

Living Life to the Fullest

Valen Keefer Inspires PKD Patients to Face Their Health Challenges With Grace



Passport to Life Rotary Event.

If you could see Valen Keefer standing behind a podium beaming with confidence as she very naturally engages her audience, it would be hard to believe that this woman hasn't been speaking her entire life. Valen, who always thought she was going to be a teacher, now captivates audiences all over the nation through her speaking engagements, blogging and interviews. Why the transformation you may ask? The answer is that everything changed when Valen realized sharing her story could help others, "If you stand in front of people and you see the impact it has on them, you can see visually the weight you are lifting from them." The community Valen is referring to are patients with polycystic kidney disease (PKD) and the transplant community. Valen is

a 37-year-old PKD survivor and dual-transplant recipient of a kidney and liver, and now a thriving advocate.

Valen would never have envisioned this path of advocacy that she is on, but now it is what she lives for, and what she feels she was meant to do. "My hope is that I can still help future generations, and touch lives." Valen explains how she "fell into exactly what I love – writing and public speaking." She is the advocate that never stops. She works tirelessly to raise awareness of kidney disease, PKD and organ donation and to help educate and empower the 37 million US adults with chronic kidney disease, the 12.5 million people worldwide with PKD, and the more than 108,000 waiting for a life-sav-



Valen with her mom and dad.



Valen with her husband in their motorhome.

ing transplant. Even during COVID, she cannot be stopped. She and her husband Noah bought an RV and she has now taken her “show” on the road. “Noah and I love the great outdoors and want to continue to honor my donors by safely living our best life no matter the circumstances.”

There are so many experiences Valen can pull from to help educate and guide others. If it is not the five generations of PKD in her family history, her kidney and liver transplant stories, or drawing upon her 32 years as a patient, it is the fact that she has an exuberance for life that is contagious.



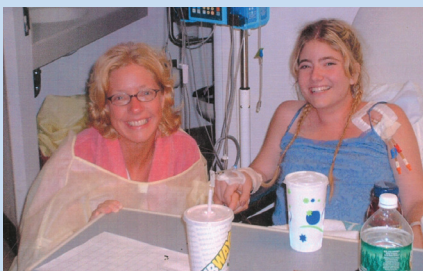
Valen’s Medical Journey

Valen Keefer was diagnosed at ten years old with Polycystic kidney disease (PKD), an inherited disorder in which clusters of cysts develop primarily within your kidneys, causing your kidneys to enlarge and lose function over time. She was sent for an immediate ultrasound when her blood pressure was 160/140 at a routine pediatric check-up.



About the time Valen was diagnosed with PKD.

Valen spent much of her childhood in the hospital with cyst bleeds. At age 18, while spending almost an entire year in the hospital, Valen had a bilateral nephrectomy (removal of both kidneys). Although her kidneys were working at 60%, they had to be removed because doctors could not stop the cyst bleeds. In addition to suffering from severe pancreatitis and being fed through a picc line, Valen had a congenital anomaly (bleeding vessel in her stomach) and endured daily dialysis.



Valen with kidney donor the day after transplant in August 2002.

Valen was too sick to be placed on the transplant waiting list but needed a kidney to survive. On August 13, 2002, world-renowned transplant surgeon Dr. Robert Montgomery performed the risky transplant surgery on 19-year-old Valen, at Johns Hopkins Hospital in Baltimore, MD. Valen’s 8th grade friend’s mother, Sally Robertson was a match and stepped forward to donate her kidney.

Navigating the typical challenges of an immunosuppressed kidney recipient over the next decade or so, Valen’s health took an unexpected turn in the Fall of 2016. Sporadic bouts of sepsis sent Valen to the emergency room with tremors, a fever, abdominal pain, and nausea. Despite a high white blood cell count and bacteria in the bloodstream, all other labs were good. Valen underwent every test possible to find the source of the infection. After several more sepsis episodes, a PET scan was approved and lit up Valen’s liver. Valen was being treated with daily IV and oral antibiotics, but by 2018, needed a life-saving liver transplant. Her doctors did not think she would survive the wait time for a liver in her home state of California, so her hepatologist suggested she get dual listed. Valen’s second life-saving transplant took place at Barnes-Jewish Hospital in St. Louis, MO on August 4, 2018 when she received a liver from a deceased donor.

Upon pathology of Valen’s native liver, it was determined that she did not have primary sclerosing cholangitis (PSC) as originally diagnosed, but rather polycystic kidney disease (PKD) had caused bile duct plate malformations with von meyenburg complexes. This bile duct complication led to the liver infections, which caused the sepsis episodes and ultimately, the need for a new liver. Valen had genetic testing done and it confirmed that she has AD-PKD, PKD1 gene.



Waking up after liver transplant surgery on August 4, 2018.



Television interview for Donate Life Month.

Valen is committed to sharing with others what has helped her be resilient through her journey. “It is worth talking about my experiences in an authentic and positive way so others can be educated and inspired by them,” Valen explains.

She constantly reminds people that it is about honoring your donor by taking care of yourself. “It is important to be an advocate for yourself and an active participant in your care. Listen to your body!” she says.

When Valen shares her experiences, she does not focus on what she went through, but rather leads with empathy - helping others navigate and learn to be their own

advocate. “I am well equipped to relate and provide education, because I know what it feels like to navigate illness and all the stages of transplant,” says Valen.

Valen’s advocacy efforts began shortly after her kidney transplant, when she lived in York, PA. She was connected to the PKD Foundation and soon began creating a local chapter in her area. There was little information on PKD back then, and she never had anyone to guide her as a young girl. “I did not have connections when I was young. I didn’t know of any support groups or others battling what I was.” Remembering that feeling of isolation, Valen says, “I surely strive to be the role model I wish I had. I think feeling alone when I was younger, and not having anyone who tremendously influenced me, has been my drive to hopefully be that person for others.” Today, Valen still works with the PKD Foundation to increase the public’s understanding of kidney disease and raising funds for PKD research.

Valen now advocates full time and has been involved in over 100 events across North America. Her efforts range from speaking engagements, videos, pharmaceutical launches, blogging, kick offs, walks, school assemblies, influencer on social media, podcast interviews, and educational and fundraising events. Working with many associations and organizations to provide hope for others, Valen is “grounded in gratitude” and a shining example of living a productive, joy filled life, post-transplant. “I want to be that hope for people, so they are not alone,” she says. One of Valen’s favorite projects



DreamWalk Fashion Show



Valen and her kidney donor celebrating a transplant anniversary.

was participating in The DreamWalk Fashion Show in NYC. This event promotes body positivity and inclusivity. Organizers choose models for this event based on the struggles they have overcome and their achievements in life. Showcasing her over 60 plus inches of scars, highlighted in glitter, Valen uniquely shared her story in a different way. Valen often describes her advocacy efforts as “therapeutic” and explains how being positive and hopeful in her work has acted as a coping mechanism for her. In the case of this fashion show, Valen says, “I did this with the hopes to inspire others, and it wound up being really inspiring for me.”

Valen and Noah moved to Auburn, CA in 2010. Valen’s advocacy work in CA started when she wrote an essay for the Astellas Contest on how transplantation has



Valen and her husband, Noah.



Riding on the Donate Life Float in the 2011 Rose Parade.

changed her life. She was the western region winner and won a “Ride of a Lifetime” on the Donate Life Float in the Rose Parade. This aided in a seamless transition of her advocacy efforts, and now her reach is coast to coast.

Despite the amazing advocacy work Valen has been doing for over sixteen years, the key takeaway for Valen is that she is impacting lives. “Knowing the impact I’ve had on others, and continue to have, fuels me to share my life, and strive to live the healthiest and most fulfilling life I can and give others hope they can too,” says Valen.

The support Valen receives from her parents and Noah, surrounding her health challenges and her will to survive, has made her more resilient and led her to find her purpose in life - connecting with patients. She now pays it forward. She can help patients with what the “waiting zone” feels like, what it is like to plan for “the call”, the emotions that come with receiving the gift of life from a deceased donor, and with self-love and acceptance. “I feel that being a patient advocate is honoring my donors, honoring the loved ones I’ve never met and lost from PKD, and also taking part in creating a healthier and brighter future for generations to come,” says Valen.

Valen has found that her work with, and on behalf of, patients, keeps her “digging deeper into me as a person





Valen speaking at Otsuka Canada Pharmaceutical's gala celebrating the first treatment for PKD released in Canada.



and why I do what I do." This is never more evident than when she is speaking or writing and her passion for advocacy overtakes her. "It is a feeling like nothing else. It's like everything else disappears, I don't think about anything but what I am saying or writing. The feeling of being so passionate about something - so focused and driven, is priceless," explains Valen.

"I strive to make my donors proud through my actions and the light, joy, knowledge and hope I spread throughout this world. By taking the best care of my health, helping others, and living life with passion, positivity, and purpose." You might say this is Valen's personal mission and she has not wavered from it. Even during COVID. Valen has shifted fear to gratitude. She still has many challenges with her health, but she makes it a priority to focus on the beautiful things.

With several momentous events to celebrate this summer, like her eighteen year kidney transplant anniversary, and her two year liver transplant anniversary, Valen and her husband Noah (who also just celebrated their ninth wedding anniversary) set out in the RV to safely make the most of Valen's beautiful gift of life. "It has been hard to just have my health restored and then be stuck at home not able to live life to the fullest," she says.

Many people are in awe of Valen and her advocacy efforts, but she selflessly says, "I am always in awe of the miracle of transplantation." She exhibits this every day as she gets out there and soaks in the beauty that surrounds us. C

Sampling of Valen's Advocacy Projects

- Founder, Chapter and Walk Coordinator of the South Central, PA Chapter of the PKD Foundation
- Campaign Chair for the PKD Foundation's "Campaign for a Cure" raising over \$1,000,000
- Published biography "My Favorite American" by Canadian author Dennis McCloskey
- Worked with local Senator in PA, Senator Waugh, on Resolutions to raise awareness.
- Coordinated a Renal Education Seminar
- Spokesperson for University Kidney Research Organization
- Ambassador for Sierra Donor Services
- Real Life Expert with Donate Life Hollywood
- Founding committee member for Corks for a Cure PKD fundraising event
- "Dreamer" in the DreamWalk Fashion Show
- Collaborates with PhRMA/Voters for Cures on video ads
- Otsuka America Pharmaceutical Inc. Kidney Patient Advisory Council
- National Kidney Foundation Kidney Advocacy Committee

Awards

- Davita "Kidney Idol"
- Byrnes Health Education Center "Celebration of Life" award
- Helene Kenigsberg Award for Excellence in Public Awareness of PKD
- Sierra Donor Services Outstanding Media Ambassador award
- 1st place winner of Renal Support Network's Annual Kidney Times Essay Contest
- Selected as one of the "12 Inspiring Women of 20 Million in 2012" by Donate Life America
- Winner of nationwide Astellas "Ride of a Lifetime" Rose Parade Contest, rode on the Donate Life Float in the Rose Parade
- Chris Klug Foundation "Bounce Back Give Back" award