ▶ For parents of children with ARPKD or ADPKD, email pkdparents@pkdcure.org.
- ▶ Call 1.800.PKD.CURE (753.2873).
- ▶ Follow us on Facebook and Twitter (@PKDFoundation).
- ▶ Visit Voices of PKD for stories about people affected by PKD: pkdcure.org/voicesofpkd.

