



American Association of Kidney Patients Field Ambassadors

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. Ambassadors are recognized as leaders in the kidney community. Their perspectives are sought after to improve diagnosis, treatment, and care for those impacted by kidney disease.

Meet AAKP's Field Ambassadors!

ARIZONA

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.

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.



DELAWARE

Bill Murray



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.

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.

FLORIDA

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 the Lap Band weight loss procedure to qualify for the weight requirement for 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.

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.

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.

INDIANA

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 27th, 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.

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.

MARYLAND

Dave White

Dave, a health care consultant with expertise in patient-centered care, patient engagement, and kidney disease awareness and prevention, is a grateful kidney transplant recipient and a veteran of in-center, in-center nocturnal, and peritoneal dialysis. Dave is pursuing a degree in Health Systems Management at the University of Maryland University College and majored in Mathematical Studies at Yale University. Dave serves on the boards of directors of the American Association of Kidney Patients, the Kidney Health Initiative, and the Veterans Transplantation Association and chairs the Kidney Health Initiative Patient and Family Partnership Council. He is also a member of the Patient-Centered Outcomes Research Institute Patient Engagement Advisory Panel, the ESRD NCC Health Services Advisory Group, the National Kidney Foundation Kidney Advocacy Committee, and the Quality Insights Mid-Atlantic Renal Coalition Patient Advisory Committee. He enjoys speaking, writing, and presenting about kidney disease and patient engagement, and has made regional and national television appearances as a health care advocate. A United States Army veteran, Dave lives in Hillcrest Heights, Maryland with his wife and hero Hilva.



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.

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.

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.

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.

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.

NEW YORK

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.

OKLAHOMA

Sonya Cochran

PENNSYLVANIA

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.

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.

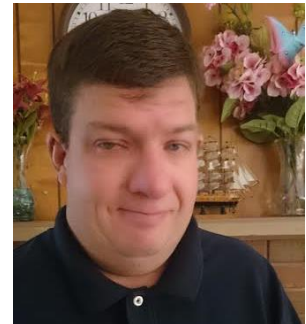
Kent has participated in chronic kidney disease research reviews for the U.S. Department of Defense, as a mentor for potential transplant recipients, on the steering committee for Nephcure International, and is currently doing peer review on research being conducted by PCORI (Patient Centered Outcomes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

UTAH

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.



VIRGINIA

Patrick Gee



Since December 2013, Patrick was a peritoneal dialysis patient until receiving a kidney transplant on April 21, 2017. Since suffering from end-stage renal disease (ESRD), Patrick has become a Health Care Advocate, fighting for a better health care system and better quality of life for those suffering from chronic illness. Patrick has been on Capitol Hill several times speaking with legislators about policies and bills that concern those suffering from chronic kidney disease and ESRD.

Patrick graduated from the M3 Church School of Ministry in November 2016 and is currently serving in the position of Minister-In-Training. He hopes that as part of his ministry, he can visit his peers on in-center hemodialysis to offer encouragement and support. Patrick also has a Bachelor's and Master's of Science in Criminal Justice and a Doctoral degree in Justice, Law and Criminology. Patrick strives to be a face for the faceless and a voice for the voiceless.

WASHINGTON

Laura Ellsworth

Laura is the Development Manager at Donate Life Northwest, in Portland, an organization she has been connected to since 1999, when after receiving a kidney from her Dad, she became a volunteer for what was then the Oregon Donor Program. Later, Laura became a member of the staff from 2002-2007 as the Program Coordinator. After leaving Donate Life Northwest in 2007, Laura served on the 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. She was a member of the Patient Affairs Committee (PAC) for 9 years, the last three years of her term as the Chair. Laura has also participated 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.



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.