



## **American Association of Kidney Patients Field Ambassadors**

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AAKP's Ambassador Program is part of our Center for Patient Engagement & Advocacy that works to ensure that the voices of kidney patients and their families are heard. AAKP Ambassadors are our most engaged volunteers. They are seasoned experts on kidney disease, dialysis, transplant, and living kidney donation, and their involvement is crucial to our mission.

Ambassadors utilize their personal experiences and professional skills to contribute to both the AAKP mission and the larger kidney community based on their desire to serve a cause larger than themselves. AAKP helps provide Federal officials with the patient input they seek, through our Ambassadors' engagement. Ambassadors maintain relationships and communications with their elected leaders to be sure kidney disease is on their radar. Ambassadors participate in focus groups, roundtables, Technical Evaluation Panels (TEPs), surveys, clinical trials, public testimony before Federal agencies, and more.

Ambassadors are part of a movement to create a more informed community locally as well as in our nation's capital. They are recognized as leaders in the kidney community, and their perspectives are sought after to improve diagnosis, treatment, and care for those impacted by kidney disease.

Meet AAKP's Field Ambassadors!

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### **ALABAMA**

#### **Katina Lang-Lindsey**



Katina, a Social Work Professor at Alabama State University, has lived with kidney disease for over 11 years. She received her kidney transplant in April 2007 from a deceased donor where she began to get involved in patient engagement through the local Kidney Foundation. Katina gained her passion for patient engagement when she returned to her full-time job as a social worker and began to work with peer educators in a research project at a hospital in Mississippi. In this position, she learned a lot about patients' experiences on dialysis including her own personal experience. Katina became involved with Mississippi Organ Recovery Agency (MORA) by participating in recipient commercials. She serves as a patient

representative with Network 8 for Mississippi, Alabama & Tennessee. In her role as patient representative, Katina has served on the Medical Review Board and a couple of patient committees such as PAC & LAN with Network 8. Lastly, she serves as a representative on the Kidney Patient Advisory Council (KPAC) and co-investigator on the PREPARE NOW kidney study as a patient representative funded through PCORI. Katina plans to continue to empower patients through awareness, advocacy, and research.

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## **ALASKA**

**Courtney Wilson**

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## **ARIZONA**

**Jerald Collens**



Jerald was diagnosed with IGA Nephropathy while emigrating to the U.S. in 1998. IGA Nephropathy is a condition that has symptomatic treatments but no known cure. Jerald's nephrologist has said that Jerald is his miracle patient due to the amount of time he has been able to sustain livelihood without yet having required dialysis or a transplant. Recently, Jerald had a fistula surgically implanted in his arm in the event that he needs to begin dialysis before a transplant can happen.

Jerald is a family man and father of four. He works daily to support his family and hopes to have transplant surgery in the next few months as his son has been identified as a donor match. Jerald wants to help those suffering with kidney disease and to raise awareness about living kidney donation.

## **Risa Simon**



Known as a positive disrupter, patient advocate and mentor, motivational speaker, published author and founder of the TransplantFirst Academy, Risa is on a mission to help eligible transplant patients bypass dialysis (or become dialysis-free) so they can live their best and longest life. Her preemptive (live-donor) kidney transplant came as a result of following her own proactive communication strategies. She has dedicated her efforts to increasing need awareness and shifting unattainable patient perceptions into a more desirable and achievable reality.

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## **ARKANSAS**

### **Dave Oberembt**



Dave is originally from Montana and earned his Bachelor of Arts in Political Science at Montana State University. Upon graduation he enrolled in the Masters of Higher Education program. After working two legislative sessions in Montana lobbying on behalf of higher education, he realized his passion was in politics and public policy. Dave spent the next 8 years working on various political and policy efforts across the country; including congressional, senatorial, and presidential elections. He married his wonderful wife Emory in

2014 and they happily spend time spoiling their two dogs. Dave currently works as Government Relations Director for the America Heart Association in Arkansas.

In May of 2016, Dave was diagnosed with stage 5 kidney disease and immediately started dialysis. His kidney failure is due to a rather rare disease called IGA Nephropathy, an autoimmune disorder that attacks the kidneys. After some time on dialysis, in January of 2017 Dave was very fortunate to receive a second chance on life and received a donor kidney.

### **Jimmy Warren II**



Jimmy D. Warren, II currently serves as a Program/Special Events Coordinator for Pulaski County Government. Jimmy previously served as a Juvenile Court Officer at the 20th District Circuit Court in Faulkner County. A strong advocate for education, he holds a Master's Degree in Higher Education Administration and a Bachelor's Degree in Communication/Sociology, both from Arkansas Tech University. He is currently pursuing a Juris Doctorate at UALR-Bowen School of Law. Jimmy has held leadership positions at Hewlett-Packard, Apple, and the Conway Area Chamber of

Commerce. He is a member of the Arkansas Tech University Young Alumni Board, City of Conway Safe Routes to School Board Member, and a Junior Achievement classroom volunteer. In 2008, he also served as a communication strategist volunteer during President Barack

Obama's National Day of Service. In his spare time, Jimmy enjoys reading, completing community service projects, and advocating for youth. Jimmy and his wife, Shakira, have 2 daughters, Amaya and Alivia. In January 2017, at a yearly Dr's appointment Jimmy was diagnosed with ESRD. He started dialysis immediately. In December of that year Jimmy received a kidney transplant through a living donor.

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## **CALIFORNIA**

### **Otito Owens**



In 1990, Otito was told his kidneys shut down from hypertension. He started hemodialysis 3 hours a day, 3 days a week – a life changing experience for sure. Otito has been on dialysis for 27 years and is now on the waiting list for a kidney transplant. He drove forklifts for a living, but due to recent complications with dialysis he is now a below-the-knee amputee. He has a prosthetic leg and is up and around, exercising and looking for work.

### **LaMonte Reed**

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## **COLORADO**

### **Jeff Leone**



Jeff was diagnosed with IgA Nephropathy in Feb. 1986 and in end-stage kidney failure by Oct. 1996. He did six months of PD, followed by clinical hemodialysis until his first transplant in Dec. 1999. He has been extremely fortunate to meet his deceased donor's family and continuously engage them in his transplant advocacy since words alone cannot express the gratitude he feels. He can only "not waste the gift" in exchange for their ultimate act of altruism during the most tragic moment of their lives. He has also benefitted from living donation through his second transplant in Jan. 2013. When his wife stepped forward to do an altruistic exchange donation in Nov. 2012, they learned that she became viable due to medical advances subsequent to when she was first ruled out as his donor in 1996!

Jeff is currently a Transplantation Science Educator for the CO and WY OPO, Donor Alliance. He has also served the American Transplant Foundation through administering their Patient Assistance Program and assisting in the development of their One-on-One Mentoring Program for organ recipients, potential recipients, living donors, and caregivers. Lastly, Jeff has served on the CareDX (a diagnostic company) Kidney Patient Advisory Board.

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## CONNECTICUT

### **Stephanie Shabanowitz**

Stephanie was diagnosed with ESRD in 2001 at the age of 15. Despite this, she graduated from high school and attended the University of Connecticut where she earned Bachelor of Arts degrees in History and English. While at UConn, Stephanie had to begin dialysis, choosing to begin on PD so she could do treatments in her dorm while she slept. After graduating from UConn, Stephanie attended the University of New Haven to earn her Masters of Science degree in Education, as well as Connecticut teaching certifications in Social Studies and Language Arts, all while still on PD. In 2010, a failed kidney transplant led to Stephanie starting in-center hemodialysis, which she did until 2013 when she made the transition to home hemodialysis (HHD). Stephanie is currently on HHD and working as a full-time instructional aide at a high school while pursuing a full-time teaching position. Stephanie is active in the kidney advocate community, having been to Capitol Hill on multiple occasions to speak with lawmakers about issues facing the kidney patient community. She also hopes to show that despite being having kidney disease, anyone can achieve their dreams!

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## DELAWARE

### **Clinton Moore**

### **Bill Murray – IN MEMORIAM**



Bill was a self-employed plumber for his company, Shamrock Plumbing, until chronic kidney disease (CKD) and end-stage renal disease (ESRD) forced him to shutter it and take disability. He was biopsy diagnosed with IgA Nephropathy in 1996, at which point his nephrologist told him that he would require dialysis to live. He followed doctor's orders, including changing lifestyle and diet restrictions along with a mind-boggling amount of medicine. He spent years researching his disease and all of his treatment options. He started on peritoneal dialysis (PD) for the first 10 months, but, because of weight gain and having to constantly use the highest strength solution due to his diabetes, he made the switch to home hemodialysis (HHD). He has continued this mode of treatment very successfully since. Bill is an active advocate with a passion for early detection, education, organ availability, and donor support.

Bill passed away on May 26, 2018, waiting for a kidney transplant. He was a super advocate, always educating others and making friends in the process. In the weeks before his death, he attended a White House Rose Garden event about lowering prescription drug costs and met



with HHS Secretary Alex Azar. Bill had a huge heart, and his beautiful blue eyes were gifted to two individuals in need.

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## **DISTRICT OF COLUMBIA**

### **Daronta Briggs**



Daronta is the Founder & CEO of Veterans Transplantation Association. He is a highly decorated Honorable Discharged Desert Storm/ Shield Veteran. A former hemodialysis patient who received a kidney transplant approximately five years ago at Walter Reed National Military Medical Center, Daronta volunteers his time throughout the community in Baltimore City, sharing his story about the importance of kidney health, proper care while on dialysis, post-transplant and organ donation. He also volunteers at Washington DC Veterans Medical Center, Renal Unit.

Daronta has a background in Criminal Justice Services, retiring after twenty years of service with Virginia Department of Corrections. Currently, he is working on establishing The Peer Mentoring Specialist Program at Washington DC Veterans Medical Center. The program will provide mentoring from pre-dialysis to post transplant veteran patients. Daronta is also a member of Team Maryland transplant team, and recently participated in the World Games in Malaga, Spain, representing Team USA.

### **Carlos Cristi**



Carlos is a corporate attorney in Washington DC. His journey with kidney disease began in his late 20's when he was diagnosed with an aggressive form of IgA nephropathy. Since then he has had personal experience with peritoneal dialysis and hemodialysis. His brother selflessly donated a kidney to him in January 2016. He is passionate about volunteering and helping others in his community. When it comes to advocating for kidney issues, Carlos believes it's important for all the different stakeholders to speak in a coordinated manner. As a result, he is active in many different

kidney organizations ranging from the National Kidney Foundation to the support group at local transplant centers. He is particularly interested in spreading the word about the Living Donor Protection Act to members of Congress.

### **Alice Thurston**



Alice retired from federal service and lives in the District of Columbia. For 25 years, Ms. Thurston worked at the U.S. Department of Justice, litigating environmental appeals on behalf of the federal government and Native Americans. She is a former hemodialysis patient and three-time transplant patient. She has periodically served on AAKP's board, including as vice president, and has been a member

of AAKP since it was known as NAPHT (the National Association of Patients on Hemodialysis and Transplantation).

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## **FLORIDA**

### **Gabi Morales**



Gabi has been on dialysis for three years, but her journey started when she was three. Gabi was born with one kidney that worked about 10% and the other just never formed. A month before her 5th birthday, her dad gave her his kidney which lasted 18 years. Gabi is currently on the transplant list at Mayo Clinic in Jacksonville, Florida Hospital in Orlando and Tampa General in Tampa.

### **Janice Starling-Williams**



Janice's kidney failure was caused by uncontrolled hypertension. She has performed all modalities of dialysis – peritoneal, in-center, and home hemodialysis. She has overcome many health obstacles, including a mastectomy, over 30 blood transfusions and IVIG treatments for 2 years to bring her antibodies levels down to receive a kidney transplant. On December 13, 2013, she was blessed with a kidney transplant. Janice's lifetime goals consist of bringing about continued awareness and education about End Stage Renal Decease (ESRD). She is dedicated to enthusiastic and dynamic teaching as a means of creating and nurturing a lifelong love of knowledge in children, women, ESRD/dialysis patients and all who are willing to learn. She has worked at family-owned Starling School in St. Petersburg for over 25 years. In 2009 Janice started AKPSG (All Kidney Patient Support Group) a non-profit organization to help other kidney patients, bring awareness and education about kidney disease.

### **Michael Yaros**

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## GEORGIA

### Edward Drake II



"Why me?" Edward Drake, II asked himself when he was suddenly and unexpectedly diagnosed with renal failure at age 20. Then he asked himself "Why *not* me?" This prompted him to use his negative experience in a positive way—to spread the word that while it is true certain people are at an increased risk, kidney disease can happen to anyone, at any time, and that's why it's so important to get checked early.

Edward received a kidney transplant from a deceased donor in October of 2008, and continues to spread the word about organ donation and early detection through his own charity, the YNOTT? Foundation (Youth Needing Organ & Tissue Transplants), and as a field ambassador for the American Association of Kidney Patients. He frequently visits kidney disease and dialysis patients of all ages, especially young ones like him, mentoring and comforting them with his own story and positive outcome. He also advocates for policies that improve the lives and treatments those with kidney disease and expand patient choices.

### Chardae Sanders



Chardae "Prima" Sanders is an Artist Liaison within the entertainment community from Decatur, GA, whose passion for advocacy was fueled after her first kidney transplant failed in 2010 after 11 months. Prima then co-founded #KidneyforPrima, a local nonprofit organization working with local members of the community and well-known entertainers from the music industry to provide support and fundraising for both #KidneyforPrima and kidney awareness related organizations including, the National Kidney Foundation of Georgia.

Prima's mission is to help empower those affected by kidney disease, provide education to help prevent end stage renal disease and to serve as a visual representation of faith and perseverance. After going into remission from Lupus (2012), losing her beloved father Bobby Sanders to kidney disease (2014), surviving open-heart surgery (2016) and a dialysis patient for 8 years, she recently received her second kidney transplant from a deceased donor on March 13, 2018!

Prima is an alumna of Southwest Dekalb High School (Decatur, GA) and received her Bachelor's of Science in Communication from Kennesaw State University (Kennesaw, GA). Prima has been featured in national publications including CNN, Al Jazeera of America and Billboard. When Prima is not advocating for kidney disease, she is an active staff member with A3C Festival and Conference. Prima's desire is to be the face of kidney disease advocacy within her local and Hip-Hop community and eventually take her mission globally!



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## HAWAII

### Christie Ramos



Christie Ramos didn't realize that during her childhood her body was going through the fight for her life. Both of her kidneys were shrinking due to Vesicoureteral Reflux Disease and that she would need a major surgery to treat the problem at the age of 21. The surgery gave her ten years free of dialysis until she was 31, when she received a diagnosis of ESRD and needed dialysis. Christie decided to be positive and continue her education and her career with the State of Hawai'i. She chose to do in-center hemodialysis and started to experience a rare side effect called temporal lobe seizures a year and half after being on dialysis. She received a Cadaver renal transplant in 2009 but after six and half years her renal transplant rejected, so she needed to go back on dialysis in 2015. She developed dilated cardiomyopathy, PTH and high blood pressure while being on dialysis the second time. She just received her second renal transplant in September 2017.

She received her Bachelor's degree in Psychology in the Fall of 2011 and had her son in the Spring of 2012 with her renal transplant. She has always talked with other dialysis patients about being an advocate and being educated about kidney disease, types of treatment options and research. She has volunteered for the National Kidney Foundation of Hawaii for over 15 years by promoting awareness, helping with fundraising for education and research and participating in events that help promote awareness and education of renal disease. She is also a Patient Advocate for the National Kidney Foundation.

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## IDAHO

### Gloria Peninger

Ten years ago, Gloria met an incredible man who captured her heart. She knew Dale had Type 1 diabetes and end-stage renal failure, but when he told her that his life was about to change because he was going to start dialysis, she had no idea how much *her* life was about to change.

Since that time, Gloria and Dale have been through what seems like a lifetime of ups and downs. Gloria has learned more about diabetes and kidney failure than she ever thought possible. She also learned some important lessons about herself. As a retired Postmaster, she didn't think she had what it takes to engage in a career such as nursing, but she was wrong. As she says, "when the need presents itself, you can do a lot of things you never believed you could."

Gloria has learned so much about caregiving and has been through numerous life-changing experiences. One of the most intense challenges has been a kidney transplant. The whole experience makes you appreciate the little things in life and leads to an awareness that you should enjoy every minute of every day. During that time, Gloria met other caregivers who were

enduring the same thoughts and emotions she was struggling with, and so they were supportive and empathetic to one another. Talking about their individual experiences offered a sense of comfort. The caregiver's role is a very important one, and Gloria believes they need as much support as their loved ones.

### **Dale Rogers**



As an infant, Dale was adopted into a family with three other adopted children. When he was 12 years of age, Dale was diagnosed with Type 1 diabetes. Some years later, as a young adult, he was diagnosed with hypertension. While working in upper management of a national food chain, the hypertension continued to escalate. As a result of job-related stress and subsequent stress in everyday life, Dale's kidneys began to fail. Within a few years it was necessary to begin dialysis. The work-up to receive a kidney/pancreas transplant stretched for a period of 11 months. Incredibly, Dale's adopted sister was a match. She

donated a kidney while an unidentified donor provided a pancreas. The pancreas lasted 18 months and the kidney, nine years and two months at which time Dale had to once again resume dialysis. After undergoing a grueling six years and eight months of dialysis and having suffered numerous life-threatening medical situations, Dale received a life sustaining kidney transplant from an unknown donor. The transplant was well-received giving Dale a new lease on life. This gift has created for him a new focus and personal commitment to help others avoid some of the health-related hardships he has miraculously survived.

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## **ILLINOIS**

### **Kevin Fowler**



Kevin is a healthcare executive with over 30 years of Life Sciences experience in pharmaceutical organizations both commercial and Research & Development. His career has encompassed a breadth and depth of skills and experiences. During his career, he has demonstrated leadership in sales management, training, public affairs, global marketing, patient advocacy, and patient marketing. He formed his own patient advocacy and patient engagement consulting business in 2014, "The Voice of the Patient, Inc. Based upon his personal experiences of having a pre-emptive kidney transplant

(receiving a transplant before even beginning dialysis) in 2004, he has a deep passion for patient advocacy and patient engagement. Kevin brings the patient voice to several organizations as a volunteer.

## Monica Fox



Monica Fox retired from 25 years as a medical administrator in 2013 due to sudden onset of ESRD. During a three week stay in the ICU, she was urgently placed on dialysis. After a total six weeks in the hospital and three weeks in a Rehabilitation Center learning to walk again, she was discharged to home and began in-center hemodialysis. Monica began to advocate for herself and other patients while on dialysis. She is a very active Ambassador for Gift of Hope Organ and Tissue Donor Network and became the face of "Waiting", while on dialysis. Monica shared her story with everyone she knew and on social media. Her gift came as a directed donation through a family who learned about her from a FaceBook friend. Monica's gratitude for her gift continues to fuel her desire to continue the conversation to raise awareness about CKD, ESRD and Transplants. She believes that it is very important to fight for early detection and management, encourage everyone to be registered donors to reduce the wait for transplants, and more research to improve outcomes for patients with CKD and transplants. Monica is living out her life's mission by volunteering with many organization and through independent projects of her own.

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## INDIANA

### Cody Maynard



Cody donated his kidney in February of 2017. Although he didn't have friends or family affected by CKD he believed that it was a simple solution to a serious epidemic--- 'someone is in desperate need of something for which I have an extra'. He wanted to remain anonymous throughout the process and learned his kidney went to a child, resulting in a paired exchange of five people receiving kidneys. Cody will be graduating from Indiana University's Kelley School of Business, majoring in Public Policy, Business Analytics, and Economic Consulting. He has experience interning for the U.S. house of representatives and will continue to pursue solutions for better, cheaper, and more efficient healthcare around the country while working as a consultant for a healthcare strategy consulting firm in Chicago called Healthscape Advisors.

## **Jim Myers**



Polycystic Kidney Disease (PKD) runs in Jim's family. He has lost 5 family members to PKD, including his father. Because of my family's history, he was diagnosed at the age of 25, and was able to put off dialysis until the age of 58. He was on dialysis for 4 years and received a kidney transplant on April 27<sup>th</sup>, 2016.

Jim is currently employed by the Crown Point Community School Corporation as a substitute teacher. He enjoys working with children, especially those with special needs. Jim is a very active kidney advocate with many organizations. His specialty is the ability to utilize social media to help fellow kidney patients and to raise awareness of the plights of the kidney patient. He is a very experienced advocate both at home and on Capitol Hill with his Members of Congress.

## **Curtis Warfield**



Curtis Warfield is a Senior Quality Analyst for the State of Indiana. In 2005 Curtis had a kidney biopsy after a routine checkup found protein in his urine. After 4 months of treatment he was given the all clear but warned this could develop into something worst later in time. In 2012 he was diagnosed with Stage 3 CKD disease due to FSGS and by December 2014 he started peritoneal dialysis. In June 2015 his daughter went to be tested to be a living donor. During the last stages of the testing it was determined that she would not be the best suitable match. His daughter's roommate and a college

sorority sister decided to get tested in October of 2015, "just because" she wanted to help someone. After completing her test she turned out to be a perfect match and on Jan 8, 2016 Curtis received a new kidney. In May of 2016 his donor graduated with her Master's Degree in Public Health.

Curtis is very passionate in advocating about CKD, organ donation and living donors. He provides peer counseling to those who are at end-stage renal failure and those on the transplant waiting list. He speaks to school and youth groups about CKD and organ donation. Curtis has done public speaking events throughout greater Indianapolis on his story, organ donation and CKD. In 2016 Curtis started an annual donor awareness day at his church. Curtis has written several articles for the St Vincent Hospital (Indianapolis) Transplant Unit newsletter about transplant, recovery and life after transplant. Curtis is advocate on Capitol Hill and in Indiana with his members of congress.

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## IOWA

### Nichole Jefferson



It has been Nichole's personal mission to tell her story and promote awareness. She was diagnosed with end-stage renal disease (ESRD) in October 2003. At that time, not only was she unaware of what that meant; she also did not know she was a high-risk factor for developing the disease. After the initial shock of the diagnosis, she decided peritoneal dialysis (PD) was the best option and utilized PD for a few years until she needed to switch to hemodialysis. She received a kidney transplant from a deceased donor on June 12, 2008, but at the time, she didn't realize it was simply another form of treatment and not a cure.

Today, Nichole is waiting for a new transplant.

Nichole has worked with many advocacy groups on Capitol Hill and has provided her personal experience with ESRD to leaders in the field of nephrology. She tries to express the feelings of those who are unable or unwilling to speak for themselves.

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## KANSAS

### Anja Schlagel



"It's probably not hereditary" is what Anja's dad was told when he was finally diagnosed with kidney failure after having suffered for months without a diagnosis. He was in his early thirties with a baby (Anja's sister) and a toddler (Anja) at home. The family lived through years of dialysis, followed by a kidney transplant. By the time Anja was in college he had another kidney transplant accompanied with a liver transplant (Hepatitis B&C likely contracted over blood transfusion to treat anemia killed the liver over time). Then Anja's sister was diagnosed with CKD when she

was barely 30. Anja offered to be a living donor but that plan was foiled when Anja received her own diagnosis in her mid-thirties. Anja's dad just celebrated his 20<sup>th</sup> kidney/liver anniversary; her sister has been on dialysis (PD and hemo) for over 4 years and is still waiting for a transplant; and in December Anja started with PD herself.

Anja works full-time as an engineer and is a mother to two children. Having seen how different post-transplant management in the 80's and nowadays are, she knows how important it is to push medical research and advancement forward. She also knows how important awareness of your risk (and early detection) of CKD is. It allows for proper patient education and a well-informed decision making of treatment modalities, as well as understanding insurance coverage when the kidneys finally fail. After researching opportunities to become involved in the world of kidney advocacy Anja believes she has found a great match in AAKP.



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## KENTUCKY

### Alex Berrios



Alex is a ten-year kidney transplant recipient and his passion is to share his story. In February 2006 when Alex was 26, he was at a local emergency care clinic for a free blood pressure screening. He was sent to the hospital and an ultrasound was completed in which he found out he was born with only one kidney. Alex did in-center hemodialysis for 18 months and in June of 2007, he was given his life back and received a kidney transplant.

Alex's professional background is in ten years in the nonprofit world of working with individuals with intellectual disabilities and helping them get their voice and help them be the best versions of themselves. He would like to now work with patients with chronic kidney disease and help them to see that from diagnosis to dialysis to possible transplant that a quality life can be achieved. Alex wants to be a voice at the table and be involved with research and education.

Alex has a blended but beautiful family. His partner Tamiera, son Zander and daughter Abigail from his previous marriage, all help Alex to be the best advocate for kidney patients and their families.

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## LOUISIANA

### Brandi Nunez



Brandi was diagnosed with kidney disease in in 2014 when she was at her yearly appointment with her lady doctor and they said she should have her high blood pressure checked. She scheduled an appointment with her General Practitioner and that got the ball rolling. She was in stage 3 of kidney failure. Due to a genetic condition, her kidney function rapidly deteriorated and by September 2017, she was on dialysis. Her doctor suggested that at her age, she give home hemo a try. It has been fabulous, and she wouldn't have it any other way. (Well as fabulous as kidney failure can be!) Brandi still works 40 hours a week and plans whatever activities around her 4 treatments. Brandi hopes to empower others to do home hemo as well as be super involved in their condition

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## MAINE

### Genevieve Morgan



Genevieve is a writer and editor in Portland, Maine. Her fiction has won the Silver Moonbeam award for pre-teen fantasy and has been a finalist for the Maine Literary Awards. She was recently the host of the regional interview TV show "The Writer's Zone" and has worked in communications and marketing for the past 20 years. As a volunteer, she is the state administrator for the Women's March on Washington-Maine, and has worked to protect health coverage for the individual market and for those with pre-existing conditions. She was diagnosed with Polycystic Kidney Disease (PKD) in 2010, the first in her family.

She is currently in Stage 4 with the expectation of undergoing a pre-emptive transplant. She has two children, to whom she is dedicating her advocacy for funding for research into a cure for PKD, better choice for kidney patients, and continued focus on quality of life and protections for all kidney patients.

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## MARYLAND

### Ray Harris



Ray has battled Chronic Kidney Disease since 1998. He was diagnosed with Focal Segmental Glomerulosclerosis (FSGS) and started hemodialysis when he was in his mid-20s. He had 2 kidney transplants and now awaits his third as he attends dialysis three times a week. Ray and his wife Lauren are very vocal advocates promoting kidney awareness at every opportunity, including newspaper articles, television interviews, radio programs, and guest speaker opportunities. Ray's many advocacy roles include AAKP Ambassador, UNOS Ambassador, NKF Kidney Advocacy Committee

Member, Living Legacy Foundation of Maryland volunteer and Decision Project Member, MARC Patient Advocate, CMS Subject Matter Expert, Johns Hopkins 5 Nuts & Beans Community Advisory Board Member, NKF of Maryland Kidney Walk Committee Member.

### **Sharron Rouse**



In 2006, Sharron Rouse heard the frightening words, "Your kidneys are failing!" Shocked, confused, and overwhelmed by the news, she decided on that fateful day to take an active role in her kidney care to ensure her kidney journey would not be in vain. The doctors diagnosed her condition as Focal Segmental Glomerulosclerosis (FSGS). The disease was controlled through medication until 2012 when Sharron began hemodialysis. She later transitioned to peritoneal dialysis. On December 2, 2013, Sharron received the gift of life from her sister, Shonte' Simpson.

Sharron actively volunteers with local kidney organizations to raise awareness on issues related to kidney disease and transplantation. She has served on the kidney walk committee for the National Kidney Foundation (National Capital Area) and has been among the top fundraisers for the past several years. To expand the scope of her reach, Sharron recently founded Kindness for Kidneys International, Inc., a nonprofit organization dedicated to educating, encouraging, and empowering kidney patients and their families. Sharron lives in Maryland with her husband Shawn and daughter Kyla.

### **Dave White**



David M. (Dave) White is a healthcare consultant with expertise in patient-centered care, patient engagement, and kidney disease awareness and prevention. He is a grateful kidney transplant recipient and a veteran of in-center dialysis, in-center nocturnal dialysis, and peritoneal dialysis. His mission is to promote population health through advocacy.

White serves on the boards of directors of the American Association of Kidney Patients, the Kidney Health Initiative, and the Veterans Transplantation Association. He chairs the Kidney Health Initiative Patient and Family Partnership Council and co-chairs the Patient-Centered Outcomes Research Institute's Advisory Panel on Patient Engagement.

White is a member of the American Society of Transplantation Transplant Community Advisory Council, the End Stage Renal Disease National Coordinating Center Health Services Advisory Group, the National Kidney Foundation Kidney Advocacy Committee, and is past chair of the Quality Insights Renal Network 5 Patient Advisory Committee. In September 2016 White received the American Association of Kidney Patients Patient Engagement and Advocacy Award and was also honored as the American Kidney Fund Hero of Hope.

White enjoys public speaking, writing, and exercise, and has made regional and national television appearances as a patient advocate. A United States Army veteran, White lives in Hillcrest Heights, Maryland, with his wife and hero, Hilva.

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## MASSACHUSETTS

### John Mazzullo



Before he retired, John was a primary care physician at Tufts Medical Center for 35 years actively involved in the care of HIV patients. He was a founding member of the Boston AIDS Action Committee and Chair of the Education Committee. John also served on the City and State Task forces on AIDS doing government policy work and patient advocacy. He worked with the Boston LGBTQ legal team in helping to extend Medicare coverage to help treat a deforming condition called HIV lipodystrophy. In 2006, John was diagnosed with a highly-invasive and malignant form of bladder (urothelial) cancer which was in the collecting duct of his right kidney. The kidney was removed and he did chemotherapy. Unfortunately, over the next two years the cancer spread into his bladder, prostate and close to his left kidney. In 2008 that kidney was removed in addition to the bladder and prostate. An ileal conduit was made with a urostomy to replace the bladder in preparation for a possible transplant. At that time, John started in-center dialysis. He wanted to continue to work and in-center dialysis was not working well enough to do his job as a physician. John could not have PD because of scarring from all his surgeries, so John and his spouse James, changed to home hemodialysis. In 2010, John wanted to do a transplant with his sister-in-law as donor but it was found, on pre-transplant work-up, that his cancer had spread to his left lung. So, the transplant had to be abandoned. He had surgery to remove the cancer and more chemotherapy, while continuing dialysis. With this life-changing news, John decided to leave work and retire. In 2011, the lung metastases reoccurred, so John did more extensive lung surgery and stronger chemotherapy while continuing dialysis. In 2015, he was cancer-free for 4 years and wanted to transplant, knowing the risks of the cancer recurring. His sister-in-law could not participate any longer, so a young pre-med researcher in Nephrology volunteered. John successfully transplanted in May of 2015. The ileal conduit and urostomy were used to replace the removed bladder but, after many bouts of sepsis and hydronephrosis, he had to have an internal nephrostomy tube placed. It runs from the transplanted kidney to the urostomy and it is working wonderfully. His donor went on to medical school and is pursuing a career in critical-care medicine. John joined the PFAC at the Tufts Medical Center in a very different role as patient, not physician. He still teaches at the Tufts Medical School and keeps busy on various committees at the hospital.

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## **MICHIGAN**

### **Erich Ditschman**



Erich was diagnosed with kidney disease while in high school, but the fifty percent function he had didn't stop him from skiing out west, backpacking the Grand Canyon backcountry, or working full time while pursuing graduate education. At age 36, he faced ESRD. FSGS had shut down his native kidneys, as well as two transplanted kidneys – one donated to him by his wife, Andria. In 2006, he found a small company making a home hemodialysis machine, and convinced his doctor that this treatment would be best for him.

Over the 17 years that he has been dialyzing, he has committed himself to helping others lead fulfilling lives. He maintains a blog and Facebook page entitled, Paddling on Dialysis for Kidney Health, to inspire dialysis patients and others living with chronic illnesses to get outdoors. He regularly visits Detroit area dialysis floors to discuss living well on dialysis and has led webinars concerning home hemodialysis.

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## **MINNESOTA**

### **Aaron Kringler**

### **Lynette Robertson**

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## **MISSISSIPPI**

### **Brenda Dyson**

Brenda started dialysis in 1987 choosing to do home hemodialysis. One year later, she began working for ESRD Network 8 as the Medical Review Coordinator. In December 1990, she received a kidney for her sister Lynda. The transplant functioned for 11 1/2 years before she re-started dialysis in 2001. At that time, she was serving as President of AAKP along with continuing to work full-time. She was chosen to be the first person in the U.S. to use the NxStage machine as part of the clinical trial. In June 2002, she received her 2nd transplant from her sister Lisa. The transplant lasted 12 1/2 years and in February of 2015 she re-started dialysis choosing to do in center hemodialysis. In December 2015, she retired from Network 8 as their Community Engagement Coordinator after working in several positions during her 28 years. During this time, she served on numerous committees, boards and TEPs serving as AAKP's president for 6 years and as President of the Board of the Mississippi Kidney Foundation (Previously NKF of Mississippi). She is currently serving on the Network 8 PAC and represents Network 8 on the national PAC (KPAC).



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## MISSOURI

### Melissa Bensouda



At 24, Melissa was diagnosed with chronic kidney disease after giving birth to her second daughter. After her third child, she had lost all functionality of her kidneys. She was placed on the transplant wait list in June of 2002. Although Melissa initially began dialysis treatments in-center, she was selected to participate in a nocturnal home hemodialysis program. After 6 weeks of extensive training, Melissa set up a machine in her bedroom and dialyzed on her own every other night for 8 hours while she slept. She received the gift of freedom from a deceased donor in April of 2012. Nearly five years post-transplant, Melissa's transplant kidney rejected, causing her to resume dialysis at home. Melissa's passion and commitment to awareness has been revived following such an extensive journey. Despite working full-time and raising three children, Melissa is determined to continue advocating for technology, education, and research to improve outcomes of those affected by kidney disease.

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## MONTANA

### Christl Domina

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## NEBRASKA

### Gary Bodenheimer



In May of 2013, Gary was diagnosed with Membranous Nephropathy disease which is a type of chronic kidney disease (CKD). He has had many ups and downs – many bouts of pneumonia, chronic anemia, severe intestinal bleeding, colon cancer, mild COPD, and Septic Shock caused by the buildup of toxins in his blood. He was given a 5% chance of surviving this infection. The doctors started him on 24-hour-a-day dialysis to and he continued dialysis 3 times a week for 4 hours each treatment until his kidneys began working again. For the last 14 months, he hasn't needed dialysis. In October 2016, he had half of his colon removed along with his appendix and, of course, the cancer.

Gary's wife of 7 years, Cathy, is his caregiver and his rock. She makes sure he takes his medicine on time and goes to his doctor appointments. Cathy supports him in his advocacy efforts by becoming a kidney advocate alongside him.

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## NEVADA

### Maile Robb



Maile has been on hemodialysis since 1995. As a dialysis patient, she takes a very active role in her care that includes keeping up with new treatment alternatives, communicating with health care professionals, and taking part in medical awareness events. Maile and her husband are Self Care Certified through her local dialysis center. Also of significant importance to Maile is her active role in participating with ESRD related organizations and committees, including Network 15, National Coordinating Center (NCC), CMS Dialysis Facility Compare Workgroup, and as Founder of the Reno Kidney Support Group, a non-profit that offers information to patients and their family members about kidney failure. As a long term ESRD patient, she has an impassioned investment to improving the lives of fellow dialysis patients through knowledge, education, projects and programs.

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## NEW HAMPSHIRE

### Paul Rakoski



Paul was diagnosed with Fabry Disease in 2007 after undergoing a series of tests to determine the cause of his kidney disease. He was the first in his family diagnosed followed by 4 other family members. At the time, he and his family didn't foresee the road and hurdles that go along with Fabry Disease and kidney failure. He was fortunate enough to undergo a pre-emptive transplant in 2009, receiving the gift of life from a very special college friend. As a result, he has taken an active role in the Fabry Disease, Kidney, and Transplant communities as a way of paying it forward to others who may benefit from improved treatment options. Paul serves on the patient advisory board for a pharmaceutical company, volunteers for Fabry Disease support organizations, and has worked with patient advocacy groups on Capitol Hill. He has also participated in the Transplant Games of America and the World Transplant Games multiple times, winning medals in swimming, track and field, and golf events.

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## **NEW JERSEY**

### **Iya Bekondo-Granatella**



Iya Bekondo-Granatella is a kidney transplant recipient, and founder of The Iya Foundation Inc., a NJ 501c3 nonprofit that promotes kidney and organ donation awareness. After dealing with chronic kidney disease from age 7 as a result of nephrotic syndrome which later progressed to focal segmental glomerulosclerosis, she was able to get a renal transplant 16 years later. Her transplant could not have been made possible without the help and outpour of support from her community and loved ones. As a result of their selflessness and generosity, she became the recipient of a lifesaving kidney from her mom, Rose. Full of gratitude and a new lease on life, Iya dedicated herself to serving humanity, one community at a time, through sensitization and awareness of kidney disease and organ donation nationally and globally. In addition to Iya's work as an avid kidney and health care advocate, she works as a Business Analyst.

### **Robert Leibowitz**



Robert is a native New Yorker residing in NJ. Diagnosed with kidney reflux at 12 years old, surgery was necessary. Entering adulthood, his creatine level increased over time and he was diagnosed with CKD. He proactively listed himself at five top transplant hospitals in the region for a deceased donor. He also needed dialysis while working full time as a single dad of 5. It appeared that good old fashion advertising secured my fate when he wore a T-Shirt for two weeks at Disney World while on a family vacation with his children. The shirt stated In Need Of Kidney, his blood type and phone number. The result was a successful transplant surgery Jan. 18, 2018 from a total stranger. His mission is to share his story, give other patients hope and educate /convince EVERY healthy person to consider being a live donor.

### **Jason Nothdurft**



After seeing a post on social media advertising the need, Jason volunteered to donate his kidney to Bill Rode, the step father of one of his close friends, on January 14, 2014. Since then, his new purpose in life has been to advocate for organ transplantation and against kidney disease. Jason, police dispatcher since 2007, graduated from Rowan University in Glassboro, NJ with a BA in Political Science. He plans to put his education and experiences to good use to help the government formulate improved health care policies.

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## **NEW MEXICO**

**Jaclyn Starr**

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**NEW YORK**

**Angela Davis**

**Fiona McKinney**



Fiona is originally from Dublin, Ireland and is a Reiki Master and registered Polarity Therapy Practitioner (RPP). Fiona started in publishing with The O'Brien Press and later Stewart Tabori & Change after emigrating to NYC in 1985. She then spent 15 years in advertising/design including the Omnicom Group and Frankfurt Balkind. She was President of New York Polarity Association and Ethics Chair for the American Polarity Therapy Association. While in private practice as an RPP, she worked with women in prison, developing a special program that included yoga/movement, mediation, non-violent communication

skills, aromatherapy, and Polarity Therapy.

After being diagnosed with end-stage renal disease and being on dialysis since April 2008, Fiona became a member of Achilles International, a non-profit, activities-based organization for people with disabilities. With Achilles, she completed the NYC Marathon twice as well as several other races. In Fall 2013, she joined the Achilles staff as Director, Community Outreach. Fiona is also an occasional freelance writer.

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**NORTH CAROLINA**

### **Scott Burton**



Born with a posterior urethral valve blockage that damaged his kidneys, with doctors not expecting him to live 2 days, Scott spent his childhood in and out of the hospital waiting for the day when dialysis would be required. He first went on peritoneal dialysis at the age of 12, waiting 4 years for his first kidney transplant. Countless episodes of rejection and finally losing his transplant 4 years later in January 2003. Scott has spent the last 15 years on in-center hemodialysis and on the list for a second transplant, but due to being highly sensitized, he is a very difficult match.

Scott has juggled day to day life around dialysis, going back to school full time in 2006 and getting a bachelor's degree in media studies - film/video production from UNCG in 2010, self-publishing a book of poetry - telling his own medical struggles through poetry and prose. Having lived this from day one, he most recently set out to turn what many would consider a negative into a positive by launching The Forever is Tomorrow Foundation, a nonprofit organization dedicated to raising awareness, educating and building a resource for both the public and patients and their loved ones through multiple web video series & local events.

### **Kimberly Robinson**



Kim is a wife, mother of 3 children, and grandmother to 3 grandchildren. She was diagnosed with kidney failure two years ago. Her father's side of the family has a hereditary gene that causes kidney failure. She started PD in August of 2017 then had to go on Hemo dialysis in the clinic in October of 2017. Kim has worked in the healthcare field for 30 years. She is a registered sleep tech and then became a regional manager for sleep labs in her area. Kim feels she can help others with CKD, as she knows a lot about the medical field. She hopes to do more to help others that need the help.



### **Celeste Fuller**



Celeste is a “miracle walking”! She retired from the US Navy at 24 with ESRD which she had never heard of before. She was immediately discharged in complete disbelief since she was an athlete and so very young. She was a “special” patient which was truly no reward as most of the time she was treated akin to a lab animal with doctors smiling with glee at her condition. Now 32 years later, Celeste is able to use her life as motivation to other patients to keep hope alive and to advocate for themselves. She has been on every modality, has many other complications, has had three transplants, and continues to support other patients with her extensive personal experience with the hope that they too will help another.

### **Ashley Martin**



Ashley, age 22, is a kidney patient and caregiver advocate. She is currently entering her junior year at The University of Cincinnati. After a recent change in majors she is now studying Biological sciences with a concentration in Biomedicine and a minor in Chemistry. In addition to a Pre-Med fast track. She hopes to go on to become a pediatric transplant surgeon at Cincinnati Children’s Hospital. She has been a caregiver for her mom since 7 years of age. She has also been attending AAKP’s national patient since she was 8 years old. In her downtime, she enjoys shadowing Dr. Gregory Tiao (Pediatric transplant surgeon and Chief of General Surgery) at Cincinnati Children’s Hospital. She also enjoys participating in a club at The University of Cincinnati called CRU and spending time with her boyfriend Miguel and her dog Bailey. Notable achievements include invited member by the FDA to the 1<sup>st</sup> Kidney Health Initiative meeting, panelist on Amgen-sponsored webinar for the American Association of Kidney Patients, invited advocate by The American Kidney Fund to Advocacy on the Hill, RenaLife contributor, and AAKP Ambassador.

### **Toni Martin**



Toni Martin is a patient advocate for kidney disease awareness. She just received a cadaver kidney transplant on 04/03/2018. She is very grateful for this blessing after waiting 7 years for her 2<sup>nd</sup> cadaver kidney transplant. She received her 1<sup>st</sup> cadaver kidney in 2006-2011 when it failed due to CMV aka Cytomegalia Virus. For approximately 6 years, she was a home hemodialysis patient with partnership of DaVita and NxStage Medical dialyzing 6/7 days a week for 2.5 hours each day while trying to work full-time. She has been off and on dialysis since 2001. She was invited in collaboration with AAKP and the American Society of Nephrology (ASN) to represent her State of Ohio on Capitol Hill on March 28, 2018 for Kidney Health Advocacy Day to introduce #KidneyX Project which provides a private-public partnership designed to spur innovation in prevention, diagnosis, and treatment of kidney disease. ASN raised over 25M for this project. The NIH has received additional financial support of 1.5M to help this initiative as well as others to get treatment improvements to patient and caregivers.

She has been on The Christ Hospital Patient and Family Advisory Council for over 10 years. Toni and her daughter, Ashley hosted a kidney diet webinar for AAKP in 2016. She is also an advocate for The American Kidney Fund (AKF) and represented her State of Ohio at Capitol Hill in March 2017 regarding third-party payment of premiums on behalf of patients. In 2015, she was engaged in the First Patient and Caregiver FDA Conference to streamline many kidney disease initiatives as well as provided improvements on missed communications between providers while treating patients as well as improvements into the complexities of getting patients sufficient treatment in a timely manner. At this conference, she learned there are many researchers working to make treatments for ESRD much better for the patients and caregivers as a whole. She has raised money for The Kidney Foundation for several years. She is employed full-time by Medpace, a Clinical Research Organization, trying to overcome many physical setbacks. Kidney disease has changed my life in so many ways. I am an advocate to help others during this difficult journey with trying to stay alive and to live life to the fullest capabilities.

### **Victoria Schmalstig**



Victoria was diagnosed with reflux nephropathy at age 3. Her disease was maintained with medication until shortly after graduating from high school. She has been blessed to have three living kidney donors as complications required her to have multiple transplants. She spent 6.5 years on dialysis between her 2nd and 3rd transplant and did plasmapheresis to bring her antibodies down. She pays it forward by volunteering for Lifeline of Ohio, Team Ohio, YNOTT, Kappa Kidney Camp and now AAKP. She competes in the Transplant Games of America as part of Team Ohio every two years. She serves as a manager for Team Ohio because it is extremely special to her as that is where she met her husband Tony who is also a kidney recipient. She is currently on disability due to multiple back surgeries and very

advanced neuropathy.

In her spare time, Victoria loves to travel, decorate cakes, and spend time with family and friends. She tends to take a lot of photos as she feels she is creating "Memories that would not have been" without her Gift of Life.

## **Sonya Cochran**



and kidney care.

In 1993, Sonya was diagnosed with IgA Nephropathy and she began dialysis in 1996. She was very emotional and cried during several of her treatments, and if it wasn't for her faith and family's support, she wouldn't have overcome the difficulty of knowing she had to be on dialysis for the rest of her life. Sonya learned the disease was hereditary on her father's side and that her grandfather and uncle passed away due to this disease. She began to educate her family and friends about staying healthy, getting yearly checkups, knowing the signs and symptoms of renal failure,

Sonya did not let being on dialysis stop her from living life, and she received her Bachelor of Social Work. She volunteered at a local food pantry and educated participants about having a healthy lifestyle. In 2001, she was blessed to receive a kidney from a deceased donor. Two months after receiving her kidney, she began the Master's program at the University of Oklahoma. She eventually received her Master of Social Work and began working for her Native American tribe as a Social Worker. She also continued to advocate for kidney care by contacting her State Representatives and Congress concerning policy changes. After seven years of having a transplant, the disease came back and affected her kidney, and she eventually went back on dialysis.

After being back on dialysis for 10 years, Sonya received her 2<sup>nd</sup> kidney in January 2017! In April 2017, she was diagnosed with breast cancer and was told she may lose her transplanted kidney due to chemo and meds. She and her family prayed and, as of today she is cancer free and her kidney is doing awesome!

## **Jerry Nailon**



involvement.

Jerry Nailon was diagnosed with ESRD on Thanksgiving Day 2009 and began In-center hemodialysis. In early 2012 a switch was made to Peritoneal Dialysis but a year later was returned to In-center Hemodialysis, due to recurring peritonitis infections, abdominal muscle weakness. On October 4, 2014 the gift of life was received with a Kidney Transplant. Jerry has been actively involved with many advocacy groups and patients to advocate on Capitol Hill and has been a presenter on a patient panel for the ESRD Network. Jerry is committed to further advocate for all patients in advancement of legislation, education, organ donation and increased local patient

### **Candie Gagne**

Candie was employed as a Certified Surgical Technologist at UPMC McKeesport Hospital and Retired Navy Hospital Corpsman, Certified Surgical Technologist.

In December of 2016, Candie broke her ankle and had to have surgery. By February 12, 2017, she was found unresponsive, with a high creatine level. She had emergency dialysis for the next several weeks and an inconclusive kidney biopsy. Her kidneys did not respond to conservative treatment and she was diagnosed with ESRD. In April 2017, she had a catheter placed and in April 2017 started dialysis. Candie is also a caretaker for her husband, who suffers from service-related partial paralysis of the left leg, A-Fib, CHF, and stage 4 kidney disease.

Upon her diagnosis, Candie knew that she wanted to take her experience as a healthcare educator to help other, newly diagnosed patients work their way through the fear of the unknown and be someone that can bridge the gap between being a healthcare provider and a patient.

### **Bobbie Reed**



In May 2013, when Bobbie's son, Alex, was diagnosed with kidney failure, she became his caregiver and biggest advocate. It took nearly a year adjusting to life on dialysis, navigating insurances, figuring out Social Security Disability, and learning the Medicare practices and policies before Bobbie began the search for a living donor.

Penn State University Office of Alumni Relations, Altoona published a newsletter on Alex's need for a kidney donor. An alumnus who read the article was tested and found to be a match. On November 9, 2015, he gave his kidney to my son. There have been ups and downs since transplant, but life is better and his future brighter. The doctors have not yet figured out what caused the kidneys of a 22-year old student athlete to fail. I continue to advocate. It is important to me for others who are in the same situation to find an easier pathway to good health and wellbeing.

## **Lisa Pappas**



Lisa's kidney disease was caused by diabetes. Diagnosed at 4 years old, she has had a lifetime of living with the disease. In her twenties, she was diagnosed with the beginnings of kidney failure. In August 2005, she had her first kidney transplant that was a gift from a special friend. Unfortunately, she had some complications and had to start dialysis the following February. She did nocturnal dialysis for just about a year. In February 2008, Lisa received the gift of a deceased donor kidney. She has been living life to the fullest ever since her transplant. Lisa enjoys traveling, cooking, spending time with friends

and family, and spreading the word about the importance of organ donation. She is looking forward to attending her second Transplant Games in Salt Lake City in August 2018. She also participated in Cleveland in 2016 and even received a silver medal in bocce! She is the current Secretary and past Vice President of the Rhode Island Organ Donor Awareness Coalition, a volunteer with New England Donor Services, a volunteer with the American Society of Transplantation, and a UNOS ambassador.

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## **SOUTH CAROLINA**

### **Angela Lattimore**



Angela Lattimore is a tremendously brave and caring person. When faced with the choice between her child's life and the life of her kidneys, she chose the former. In 1999, Angela was diagnosed with kidney trauma during pregnancy. She also suffered from preeclampsia and toxemia. She was advised to terminate her pregnancy so her kidneys might be saved. She decided to have her baby. After delivering a healthy boy, it was determined Angela had end-stage renal disease (ESRD), and she was placed on dialysis in 2000. While dealing with and learning about ESRD, Angela decided to help other

people. She started by becoming the village greeter at her clinic, then joined Dialysis Patients Citizens and NKF, and she became a subject matter expert on ESRD. She has been to her state capitol in SC to lobby for Medigap coverage, as well as Washington, DC, to testify before the Ways and Means Committee concerning Medigap and other insurance coverage. Angela, who continues to educate her community at health fairs and in one-on-one conversations and support groups, is a strong patient advocate.

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## **TENNESSEE**



### **Tessa Byars**



Tessa is a nursing instructor with Western Governors University with over 15 years of healthcare experience. She was propelled to go into the medical field after being diagnosed with FSGS at the age of 19. The diagnosis came after complications from her pregnancy with her son. She gave birth to a healthy baby, but her kidneys struggled to return to baseline. After several years of aggressive therapy controlling blood pressure, cholesterol, and starting an ace inhibitor, her kidneys began to stabilize and she has been fortunate enough to avoid renal failure at this time. She wishes to help spread awareness & education about kidney disease and management as it affects so many people. In addition to nursing, she is an amateur photographer and avid reader. She is married to her high school sweetheart and has one son and a step-daughter.

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## **TEXAS**

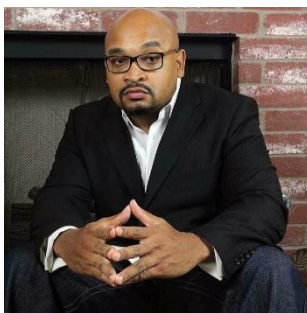
### **Kent Bressler**



In 1982, Kent was diagnosed with focal segmental glomerulosclerosis (FSGS), a disease that causes scarring in the glomerulus of the kidney and is notorious for additional health problems including large amounts of protein in the urine, loss of protein in the blood, high cholesterol, and high blood pressure. In 1987, Kent received a kidney from his brother, Kip. For the past 30 years, Kent has been on immunosuppressive drugs that are essential in guarding against rejection of the transplanted kidney but also can have harmful, long-term side effects.

Kent has participated in chronic kidney disease research reviews for the U.S. Department of Defense, as a mentor for potential transplant recipients, on the steering committee for Nephcure International, and is currently doing peer review on research being conducted by PCORI (Patient Centered Outcomes Research Institute). Kent is a retired Registered Nurse and is active in his church. Kent has two daughters and four grandchildren.

### **Jonathan Johnson**



Jonathan was diagnosed with end stage renal failure at the age of fifteen as he and his family found out that his native kidneys were the size of a baby's kidneys. After one failed transplant attempt, he received his kidney at the age of seventeen on Thanksgiving Day, 2001. Sixteen years later, he is still going strong.

Jonathan has turned his pain into purpose by authoring health and children's books along with public and motivational speaking, and even starting a nonprofit foundation named Mae Brown's Kidneys 4 Kids. Jonathan received his BA in Political Science from the University of North Texas in 2008 and received his MBA from the University of Phoenix in 2011. He currently resides in Desoto, Texas with his wife, Brittane and

their two sons.

### **David Rodriguez**



In 2008 David was living in Austin, TX when he was diagnosed with focal segmental glomerulosclerosis (FSGS). In 2011 David received his kidney transplant through the Pair Exchange Donation Program from University Transplant Center in San Antonio where he currently resides for 7 years.

Born and raised in Brownsville, TX, David serves as a patient advocate and spokesperson for organ, tissue and eye donation, leading awareness campaigns about the benefits of organ donation throughout the Texas border regions from Brownsville to El Paso, including Corpus Christi and San Angelo. David has volunteered for National Kidney Foundation, Texas Kidney Foundation, Texas Organ Sharing Alliance, and University Health System. As a member of the Advocacy Committee, he has lobbied for the National Kidney Foundation at our Nation's Capital in Washington, D.C. and the Texas State Legislature on behalf of the Texas Kidney Foundation. Professionally, David is Patient Relations Specialist at the University Transplant Center. He has served in several leadership positions in local, state and national political campaigns. David likes to read history and biographies, golf and the San Antonio Spurs basketball team.

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## **UTAH**

### **Dax Francis**



In 2003, at the age of twelve, Dax was diagnosed with Nephrotic Syndrome that would later progress to become Focal Segmental Glomerulosclerosis (FSGS). Six years of fighting his illness with various types of treatments, FSGS eventually progressed to end-stage renal failure, and at eighteen, Dax began dialysis. Enrolled in college at the time, it became apparent that school and dialysis were too much at this point in his life. After waiting for an agonizing two-and-a-half-year period, Dax received a kidney from a deceased donor in 2012. With what seemed like a new lease on life, Dax re-enrolled in school, determined to be a social worker so that he could help those who have struggled like he has. However, less than a month after transplant, FSGS recurred in the new kidney. Plasmapheresis was required immediately, and for three days a week he was back in the dialysis chair with the new lease on life disintegrating before his eyes.

Dax, determined to take advantage of the gift he was given, stayed enrolled in school and achieved his goal of attaining his Bachelor's Degree in Social Work all while undergoing treatment. It was not easy, and poor decisions in life made it even harder, but Dax has always learned from his mistakes, and today is the proud founder and manager of Ivye Wear, LLC. Dax's company specializes in apparel for people who are chronically ill and need a way to stay warm and comfortable during, oftentimes grueling, treatments. He did all this while he was on dialysis and is a testament to the warrior's attitude many dialysis patients have. Dax tries to travel as much as he can to visit with other dialysis patients to encourage them to stay strong and stay

positive. He also makes inspirational and motivational videos while on dialysis for anyone to view. He very much hopes to be an advocate for organ donation, rare disease research, bringing awareness to vital causes related to chronic kidney disease at the highest level, and first and foremost, is committed to helping others.

### **Bruce Tippetts**



Bruce receives dialysis treatments three times a week for four hours each time at the Uintah Basin Health Care Dialysis Center in Vernal, Utah.

He first started to get dialysis treatments in May of 2014 at Fort Washakie, Wyoming. He now lives in Vernal, Utah, and works full-time at UB Media as a sports writer and news reporter. Before that, Bruce was the sports editor at The Ranger newspaper in Riverton, Wyoming, for 13 years. Bruce is a contributing writer to aakpRENALIFE.

### **Brandy Webster**



Brandy was diagnosed with IgA Nephropathy at the age of 14 and after many years with no signs of the disease, her kidneys failed. Brandy is now 31 and received her first kidney transplant in October of 2017. She loves to advocate on behalf of kidney patients and looks forward to her new life with her new kidney.

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## **VIRGINIA**

### **Kelly Cline and Hannah Shelton**



Kelly's daughter Hannah was diagnosed with a kidney cancer called Wilm's Tumor when Hannah was just 13 months old. A year later Hannah was diagnosed with FSGS, a type of kidney disease. That was the beginning of many years of medication management until Hannah's remaining kidney failed in 2011. Hannah received a living donor kidney from her dad on September 29, 2011

and has been thriving ever since.

Both Hannah and Kelly are excited to be involved in advocacy and in getting information out about kidney disease prevention. As a family team, they are able to provide the perspective of both the patient and the caregiver and how both roles are affected by kidney disease.

### **Patrick Gee**



Patrick Gee had been a peritoneal dialysis patient since December 2013. On April 21, 2017, Patrick received a kidney transplant at the Hume-Lee Transplant Center at the Medical College of Virginia/Virginia Commonwealth University. After spending 33 days in the hospital, 4 surgeries and a 47-day wait until his kidney began to function, Patrick is back to advocating for a more comprehensive healthcare, patient engagement, community educational resources and a better quality of life for kidney patients.

Patrick retired from the Virginia Department of Corrections as a Major/Chief of Security. Patrick has a Bachelor's and Master's in Criminal Justice, with an emphasis in Public Administration from the University of Richmond, in Richmond, VA. He also has a Doctorate of Philosophy in Justice, Law and Criminology. Patrick is also a licensed Associate Minister at Mountain Movers Ministry Church, Richmond, VA. His ministry is working with those suffering from kidney disease. Patrick is a husband, father of 5 and a grandfather of 7. Patrick's motto is, "I am the Voice for the Voiceless and the Face of the Faceless in the fight against kidney disease." My mission is not to stop fighting for those suffering from a chronic illness until the Lord calls me to glory!

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## WASHINGTON

### Laura Ellsworth



Laura is the Strategic Partnerships Manager at the Council for the Homeless in Vancouver, WA. Laura received a kidney from her dad in 1999 and started giving back through volunteerism and her career. Laura has worked to inspire organ, eye and tissue donation, and in other human services and social justice non-profits. Laura worked for Donate Life Northwest in Portland, OR from 2002-2007 as the Program Coordinator. After leaving Donate Life Northwest in 2007, Laura served on the Donate Life NW Board of Directors from 2009-2015 and was the Chair of the Fund Development Committee. Laura

has also served on the United Network for Organ Sharing's Patient Affairs Committee (PAC) for 9 years, the last three years of her term as the Chair. Laura also participates in the Transplant Games of America and the Transplant Trotters Portland to Coast team to promote the need for and success of transplantation. Away from work, Laura enjoys traveling and spending time with her husband and 2 dogs.

### Glenda Roberts





Glenda V Roberts is the Director of External Relations and Patient Engagement for the Kidney Research Institute (KRI), a collaboration between Northwest Kidney Centers and UW Medicine dedicated to transforming the lives of people with kidney disease through innovation and discovery.

Diagnosed with kidney disease just out of college, Glenda has first-hand knowledge of the challenges faced by patients and family. Refusing to accept limitations, she managed the progression of her disease through diet and exercise and enjoyed a stellar career in the corporate world, evolving from a software developer to a senior business executive managing multi-million-dollar business units for top-caliber corporations, including General Electric and Microsoft. Simultaneously, she has been a passionate advocate for kidney disease patients and research. Glenda co-founded a non-profit to support kidney disease advocacy, community outreach and collaboration with external groups. She's a member of the KRI Patient Advisory Council, the Patient Advisory Board for the Center for Dialysis Innovation, the planning committee of Northwest Kidney Centers annual gala that supports kidney research and the outreach committee for the UWMC Team Transplant. Most recently she served as Executive Director for Transplant House.

Prior to a kidney transplant, she experienced in-center hemodialysis and at-home peritoneal dialysis with the help of Northwest Kidney Centers. Glenda brings to her role a combination of corporate leadership and patient experience and views herself as being uniquely positioned to be a positive force for advocacy, advancement and awareness.

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## **WEST VIRGINIA**

### **Nieltje Gedney**



Nieltje has been an advocate for various causes, from lowering the voting age to preventing child abuse, since she was 16. When she crashed into dialysis in 2014, she had planned to refuse treatment. Instead, her doctor insisted she try home hemodialysis. She soon became an avid supporter for home hemodialysis, which has allowed her to travel to conferences to speak on behalf of home dialyzors and advocate for policy changes that are so necessary to improving the quality of life for the home dialysis community.

Thanks to home hemo, Nieltje's health is better than it has been in years. She is thinking clearly and is able to volunteer at her grandkid's school, as well as with various dialysis advocacy groups. She has been Vice President and Treasurer of Home Dialyzors United for four years, spoken at CMS, ANNA, ADC, and many other ESRD settings, including clinics and patient groups. She returned to her love of travel, and spent a month driving across country, visiting friends and family in Colorado, with R2D2 (as her friends aptly called her dialysis machine) firmly strapped to the back seat! She also took a 2-week cruise to Alaska last year. At 65, with the help of home hemo, Nieltje is back in the driver's seat and loving life!

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## WISCONSIN

### Mary Baliker



Mary has been a healthcare advocate most of her life, after being diagnosed with kidney disease at the age of nine, living with chronic disease, undergoing dialysis, and receiving four kidney transplants, the last of which was 1999. She has also written a children's book "Maria Never Gives Up" in hope that it will help others in their struggle with a health crisis.

Mary's professional work experience includes many healthcare organizations, and she now works as a healthcare consultant, as well as an inspirational speaker educating and informing and sharing her stories. As a patient advocate, Mary has been involved in legislative work and serves on various committees and advisory groups. Mary enjoys spending time with her husband Jim, her family, and friends as well as her dog Kona who is being trained as therapy dog. Mary can be found hiking, biking, doing Pilates and yoga. She enjoys traveling as well as her volunteer work.

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