

---

## 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.

---

## ALASKA

### **Courtney Leigh Wilson**

Biography coming soon!

---

## ARIZONA

### **Jessica Bates**

Biography coming soon!

### **Canna Caldwell**

Biography coming soon!

### **Jerald Collens**



Jerald was diagnosed with IGA Nephropathy while emigrating to the United States from Canada in 1998. IGA Nephropathy is a condition that has symptomatic treatments but no known cure. Jerald's Nephrologist has said that Jerald was his miracle IGA patient having gone over 20 years without requiring dialysis or a transplant. After 21 years that changed, and Jerald required a transplant in 2018 and received a great gift from his son Barry in the form of his living donation.

Jerald is a family man and father of four. He works daily even after the transplant and is looking forward to also serving the CKD world. Jerald

## Meet AAKP's Ambassadors!

Updated 12.09.19

wants to help those suffering with kidney disease and to raise awareness about living kidney donation.

### **Sachi Kuwahara**

Biography coming soon!

### **Risa Simon**

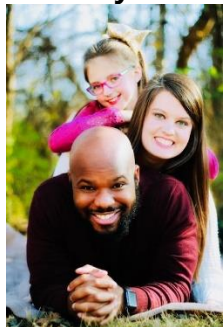


Known as a positive disrupter, patient advocate and mentor, motivational speaker, published author and founder of the TransplantFirst Academy, Risa is on a mission to help eligible transplant patients bypass dialysis (or become dialysis-free) so they can live their best and longest life. Her preemptive (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.

---

## **ARKANSAS**

### **Kimberly Jordan**



Kimberly is a 2018 kidney donor whose experience throughout the testing, surgery and recovery inspired her to become part of the advocacy effort of living donation and organ donation. Growing up in central Arkansas, Kimberly graduated high school and attended the University of Central Arkansas, graduating with a BA in Communication with a minor in Sociology and English. She is a wife to her football coach husband, Justin and they reside in Fayetteville, Arkansas with their 11-year-old daughter, Kamryn, and a new baby set to arrive in November 2019 as well as their Schnauzer, Riley.

Kimberly is an active member of Christian Life Cathedral in Fayetteville and served as volunteer coordinator for the Susan G. Komen More Than Pink Walk 2019 for CROSSMARK where she is currently employed as a Business Operations Manager with the Sam's Club Events team. She has also recently implemented projects within the community with her up and coming organization, Beloved Endeavors. This organization depends on donations to fill small cosmetic bags with beauty products for women's shelters in Northwest Arkansas and, hopefully, one day, throughout the state. Kimberly looks forward to her involvement with the Arkansas Association of Kidney Patients both in learning, raising awareness and advocating for the cause. She gave her cousin's wife, Stephanie a kidney in March of 2018 and hopes to use their story to let those who have loved ones seeking organs that can be received from a living donor that you do not have to be blood related to donate life.

## Meet AAKP's Ambassadors!

Updated 12.09.19

### 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 at kidney transplant through a living donor.

---

## CALIFORNIA

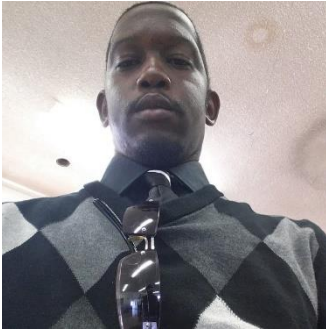
### Leslie Cox

Biography coming soon!

## Meet AAKP's Ambassadors!

Updated 12.09.19

### Philip Jones, Jr.



At the age of four years old, Philip was diagnosed with chronic kidney disease. This was caused by post-strep. He was hospitalized for a month and a half on dialysis due to this illness. After being released from children's hospital his doctors informed him he would only have 30% kidney function and would eventually need a kidney transplant. Philip lived his life like a regular kid his entire childhood, then one day in June of 2006 he was informed his kidney function was rapidly declining and it would be time to start looking at a transplant and dialysis. In Aug 2006 he was placed on dialysis and

the transplant list. By the grace of God, Philip was blessed with the second chance at life on Feb 25, 2007. This is one of the most emotional days of his life. After being released from UCLA Medical Center Philip did everything and beyond to make sure this kidney did not reject, so much so that within 7 months he was only on the 2 anti-rejection medications. In 2008 Philip went to his first Transplant Games in Pittsburgh, PA with Team SoCal and took home two bronze medals and one gold medal. Two years later is where everything seemed to go out of control for Philip. In Aug 2010 he was placed back on dialysis because his kidney rejected from a medication he was given for the torn meniscus he suffered at the Pittsburgh Games. In Sept, he suffered a major seizure that put him in the hospital for 2 weeks. 2 weeks later, Philip suffered a horrible brain bleed due to the heparin from his dialysis. It took Philip 3 ½ years to slowly get back to his usual self. When that happened, he enrolled back in school to become a teacher. Philip has had multiple jobs and has served on the executive board for Student California Teachers Association for a year to make a difference in teachers' and students' lives. As of now, Philip is still fighting every day to achieve all of his goals and to receive another kidney.

### 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

## Meet AAKP's Ambassadors!

Updated 12.09.19

for organ recipients, potential recipients, living donors, and caregivers. Lastly, Jeff has served on the CareDX (a diagnostic company) Kidney Patient Advisory Board.

### 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



LaMonte began fighting kidney disease at age 12. A virus attacked his kidneys and caused great damage. Ultimately, LaMonte went on dialysis at the age of 42 and has been on dialysis for 2 years, 3 times a week. He has been diligent to learn the best way to continue to live a normal life. LaMonte has two kids who still need him, and he runs a fitness business. He was determined not to allow kidney disease to turn his life upside down. LaMonte has always been active and wanted to continue. He refused to let this situation put his life on hold. The first thing he did was to become pro-active. He began asking his technician, doctor nurse and dietitian tons of questions, the first being "can I exercise?"

LaMonte understood having the fistula created some limitation but it did not stop him. The more he could regulate his fluid and nutrition, the better he would feel and prolong his life. This is what has generally worked for LaMonte in fighting kidney disease: 1) Exercise – Crossfit has been his personal choice; 2) Nutrition – It is not easy, but LaMonte made up his mind to eat good to feel good; 3) Support group – Giving to others takes your mind off what you are going through, and it is empowering to know you are helping someone in the mist of your own struggle; and 4) Minimize stress – Talk to someone and open up about this journey. It helps when you can get it out. When kept in it becomes unbearable and affects blood pressure. Our bodies do not deal well with stress. Isn't dialysis enough?

### Nnamdi Uyalor, Jr.

Biography coming soon!

### Mihi Wickramasinghe

Biography coming soon!

---

### COLORADO

#### Jill Morton



Jill specializes in forensic accounting, valuation and litigation support as well as business development with an extensive background in accounting, audit, and investigative analysis.

Jill is extremely active in fundraising for research and education related to organ donation. Her passion is to help others with kidney disease, prevention, transplantation, and organ donation. Her passion includes support for the donors and donor families who are our true heroes. Jill is a 16-year kidney transplant recipient and lives her life thankful for

every day.

Her passion began with her mother's kidney failure in 1985 when she saw her mother proactively fight to live and be as healthy as possible with kidney disease. Carol was on dialysis for many years awaiting a transplant. Jill saw her determination to live and ultimately, she was blessed with a kidney transplant. Carol's transplant ultimately failed, and she went on dialysis again. Jill learned much from her mother about being proactive, and from her father who was instrumental in helping with legislation to get EPO approved in the U.S. when her mother was in great need.

Jill is a very active patient advocate, receiving the Champion Award in 2012 as a Donate Life Ambassador. She has been featured in numerous articles and TV programs regarding organ donation. She is a gold medalist in numerous sports including Tennis, Golf, Cycling and Running at the U.S. and World Transplant Games. She serves on committees at Weill Cornell and The Rogosin Institute in NY, has helped support UM Life Alliance in Miami, FL and has volunteered at the New Jersey Sharing Network.

Jill is grateful for the opportunity to follow in her parents' footsteps to help others with kidney disease. She has two sons and was recently blessed with an adorable grandson.

#### Denise Steininger



Denise is a Colorado native. She has IgA and has been on PD since March of 2018.

---

### 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 Master 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 having kidney disease, anyone can achieve their dreams!

---

### DELAWARE

#### **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 was an active advocate with a passion for early detection, education, organ availability, and donor support. Bill served on AAKP's Board of Directors.

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.

## Meet AAKP's Ambassadors!

Updated 12.09.19

### 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 kidney transplant from a deceased donor 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.

---

### DISTRICT OF COLUMBIA

#### John Bayton, Jr.

Biography coming soon!

#### 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.



## Meet AAKP's Ambassadors!

Updated 12.09.19

### Latitia Felus



Latitia is a motivated advocate for renal patients as it relates to ethical and quality-of-life concerns. She educates in center and at renal educational/awareness events. Latitia is a former peritoneal dialysis and in-center patient who received a kidney transplant (deceased donor) in June 2015. Kidney disease has been a generational battle for Latitia, impacting two of her three brothers along with several first cousins. She is no stranger to renal failure and its impact on the individual, family and caretaker.

Latitia has been a keynote speaker at the National Kidney Foundation, serves as a Donate Life Ambassador for the Washington Regional Transplant Center (WRTC), and a member of the American Association of Kidney Patients, a Member of the Mid-Atlantic Renal Coalition's Patient Advisory Committee, and a member of the National Kidney Foundation and American Kidney Fund.

Latitia remains a 30-plus year civil servant for the Federal government. She holds a Bachelor of Arts Degree in American Literatures the University of Maryland University College, College Park. She is currently pursuing her master's degree. She and her husband currently reside in the District of Columbia.

### Prithvi Kumar



I migrated to US from India in 1970. I received my Master's degree in Electrical Engineering from University of Massachusetts. After graduation I pursued a career in Cyber Security as a systems analyst. Additionally, I worked on Refugee resettlement efforts as a part of United Nations Refugee resettlement program. I am retired and live with my wife Kala and two lovely grandsons in Washington DC.

I was diagnosed having MPGN type-1 kidney disease undergoing peritoneal dialysis at home. Kidney disease opened up a new opportunity for me to share and help patients in diet, policy, and technology areas.

### 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).

## Meet AAKP's Ambassadors!

Updated 12.09.19

---

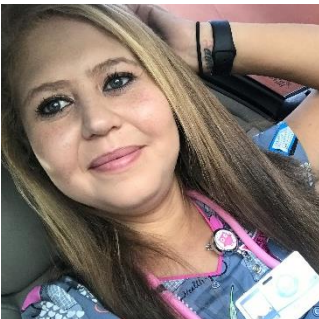
### FLORIDA

#### Shameka Ausborn



Shameka has been on dialysis for 19 years, she started in-center at the age of 15. She has had 2 kidney transplants, in 1999 and in 2005. It lasted 10 years until it failed due to Nephrotic Syndrome and FSGS. She returned to in-center hemodialysis until she started home hemodialysis in 2016. She has two children ages 25 and 13. She enjoys reading, volunteering and spreading awareness of kidney disease and advocacy for other kidney disease patients.

#### 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.

#### Terre Perez

Biography coming soon!

#### Chryl Sage



Chryl is retired from the State of FL. She has 2 loving children, a daughter Dominique and son David. She also has a loving extended family of many other Sons and Daughters! She has battled type 2 diabetes since 1993. In 2007 her right leg had to be amputated below the knee due to a wound that would not heal and a bone infection. And in 2010 she was diagnosed with ESRD and started in-center hemodialysis. In her journey to receive a transplant she had gastric sleeve surgery in 2015 to lose weight, which she did and was put on the transplant list on August 5<sup>th</sup> of 2016. She received that wonderful call for her transplant from a deceased donor on August

15<sup>th</sup>, just 10 days later!

## Meet AAKP's Ambassadors!

Updated 12.09.19

Chryl lives every day to educate and bring awareness to her community about kidney disease, diabetes and amputation. She is a member of several organizations and support groups in her area. Chryl believes its best to always step outside your comfort zone. Try something new, meet new people. You never know whose life you may impact or who you might learn from or educate!

### Payal Shah



Payal was diagnosed with renal failure at 15 years old. She was placed on dialysis (HD for 6 months and PD for 6 months) for 1 year before receiving a kidney transplant from a living, unrelated donor. Payal has been rejection-free and thriving with her transplanted kidney for the past 21 years which she attributes to a number of reasons, one of which is adherence to her immunosuppressive therapy. Understanding the importance and necessity of her medications moved Payal to go to pharmacy school to help others achieve the same success stories around their health. She received her PharmD degree from the University of Michigan in Ann Arbor--Go Blue!

While Payal has spent time volunteering with NKF and local support groups, Payal wants to dedicate more of her time to raising awareness around organ donation and offer lifestyle support to patients as they travel their CKD journey. Another component to her kidney's longevity has been the lifelong support from the people around her which she wants to pay forward. Payal currently works and lives in Southeast Florida with her husband and new puppy. Together, they enjoy traveling the globe, boating, checking out surrounding islands/beaches, fitness and eating good eats!

### 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.

## Meet AAKP's Ambassadors!

Updated 12.09.19

### **Sherri Thomas**

Biography coming soon!

### **Michael Yaros**



Michael lives in Orlando and is a kidney transplant recipient from April 2014. For two years prior to transplant, Michael completed in-center hemodialysis and at-home peritoneal dialysis. Michael has been under the care of a nephrologist since he was a child due to the nature of his hereditary kidney disease, Alport Syndrome. Michael holds a Bachelor of Arts in Political Science from the University of Central Florida. Michael had plans to attend law school prior to finding out about his need for dialysis treatment and transplant. Upon graduation from UCF, Michael found out from his nephrologist that he would need to begin dialysis treatments and be listed on the transplant list.

During dialysis, Michael found a love for the healthcare field and started taking courses so he could enroll in a nursing program. Michael graduated nursing school and is currently a transplant nurse with AdventHealth Orlando where he is currently employed as Clinic Manager. Michael spent nearly two years working as a bedside post-surgical transplant nurse before transitioning to outpatient transplant care.

Some of Michael's passions include politics, policy, and travel. Making access to life-saving medications and access to transplantation are some of the most important policies Michael is focused on.

---

## **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

## Meet AAKP's Ambassadors!

Updated 12.09.19

improve the lives and treatments of those with kidney disease and expand patient choices.

### Cyrelle George



In 2017 the entire scope of Cyrelle's life shifted when she was diagnosed with End Stage Renal Disease. Not one to back down from a challenge nor buckle under pressure, Cyrelle took that diagnosis and became an advocate bringing awareness about kidney disease. Cyrelle is the host of a weekly kidney disease Facebook Live show promoting awareness, prevention, education and an overall zeal for life called, "Sisters Against Kidney Disease." As well as, speaking publicly in the community educating the masses about CKD awareness and prevention.

It is her work as a chronic kidney disease advocate that Cyrelle says has been the most rewarding. Partnering with various kidney awareness organizations has allowed Cyrelle the opportunity to be a voice in the community and for those who are battling this disease on a daily basis.

### Dammeon Marshall



Dammeon is a social worker and has always expressed a genuine interest in helping people. As an advocate for education, health, and wellness, he volunteered with the Big Brothers Big Sisters program, helped raise his brother and sisters, and developed community resources for public agencies. In these social ventures, Dammeon assisted children and families to improve behaviors, grades, and attitudes through positive dialogue that resulted in a greater understanding of their power and self-worth. He graduated from Georgia State University in Atlanta, GA in 2009 with a bachelor's degree in Social Work. Upon graduation, he was admitted into

Western Kentucky University's accelerated social work program, awarded a full scholarship as a graduate research assistant, and graduated in 2010 with a master's degree. While in his doctorate program, Dammeon was diagnosed with chronic kidney disease in 2012. He went through periods of grieving the mere thought of experiencing kidney failure. It left him feeling helpless, hopeless, confused, and scared. The emotional and psychological impact caused Dammeon to internalize, worry, and question his worth, vitality, and destiny. In October 2016, he made a conscious decision to push forward and re-enroll in school to pursue a Doctorate in Social Work at Capella University. On October 1, 2018, Dammeon birthed Love's Pursuit out of emotional hardship, love, and forgiveness. In a robust effort to change lives across the world, he has dedicated his experiences, time, gifts, talents, and voice to empower others to live well. Dammeon's comprehensive wellness model to life encourages others to increase self-love, self-confidence, and self-awareness. In 2019, Dammeon discovered his purpose and became an AAKP Ambassador to support, advocate, and engage communities and stakeholders for other CKD patients.

## Meet AAKP's Ambassadors!

Updated 12.09.19

### Stuart Miller



kidney disease.

Stuart was diagnosed with IGA Nephropathy in May of 2008. Making some lifestyle changes and with good care from his doctors Stuart was able to manage his IGA until July of 2018. Thanks to his wife Carole and the Paired Kidney Donor Exchange, Stuart was able to have a preemptive transplant at Emory Hospital in Atlanta. Stuart and his wife own a Wholesale home décor business. When he is not working, he enjoys spending time with friends and his two dogs (Theodore & Oliver) and following his favorite sports teams from his hometown, Boston. He became an Ambassador to help spread the word about organ donation and to help AAKP in its mission to encourage patients to become the own advocates and to help work on legislation that will improve the lives of others who live with

### Chardae Sanders



Chardae "Prima" 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 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 Assistant General Manager of A1 Promotions and artist consultant for Last Supper Music Group. 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!

---

### HAWAII

#### **Noreen Baldwin**

Biography coming soon!

---

### 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

## Meet AAKP's Ambassadors!

Updated 12.09.19

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.

### Christy Stutzke



Biography coming soon!

---

## 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. Kevin serves on AAKP's Board of Directors.

### 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



## Meet AAKP's Ambassadors!

Updated 12.09.19

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 organizations and through independent projects of her own.

### **Gail Glasser**

Biography coming soon!

### **Martin Jimson**

Biography coming soon!

### **Della Major**



Della is a resident of Chicago, Illinois. She has been an ESRD patient since November 2011. Della is a certified Kidney Health Coach for the American Kidney Fund and Della is a Facility Peer Representative for the Renal Network 10, a member of the Patient Advisory Council (PAC), a Patient Ambassador of the Dialysis Patient Citizens group, a Subject Matter Expert (SME) for the National Coordinating Center (NCC) Patient and Family Engagement Learning and Action Network, a member of the Medical Review Board for Network 10, and a Patient Advisory Council member for the National Kidney Foundation of Illinois. In 2017,

Della received the Robert Felter Memorial Award from the Renal Network. This award recognizes patients who are champions for dialysis and transplant patients, and a guiding force for patient-centered activities. In addition to her Kidney advocacy, Della is an Ordained Minister/Elder at her church Valley Kingdom Ministries International where she serves as the lead facilitator of the Teachers Training program. Della has a strong outreach ministry where she volunteers at the local food pantry who provides assistance to low income families within the urban community of the city of Chicago. Recently, Ms. Major launched a new business venture called L.Y.V.E. which stands for Living Your Victorious Life Through Encouragement and Education. She wants to do more motivational and inspirational speaking as well as advocacy work, on behalf of kidney disease patients. Her passion to educate comes from the below quote from W.B. Yeats: *"Education is not the filling of a pail, but the lighting of a fire."* W.B. Yeats

Della received a kidney transplant in August 2018!

## Meet AAKP's Ambassadors!

Updated 12.09.19

### Daniel Perez



Daniel is a communications manager and mentor who works full-time with a non-profit organization in Chicago that assists at-risk youth to help remove themselves from the perils of gangs and drugs and helps getting them on a track of success. Daniel brings a unique combination of advocacy leadership, advancement of community issues and public awareness to AAKP.

Daniel believes that everyone deserves a fair shot at life and should not have limited access to crucial and important information because of where they may live or because of the neighborhood that they grow up in. Being a communicator is vital and helping to share information to those in need is truly the essence of advocacy work. Daniel has partnered with several elected officials including Senators, Chicago's Mayor, Cook County Commissioners, State Representatives, Secretary of State, Ward Aldermen and Law Enforcement to help share his passion for helping others and to work on solutions for Chicago.

Daniel was diagnosed with focal segmental glomerulosclerosis (FSGS) and continued his work although he was on dialysis for 3.5 hours a night, three days a week. Since his diagnosis, Daniel volunteered to help promote Kidney Disease awareness with the National Kidney Foundation of

Illinois, The Renal Network ESRD Network 10, The National Patient/Family Engagement Learning and Action Network (NPFE-LAN) as a Subject Matter Expert and as a patient ambassador at his dialysis clinic. He has spoken on behalf of organ donation in Illinois and has spearheaded Kidney screenings in several communities across Chicago.

Daniel is a certified social media engagement professional and was awarded the 2016 Robert Felter Memorial Award for working on behalf of kidney patients and was awarded the 2017 "Doin' Good in the Hood" award for his youth advocacy work. Daniel holds a B.A in Multimedia Graphics and Advertisement from The Illinois Institute of Art and will be pursuing his Master's in Communications in 2019.

### Lana Schmidt, MBA



Lana is a kidney transplant recipient after being on dialysis for over 13 years from Liberty, IL, with a master's degree in Business Administration and is Owner of Strategic Marketing Specialists. Lana is on the AAKP Board of Directors, editorial board for Nephrology News magazine, a member of American Kidney Fund, National Kidney Foundation, Renal Network 10. Lana has served in numerous capacities throughout the kidney community, published articles with a patients' perspective and regularly speaks on kidney disease issues. Lana also started the Kidney

Patients Support Group in Quincy, IL and Hannibal, MO.

## Meet AAKP's Ambassadors!

Updated 12.09.19

---

### INDIANA

#### Lisa Misiolek



Lisa has lived with chronic kidney disease for 20 years, six of those years were on dialysis. For the last six years, Lisa has enjoyed the freedom of living with a kidney transplant.

During these years she was able to achieve her bachelor's degree in Sociology. Lisa was also able to have two children, also get married. She enjoys reading, traveling, and cooking in her spare time.

#### Jim Myers



Jim lost 5 members of his family to PKD, including his Father. Because of his family's history, he was diagnosed at the age of 25, and was able to put off dialysis until the age of 58. Jim was on dialysis for 4 years and was transplanted on April 27<sup>th</sup>, 2016. He named his new kidney Woody. Woodrow is a family name, so he did this to honor his father and my grandfather.

Jim is a full-time kidney advocate. He is a Member of the Board of Director for AAKP and has won several professional awards and honors including the Inaugural National Social Media Education and Advocacy Award from the AAKP and Robert Felter Memorial Award. Jim has given multiple seminars for the AAKP on the use of social media to advocate and raise awareness for kidney disease. He is an administrator for 72 kidney pages on Facebook, another 50+ kidney groups of various topics, 10 blog pages and 9 e-newspapers. He is a very experienced advocate both at home and on the hill with his Members of Congress. Jim helped to initiate Kidney Pals, the pediatric kidney patients initiative, and is part of the initiative for kidneys and veterans. Jim also serves as Chair of AAKP's Strategic Communications Committee and on the 2019 National Patient Meeting Committee.

#### 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

## Meet AAKP's Ambassadors!

Updated 12.09.19

someone. After completing her tests, 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.

---

### IOWA

#### Adam Akers



I was diagnosed with IGA Nephropathy in 2001 after failing a routine physical as a member of the Iowa Army National Guard. With good care from my nephrology team and staying active, I was able to slow the progression of the disease for about 10 years before I was told it was time to either look into dialysis or a transplant.

After being put on the list, my younger brother came forward and volunteered to donate one of his kidneys to me. I am fortunate enough this was done before having to be on dialysis. I'm glad I did not pick on him any more than I did when we were younger and he likes to say he doesn't have to get me christmas gifts any longer.

I am now retired from the military and have had few issues since my transplant. I am a member of our local Kiwanis club and enjoy volunteering at our county fair. Living in rural Iowa I do not have the opportunity to interact with many transplant patients, so I finally decided to come to an AAKP patients meeting. I am glad that I did as I had the opportunity to meet so many other people that have gone thru the same thing as I had. I learned in the military that serving others is the most satisfactory job you can have so I decided to take that and try and apply it to becoming an AAKP ambassador.

I look forward to meeting others that have walked the same path and helping others on their journey.

---

---

### 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.

---

### 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.

## Meet AAKP's Ambassadors!

Updated 12.09.19

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.

### **Bruce Kleinschmidt**



Bruce has been aware of living with health challenges since his earliest days. At age two, he contracted a mild case of polio and was quarantined in a hospital ward for several weeks. Bruce has minimal physical damage from the experience but it left him with a very compromised immune system. Bruce observes that when he wears shorts and people can see his leg brace, they treat him differently. When it is covered, he become invisible, just like the challenges faced by kidney patients.

Bruce has practiced law for 40 years. Because of the hostility of the legal profession and society in general towards gay men, Bruce was forced to leave a corporate law position and re-educated himself to become a law librarian, working at law schools in Texas and Indiana.

Bruce began actively working with and advocating for men dying with HIV/AIDS in 1991. Bruce's *pro bono* efforts were recognized by the Chief Justice of Texas in 1994. Bruce was instrumental in organizing the LGBT Law Section of the Kentucky Bar Association and has served as leader of the group since its inception.

In May 2014, Bruce began taking a prescription medication approved by the FDA for the prevention of HIV/AIDS. By April 2016, Bruce had developed chronic kidney disease stage 4 and anemia. Working with his nephrologists and hematologists, Bruce is now a stage 3 CKD patient and has had a significant improvement with regard to the anemia.

Bruce was married and has three grown sons and six grandchildren. In addition to them, he mentors gay college students who've been viewed as disposable by their own biological families.

### **Christina May-Scott**



Christina is 38 years-old and a current student with Sullivan University. She has completed two associate degrees – one in Legal Office Management and one in Accounting. She is currently working towards her bachelor's in Interdisciplinary Business Studies with concentrations in Management and Human Resource Leadership and plans to pursue a master's degree in Human Resource Leadership. Christina previously worked for a non-profit treatment facility for those struggling with alcoholism and addiction. She became an advocate for those individuals and tried to break the stigma.

She was recently diagnosed with kidney disease and has begun to research and learn all she can about it. Christina loves to help people and do research and educate. Her passion and purpose in life is to help others. It is a very scary time when you are first diagnosed and for some

## Meet AAKP's Ambassadors!

Updated 12.09.19

time after. She wants to help those like her with ways to make it easier and to get through those times and what they can expect next. Her mother and daughter have been a huge support.

---

### 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.

Update: As of June 21, 2018, Brandi received a transplant from a directed donation. It ended up being a perfect match and she has been doing well. She has had more energy and desire to accomplish tasks than she can ever remember.

#### Leigh-Ann Williams



Leigh-Ann is a graduate student at the LSU Health Sciences Center in New Orleans studying epidemiology. Her research interests are chronic disease epidemiology with hopes of eventually doing research on chronic kidney disease epidemiology.

Leigh-Ann's journey with kidney disease began in September of 2012 while away at college when she was diagnosed with acute kidney failure and FSGS. After being transported to medical facilities in her hometown, it was suspected that she also had lupus. Leigh-Ann continued to be seen routinely by a local nephrologist and in 2014 she was officially diagnosed with lupus. In April 2016, one month before she was set to graduate from college, Leigh-Ann was diagnosed with End Stage Renal Disease and began dialysis immediately. Leigh-Ann graduated less than a month later and moved home where she did dialysis in-center for a little over a year. During the 16 months she was in center, Leigh-Ann served as the international 3<sup>rd</sup> vice president of her sorority and did dialysis at a total of 19 different clinics due to travel! With her hectic travel schedule, when the clinic had patients come in to talk about different modalities, Leigh-Ann was overjoyed to hear that she would have even more flexibility for travel and less dietary and fluid intake restrictions on home dialysis. Leigh-Ann knew this was the best treatment option for her.

Leigh-Ann began training for home hemodialysis in August 2017, and in September she completed her first treatment at home. As someone who has not allowed kidney disease to

## Meet AAKP's Ambassadors!

Updated 12.09.19

control her life, Leigh-Ann adopted the mantra, "These kidneys won't hold me back!" It is a declaration that despite her disease, she will still live her life to the fullest. Leigh-Ann's hope as an Ambassador is to continue the work she has been doing with her foundation, The LeighWilli Foundation, to Advocate, Educate, Encourage, and Empower people with kidney disease. Leigh-Ann is an avid public speaker and motivator and is involved in several social, civic, and service organizations. In her limited spare time, Leigh-Ann loves to travel, go to the movies, spend time with family, and meet new people.

---

### 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. Genevieve received a pre-emptive kidney transplant in December 2018.

---

### MARYLAND

#### 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.



## Meet AAKP's Ambassadors!

Updated 12.09.19

### Mike Butler



Mike is a 25-year kidney/pancreas recipient, who spent 18 months on dialysis before receiving his transplant. He is an active volunteer an Ambassador for The Living Legacy Foundation of Maryland, Local OPO, the National Kidney Foundation Western Maryland Region, a member of TRIO and active volunteer at Meritus Medical Center, UMMS and Union Memorial Hospitals.

Mike is a retired Frederick County, MD government employee and current Motivational/Public Speaker and Life Coach. Mike is also a Master Trainer in teaching self-management classes in Hypertension, Diabetes and Chronic Illness with the Washington County, MD Commission on Aging. He brings awareness about kidney disease, diabetes, chronic illness, organ, eye and tissue donation to national, state, and local communities.

### 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.

### Alana Hunnicutt-Carroll



Alana is a two-time kidney transplant recipient from two living donors. She has lived with kidney disease for over 23 years and was diagnosed with FSGS and nephrotic syndrome as a teenager. Alana's first transplant lasted for 10 years, and after it failed, she spent one year on hemodialysis before receiving a kidney from her husband in 2016.

The road to receiving her second transplant was a difficult one. Alana and her husband were denied 3 times before she was able to receive his kidney. She decided at that point to advocate by sharing her story, being a voice for the voiceless, and inspiring others to advocate for themselves. A "no" is not the end of the road. Alana has partnered with the transplant surgeon at GW Kidney by doing a vlog for their website, sharing her story in the local newspaper, with local news stations,

## Meet AAKP's Ambassadors!

Updated 12.09.19

as well as a commercial. Both Alana and her husband are hired contractors for a large pharmaceutical company as traveling keynote speakers educating others on the kidney transplant process, their resources, and all options to become a donor and a recipient. It is Alana's mission, passion, and duty to serve her fellow kidney warriors. She is at the beginning stages of starting a nonprofit as she continues to form partnerships with kidney disease advocacy as the mission.

### Austin Lee



Austin is a two-time kidney transplant recipient, both donated from living Donors. Austin was born in Germany and diagnosed at birth with ESRD. He received his first kidney from his mother in 1993 that went on to function for 14 years. His first transplanted kidney went into rejection in late 2007 and he had to undergo peritoneal dialysis for 3 years. In June of 2010, Austin received his second kidney from an unrelated living donor.

Having a kidney transplant has allowed Austin to be a voice in his community of the DC, Maryland and Virginia where he is currently an Organ Donation Advocate for Washington Regional Transplant Community and a Patient Care Transplant Volunteer for Children's National Medical Center. He has shared his story with many people to help inspire, educate and motivate others to learn more about Kidney disease and organ donation. He has had the opportunity to receive the 2017 NBC4 Working 4 You and 2017 WRTC Donate Life Volunteer Of the year awards and is very excited to help join the efforts of AAKP.

### 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.

## Meet AAKP's Ambassadors!

Updated 12.09.19

### David M. White



Dave is a healthcare consultant with subject matter expertise in person-centered care, patient engagement, and living with a serious illness. His mission is to promote population health through advocacy and engagement.

A very grateful kidney transplant recipient, Dave serves on the Boards of Directors of the Kidney Health Initiative, Quality Insights Renal Network 5, and the Veterans Transplantation Association. Dave also chairs the Kidney Health Initiative Patient and Family

Partnership Council and the Patient-Centered Outcomes Research Institute's Advisory Panel on Patient Engagement and is an inaugural member of the FDA/CTTI Patient Engagement Collaborative.

Dave serves on the National Kidney Foundation Kidney Advocacy Committee, Quality Insights Renal Network 5's Patient Advisory Committee, and many other regional and national groups. In 2016 Dave received the American Association of Kidney Patients Patient Engagement and Advocacy Award and was also honored as the American Kidney Fund Hero of Hope.

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

---

## MASSACHUSETTS

### John Mazullo



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

## Meet AAKP's Ambassadors!

Updated 12.09.19

spouse James changed to home hemodialysis. In 2010, John wanted to undergo 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 postponed. 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 no longer participate, so a young pre-med researcher in nephrology volunteered.

John was 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.

---

### 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.

## Meet AAKP's Ambassadors!

Updated 12.09.19

### Oliver Hale



Chef O is a two-time kidney transplant recipient, with over 30 years of his life as a successful kidney transplant patient. Chef O's kidneys failed 2 weeks after he played in and won a United States Tennis Association Regional 5 states doubles tennis tournament in July 1983. After his first transplant in January 1985, he hit the ground running and has not stopped running since. He is a patient advocate, mentor, public speaker, transplant athlete and a retired internationally known, award-winning healthy lifestyle chef. He has served twice on a United Network for Organ Sharing (UNOS) committees Network 10 and is a national speaker for the Renal Support Network and other national committees.

Chef O's life has been filled with a lot of enjoyment and has been very rewarding. From hosting an award-winning TV cooking show for 11 years, 315 shows, 9 Video Awards and a Producer of the Year to being voted twice BEST CHEF in GR, to be a representative on TEAM USA and TEAM MICHIGAN at 8 World Transplant Games and 14 Transplant Games of America, 33 medals in track and fields, tennis and fencing. He says his transplant life is like climbing a ladder, going higher and higher. But as he climbs, he wants to reach back and bring some people along with him. Chef O's goal is to take an RV and travel the United States to help show dialysis patients how to cook, eat and live a better life while on dialysis and even after their transplant.

---

### MINNESOTA

#### Aaron Kringler

Biography coming soon!

#### Lynette Robertson

Biography coming soon!

---

### 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

## Meet AAKP's Ambassadors!

Updated 12.09.19

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).

---

### MISSOURI

#### Margaret Baggett



Margaret has had kidney disease for 20 years. She is an original member of a small local support group called "Kidney Friends" which began in 2009. In addition to her own experiences, she has seen the difficulties her friends have gone through.

Margaret retired early from her work as an analyst with the Missouri Department of Health because she had kidney disease. After additional years dealing with the disease, she went on Peritoneal Dialysis with only a short time on in-center hemodialysis. She received a transplant in 2009 from a deceased donor. Her kidney transplant has been successful.

She has participated in Kidney Day at the Missouri state capitol in Jefferson City. Also, she has been able to attend several AAKP Annual Meetings.

#### John Thomas

Biography coming soon!

---

### MONTANA

#### Christl Domina



Christl's kidneys started to fail in 2007, and by 2009, she was in complete renal failure. She has had some pretty rocky times throughout the years, but she realizes how very fortunate she is to have the support of her husband and son and still be able to do most of what she wants when so many aren't as fortunate. Besides being a Patient Ambassador for AAKP, Christl became an advocate for the National Kidney Foundation in 2013. She advocates for local patients, is a Peer Mentor on a National level, and travels to Washington, DC once a year to appear before Congress to lobby for issues important to kidney patients.

A few years ago, Christl got really involved in the political process. She worked on the Hillary campaign, a Billings City Council race, two federal Congressional campaigns, and is now a Campaign Manager for a State of Montana legislative candidate running for re-election. Christl also sits on the Yellowstone County Democratic Central Committee as a Precinct Captain.

## Meet AAKP's Ambassadors!

Updated 12.09.19

In her spare time, she is the Montana State Data Lead for Moms Demand Action. She is a founding Board member of Montana Voters Policy Institute, part of a Human Trafficking Task Force, and a member of Standing Up for Racial Justice (SURJ). Christl also crochets and quilts.

She fishes and spends as much time outdoors with her family as she can. Two crotchety old cats and five crazy birds allow Christl and husband Paul to live in their house.

---

### 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 HAMPSHIRE

#### **Melissa McCutcheon Lamothe**

Biography coming soon!

#### **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.

---

### 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.



## Meet AAKP's Ambassadors!

Updated 12.09.19

### Bill English



Bill grew up in Edison and now resides in Bellmawr, NJ with his wife, Laura and two boys. Bill received a kidney transplant from an altruistic kidney donor in July 2018 after spending almost 3 years on dialysis. Thanks to his wife's advocacy on social media, by creating campaigns on Facebook, Instagram & Twitter, he found his donor. Our pages are still active to continue to raise awareness for living donation and kidney disease. After Bill received his transplant, his wife accepted a position as the dialysis social worker at his former dialysis unit.

Originally diagnosed with chronic kidney disease in 2012, a kidney biopsy in 2013 revealed a diagnosis of interstitial nephritis. His nephrologists believe this was caused by a medication he took for ulcerative colitis. Following these results, Bill was treated with high doses of prednisone and his function remained stable for about 2 years. In October 2015, shortly after his 33<sup>rd</sup> birthday and after feeling ill for many months blood work revealed he was in end stage renal disease and started dialysis. Having no family history and limited knowledge about dialysis and kidney disease, he and his wife turned to social media and found a wonderful online community and support through others with similar experiences.

In April 2018, Bill completed his first Donor Dash with the Gift of Life in Philadelphia and is active with Power2Save an initiative of the American Society of Transplantation. Bill hopes to continue his advocacy work as an AAKP Ambassador.

### Sarah Ford



Sarah donated her kidney in March 2018 after reading the story of a friend of a friend on social media about 18 months earlier. After having such an amazing and moving experience, she hopes to not only help spread the importance of living kidney donation by sharing her story but also help advocate for improved policies. Sarah – whose day job is in print sales – is an active mom of two, a marathon runner, a mentor in her local running club, and a spin instructor.

### 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

## Meet AAKP's Ambassadors!

Updated 12.09.19

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.

### Halden Smith



Halden was born in Jamaica and immigrated to the United States at the age of seven. He is a big sports fan and also enjoys writing poetry which gives him a chance to express himself. He hopes to use that to inspire others going through the kidney process so it can bring them positivity.

Halden graduated from Felician University in Rutherford, New Jersey in 2006, receiving his bachelor's degree in journalism. He enjoys doing research on different topics especially about the kidney and how he can help others. Halden received his transplant in August 2012, giving him seven years of great blessings. Halden wants to help others cope effectively with this disease.

---

## NEW MEXICO

### Ashley Fastle

Biography coming soon!

---

## NEW YORK

### Rahmeka Cox

Biography coming soon!

## Meet AAKP's Ambassadors!

Updated 12.09.19

### Angela Davis – IN MEMORIAM



Angela, the CEO of For Kidney's sake, was born in Queens, NY. It was in Albany, NY where she used her talents and interpersonal skills to shape a career that began in the political arena. When she stepped away from politics, she followed another passion of hers which is business. Years later she started her own business which was a result of her greatest achievement...the adoption of her son Lewis Elijah Davis.

In 2008 when she was diagnosed with End Stage Renal Disease (ESRD) it was both shocking and devastating to Angela and her family. She was hospitalized for about 4½ months while her aging mom lay in a Nursing Rehabilitation Facility during the same period. But Angela never asked, "Why me?" Instead her response to the staff was, "What happens next? When and how can I get on a transplant list?" It was this attitude that kept her going. Her strong faith in God, encouraging strength and spirit, and the belief that her life has a greater purpose that is not yet fulfilled has kept her going for over 8 years on dialysis.

Angela volunteered as a Patient Advocate and heard many stories from dialysis patients and saw a depression and isolation firsthand. It was then that For Kidney's Sake began! FKS was developed out of partial frustration with the way the health system treated CKD and dialysis patients and a desire to be a powerful force for change in the way CKD and dialysis patients live their lives. Angela's motto is, "I have kidney disease, kidney disease does NOT have me!"

Angela passed away June 16, 2019. While we mourn the loss of a strong patient advocate, we will continue the fight against kidney diseases in her memory.

### Jane DeMeis



Jane decided that she would advocate for better kidney education early in the disease process. When she retired after many years as a Director of Education and health advocate for large size people, she set out to become educated on nutrition and healthy living for patients with kidney disease who were not yet on dialysis. Jane is licensed as a public-school teacher, a certified Organizational Development Professional, a Lean Practitioner and certified Trauma Professional.

Jane remained at CKD Stage Three for over 10 years. Being diagnosed in 2018 with Stage Four kidney disease was eye opening, and Jane stepped up to become a volunteer with her local kidney organization. She also completed course work to become a kidney coach, a peer mentor and participates as an Ambassador on Health Unlocked in their kidney forum. Jane feels very strongly that all patients deserve respect and the best treatment possible no matter their size. The medical/health field which she has been a part of for over eleven years is very

## Meet AAKP's Ambassadors!

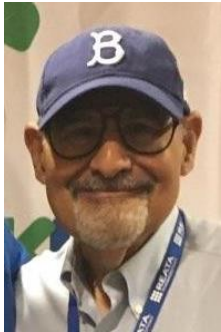
Updated 12.09.19

discriminating against large size patients. She feels that many large size people do not participate in proper medical treatment in order to avoid the guilt and shame.

Jane spent over two years suffering with ongoing joint pain. She was told repeatedly that it was due to her weight. When her hands began curling into fists, she was finally diagnosed with Psoriatic Arthritis (PsA). PsA causes high uric acid and her kidneys filled with very large kidney stones that caused a lot of damage. All during that time she was prescribed large doses of OTC ibuprofen to manage her pain. If she had been diagnosed properly and earlier, she may not have the damage she has.

Jane has been able to maintain her remaining kidney function with a renal diet using plant-based meals. Although not the reason, she has lost almost forty pounds. She advocates for fresh homemade meals. She grows her own vegetables and herbs when she can and bakes her own breads from scratch. Jane feels strongly that patients should receive better education starting with Stage Two CKD diagnosis. She feels that through better nutrition and lifestyle changes, many people can live healthier lives and slow the progression of kidney disease.

### Robert "Bob" Friedman



Bob was born to believe in an America of social justice. As a youngster, his heroes were the freedom riders and those who fought for organized labor and progressive values and against fascism. He graduated with a master's degree in social work from SUNY at Stony Brook and specialized in health planning and advocacy. He worked in government and established some of the first Meals on Wheels and casework programs. In the nonprofit world, he became an active grant and program developer and set up some of the first adult protective and guardianship programs.

Bob was diagnosed with type one diabetes in 1977 and remained very healthy until 2010 when he succumbed to end-stage renal disease and began hemodialysis. On March 6, 2018, after 7 years of declining health on the UNOS wait list, Bob received a kidney from an altruistic living donor. Apart from some annoying complications, he is otherwise beginning to become active and involved, including his newfound admiration for AAKP, its leadership and its approach.

### Jonathan Haydak



Jon was diagnosed with pauci immune glomerulonephritis when he was 22 years old and started peritoneal dialysis at age 23. He was on PD for 2 years before receiving a kidney from his sister Rachel on March 14, 2019 (World Kidney Day)! Jon recently finished graduate school with an MS in chemical engineering from Georgia Tech.

## Meet AAKP's Ambassadors!

Updated 12.09.19

### David Kleehammer



David taught biology for 32 years and coached soccer for over 25 years. He was diagnosed with FSGS and left renal agenesis after a routine yearly physical. This early detection allowed him to get the proper care until testing revealed that his wife and two of his four children were matches. David's wife gave him a kidney in August 2007.

### 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 and 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.

---

## 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

## Meet AAKP's Ambassadors!

Updated 12.09.19

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.

### Andrea Cox



Andrea is a retired second grade teacher of 32 years. She was diagnosed with ESRD at the age of 50, in 2004. This discovery was through her requesting an increase in her life insurance policy which was denied. She found this news to be devastating because she had no symptoms of this disease and did not have diabetes or hypertension. The actual cause of Andrea's kidney failure is unknown.

The journey of hemodialysis was frightening, challenging, and sometimes painful. It caused other medical problems. She had to have her aortic valve replaced due to endocarditis while receiving dialysis.

Andrea received a kidney transplant from her oldest son David on April 17, 2006. This past April 2018 marks her 12<sup>th</sup> Kidney Anniversary. That phenomenal "Give of Life" improved her quality of life. Andrea and her daughter, Rahmeka are on a mission to create awareness for organ donation, transplantation, and kidney disease through their organization, "It Only Takes One."

### 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.

---

### NORTH DAKOTA

#### Becky Ronkowski



Becky Ronkowski is a transplant recipient. She received a kidney from her husband in 2000.

Becky is a retired elementary teacher and a private piano instructor. She is very involved politically, having served in local and statewide leadership positions and worked on staff for federal campaigns. She has also twice been a delegate to the Democratic National Convention. Becky volunteers for several organizations in her community. She is the wife of Keith, a retired educator, and the mother of three children.

---

### OHIO

#### Jay A. Blum



Jay A. Blum is a published author and currently serves as a patient advocate for NxStage and DaVita Home Dialysis; promoting the values of home-hemodialysis and the right for patients to choose their treatment modality and frequency. Jay previously served as a civilian contractor for the Department of Naval Intelligence as a Forward Deployed Tactical Intelligence/Counterintelligence Officer before losing both kidneys to cancer. A strong advocate for education and legislative / governmental affairs he holds a master's degree in Business Administration with a Specialization in Marketing and a bachelor's degree in Applied

Management. He was in the process of pursuing a Doctorate in Business Administration when he had to part ways with his second kidney. At that time, kidney advocacy came a priority.

Jay has had the privilege of living in nineteen (19) countries, on four (4) aircraft carriers, on three (3) submarines and has both a private and commercial pilots license for both fixed-wing and rotary aircraft. From 1992 to early 1994, he also served as the Terrorism/Antiterrorism Intelligence Attache' to President-Elect and then to President Bill Clinton. In his spare time, Jay enjoys reading, speaking to intimate groups of 1 to 200+ people about his kidney journey, and advocating for patients' rights. Jay and his wife, Sheri, have 1 son, Aidan and 2 fur-daughters, Bracha (Hebrew for Blessing) and Kya (Expert in Islam). On October 4, 2016, Jay began hemodialysis and is currently traveling from transplant center to transplant center until one of them wakes up and places him on the transplant list. Stay tuned to find out which one does.

#### Ashley Eastlake

Biography coming soon!

## Meet AAKP's Ambassadors!

Updated 12.09.19

### 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.

### Jack Lennon



Jack is a life-long kidney patient, having been born with Post-urethral Valves (PUV) which is a blockage that develops before birth and causes urine to back-up into the bladder then up into the kidneys, causing significant damage. Throughout Jack's life he has experienced many elements of kidney care including, both hemo- and peritoneal dialysis as well as being a three-time kidney transplant recipient. Due to the nature of the PUV and resulting kidney disease, Jack (with the help of many dear family and friends) has grown up having to manage his condition. As a result, he has a very special place in his heart for children struggling with kidney disease.

Jack has spent his entire young career in healthcare, trying to improve the lives of patients by spending over seven years at the pediatric hospital system in his hometown. He worked within the Division of Nephrology, managing the Kidney Transplant Program prior to assisting institutional leadership in the development of organizational strategy and growth.

Since March 2019, Jack has been the Executive Director of the Improving Renal Outcomes Collaborative (IROC), a network-based learning health system of patients and families, clinicians, and researchers from 30+ pediatric kidney transplant programs in the country. The network works together to solve some of the difficult problems for children with kidney disease by harnessing the inherent motivation and expertise of all stakeholders to improve care and spawn innovation, while sharing best practices and data about medical care, followed by the application of quality improvement methods to advance health outcomes.



## Meet AAKP's Ambassadors!

Updated 12.09.19

### Ashley Martin



Ashley is a caregiver advocate. She is currently studying 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 she 7 years old. She has also been attending AAKP's National Patient Meeting since she was 8. 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 has been on and off dialysis since 2001 and just received her second kidney transplant from a deceased donor in April 2018. She is very grateful for this blessing after waiting 7 years for her. Her 1<sup>st</sup> kidney transplant failed due to CMV aka Cytomegaly Virus. For approximately 6 years, she was a home hemodialysis patient with partnership of DaVita and NxStage Medical dialyzing 6 or 7 days a week for 2½ hours each day while trying to work full-time.

Toni has been on The Christ Hospital Patient and Family Advisory Council for over 10 years. She is also an advocate for The American Kidney Fund (AKF). In 2015, she was engaged in the First Patient and Caregiver FDA Conference to streamline many kidney disease initiatives. At this conference, she learned there are many researchers working to make treatments for ESRD much better for the patients and caregivers. Together with daughter Ashley, Toni hosted a kidney diet webinar for AAKP in 2016. Over the years, she has raised money for The Kidney Foundation. Toni is employed full-time by Medpace, a Clinical Research Organization, trying to overcome many physical setbacks. Kidney disease has changed her life in so many ways. She is an advocate to help others during this difficult journey with trying to stay alive and to live life to the fullest capabilities.

### Jason Miller

Biography coming soon!

## Meet AAKP's Ambassadors!

Updated 12.09.19

### 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 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.

---

### OKLAHOMA

#### Sonya Cochran – IN MEMORIAM



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 heredity 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, and kidney care.

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 OK. 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 with 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

## Meet AAKP's Ambassadors!

Updated 12.09.19

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!

AAKP was very sad to learn of Sonya's passing in 2019. We will continue to educate and advocate on her behalf.

### Jerry Nailon



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

involvement.

---

## OREGON

### Carolyn DeMarco

Biography coming soon!

---

## PENNSYLVANIA

### Margo Bowman

Biography coming soon!

### 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.

## Meet AAKP's Ambassadors!

Updated 12.09.19

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. Candie received a kidney transplant in June 2018.

### **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.

### **Mike Rudolf**



On August 30, 2017 at the University of Tennessee Medical Center, Knoxville, TN, Mike donated his left kidney to his oldest brother Al, CPO, USN (ret.). He now serves as a Volunteer Ambassador for the Living Kidney Donor Network speaking on the 'Joys of Becoming a Living Kidney Donor' using the hashtag #dontwasteyourkidney.

Mike has over thirty-five years of healthcare industry experience in the areas of food & nutrition, quality improvement, and facilities management. He is a four-time Malcolm Baldrige National Quality Award examiner and co-authored a Baldrige application for the 1995 healthcare pilot. Mike has served on multiple not-for-profit boards and has twice served as board chair. For eight years, he taught at Penn State Great Valley in their MBA Program and in both the Quality and Supervisory Management Programs. He was recognized as Outstanding Instructor in 1997 by Penn State's Smeal College of Business Administration and was the inaugural recipient of its 1998 Innovative Instruction Award. Mike holds a BS in Nutrition from Penn State and a MBA in Finance from Thomas Jefferson University. He is married to his college sweetheart Priscilla and lives outside of Philadelphia PA.

## Meet AAKP's Ambassadors!

Updated 12.09.19

---

### RHODE ISLAND

#### 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.

---

### 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.

---

### 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 stepdaughter.

#### AK & Orrie Diefenbach

Biographies coming soon!

#### Ralph W. Mickle



Ralph is Mexican American, and diabetes runs in his family. He was diagnosed with diabetes first and then with ESRD (End Stage Renal Disease) in his mid-30's. He spent about four years on dialysis and then was blessed with a kidney transplant from a deceased donor on December 3rd, 2014.

Ralph became an advocate for a couple of non-profit organizations and had the honor to share his story and advocate for the over 30 million kidney disease patients up on Capitol Hill. He is dedicated to spreading awareness and being the best Kidney Warrior possible. Ralph is a team member for the Salem 5K for Kidneys (Salem, OR) organizing board. Right now, he is focusing on Hispanics by taking advantage of his bilingual skills and reaching them in a more comfortable environment. His goal is to become a stronger and more active advocate, and he is being mentored by a lot of other Kidney Warriors/advocates.

Ralph wants to share his story of how he overcame what he went through, with the assistance of many, and hopefully it will become a part of someone else's survival guide and game plan. Ralph says, "We are Kidney Warriors and WE ALL need to Be Strong and Courageous!"

## Meet AAKP's Ambassadors!

Updated 12.09.19

---

### TEXAS

#### 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.

#### 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 32 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 served in the United States Army Medical Corps from 1970-72, and was an RN in the Veterans Administration for 22 years. In addition he has a 20 year career as an RN at Peterson Hospital in Kerrville, Texas, where he was Administrative Director of Medical Staff Services. He has an active interest in FSGS research and was a steering committee member for Nephcure International.

Kent is an active Peer Mentor and Consumer advisor participating in chronic kidney disease research reviews for the U.S. Department of Defense and is an experienced consumer peer reviewer for PCORI (Patient Centered Outcomes Research Institute). He actively participates in kidney advocacy efforts on the hill and was the recipient of the 2017 Richard K. Salick Advocacy Award.

Kent retired in 2018 and founded Kidney Solutions a 501c that works with patients and families to locate kidney donors. Their services are free and they work closely with the medical community in the San Antonio area.

## Meet AAKP's Ambassadors!

Updated 12.09.19

### **Catherine Campbell**

Biography coming soon!

### **Amanda De León**



Amanda grew up on the south side of San Antonio, TX. Throughout her life, she witnessed multiple family members go through dialysis. It was scary and heartbreaking to see her loved ones go through exhaustion, constant itching all over their bodies, painful muscle cramps, insomnia, and depression. In San Antonio alone, there are over 5,000 patients on dialysis – a staggering number.

In 2011, Amanda and her family got the news they never wanted to hear. Her father, Baldomero, was diagnosed with kidney cancer and was to start dialysis immediately. After five long years of dialysis, her father was exhausted. Dialysis had changed who he once was, and he voiced his need and desire for a kidney. While Amanda was busy raising her five children, she knew she needed to do something and so she began the testing process to see if she was a match to donate her kidney to her father. She searched the internet high and low for information on kidney donation and it all seemed positive and encouraging, but she never found exactly what she was looking for – an actual donor, a person she could relate to. So, it was then that she decided to start up her own YouTube channel and document the whole testing process. With her family in mind she named her channel, Table For Seven. She documented the highs and lows of the testing process, the exciting day she received the phone call that she WAS A POSITIVE MATCH, and even documented the glorious day of her father's kidney transplant! Through Amanda's channel she has met numerous kidney donors thanking her for sharing her story.

Two years post kidney donation, Amanda De Leon is now the CEO of Kidney Solutions, a non-profit in which she and her partner Kent Bressler help ESRD and dialysis patients find their living kidney donors. They provide patients and their families with support, encouragement, and even a professional photo shoot that they share on all of their social media sites, asking for a kidney donor to be their hero, at no cost to the patients. Amanda's life has changed since donating her kidney, and her hope and dream is that through her advocacy and non-profit she will help change someone else's too.



## Meet AAKP's Ambassadors!

Updated 12.09.19

### Lindsay Gath



In 1992 Lindsay became very sick one weekend. After her doctors ran lab work, it pointed to her creatinine being elevated, a kidney biopsy was done, and she was diagnosed at the age of 11 with Membranoproliferative Glomerulonephritis (MPGN Type I), caused by a Strep infection. Over the next 25 years she was treated with different medications to slow the progression of the disease, but would go on to have 2 children, delivering her second 7 weeks early because of her kidneys. Her kidneys stabilized after delivery but declined in function more over the years and in 2016 she was told it was time to start looking into a transplant. She went to social media to let her friends and family know the position she was in and educated them on what she knew about living donation in case they were interested, trying to be proactive and get a preemptive transplant before needing dialysis. Through the testing process to find a match, it was found that her sister, Courtney, was a perfect match, but she ultimately was not allowed to donate due to kidney stones that she didn't even know she had. The testing process continued and ultimately it was her sister's best friend, Shea, that was her match! On October 26, 2017 she received the gift of life through a preemptive unrelated living donor transplant. Since her transplant, Lindsay has enrolled in school and enjoys all the extra moments she has been given with her family and friends. She enjoys being outdoors, walking, and golfing in her spare time, and is always up for an adventure!

Lindsay was born and raised in the Austin area and still lives there with her husband and two kids. She has been involved with the Texas Organ Sharing Alliance as well as The National Kidney Foundation, helping to organize the Austin Kidney Walk in 2017. She looks forward to getting involved with AAKP, hoping to raise awareness about early detection, preemptive transplant when possible, and living donation.

### 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.

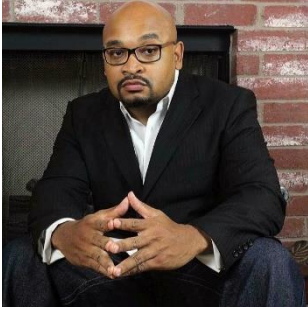
Today, Nichole is waiting for a new transplant.

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.

## Meet AAKP's Ambassadors!

Updated 12.09.19

### 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, Brittanee and their two sons.

### Darin Lane

Biography coming soon!

### 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. David serves on AAKP's Board of Directors.

## Meet AAKP's Ambassadors!

Updated 12.09.19

### Jaclyn Starr



Jaclyn was diagnosed with kidney failure at only 24-years-old in early 2012. She had no idea she was sick and in fact, she felt "normal." When she went to the hospital her kidneys were only functioning at 6%. The doctors did a biopsy and ultrasound, but they knew the outcome was grim. She started dialysis 3 days after being admitted to the hospital. She did 11 months of hemo-dialysis, until her oldest brother donated a kidney to her November 28, 2012. She wants to turn her negative diagnoses until a positive experience and educate others on the importance of getting yearly checkups, and also

educate on becoming an organ donor.

Jaclyn was born in Texas but raised in New Mexico and has just moved back to the Dallas area. She graduated with her BBA in May 2018 from the University of New Mexico. Jaclyn's favorite quote is by Helen Keller: "Optimism is the faith that leads to achievement. Nothing can be done without hope and confidence."

---

## 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

## Meet AAKP's Ambassadors!

Updated 12.09.19

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 received his kidney transplant on Oct. 18 from the University of Utah hospital in Salt Lake City, Utah. He is grateful for the second chance at life and is thankful for all the people who donate organs. After spending three weeks in Salt Lake with his father, Dennis Tippetts as his caregiver, Bruce was able to go back to work full time as a newspaper reporter at UB Media (Vernal and Roosevelt, Utah).

Bruce wanted to thank his family for supporting him on this journey and his coworkers at the newspaper. Before his transplant, Bruce received 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. With his transplant, he wants to make a difference in peoples' lives and bring kidney awareness to people he meets.

### 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 a 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.

---

## VIRGINIA

### Meshia Adams

Biography coming soon!

### 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.

## Meet AAKP's Ambassadors!

Updated 12.09.19

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 Doctor 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! Patrick serves on AAKP's Board of Directors.

### Jennifer Jones



Retired Marine Veteran Jennifer Jones' life changed drastically in a matter of months due to kidney disease. Her kidneys began to fail while deployed to Afghanistan which resulted in immediate medical evacuation to Germany to receive a diagnosis of Nephrotic Syndrome. Upon returning to the states, she was immediately admitted as a patient at Walter Reed National Military Medical Center in Bethesda, Maryland. After months of testing and multiple medications, J. L. was diagnosed with Membranoproliferative Glomerulonephritis (MPGN) shortly after her 28th birthday. The cause is unknown and there is very limited information on MPGN Type 1 Idiopathic.

Jennifer was medically retired after almost 12 years of service as a Combat Camera Videographer including 3 tours to Iraq and the 1 to Afghanistan which ended her career. Facing physical and mental challenges while living alone with limited assistance from friends and family caused isolation, depression, and even suicidal ideations. She knew that she had to make a decision, is she going to become her own advocate in order to take charge of her health and well-being, or is she going to give up and succumb to this disease?

## Meet AAKP's Ambassadors!

Updated 12.09.19

Jennifer decided to focus on her quality of life, being a compliant patient and began an active pursuit for a living altruistic donor. On April 2, 2015, she received a kidney transplant and a new sister, a selfless person who did not know her but felt compelled to save her life after hearing her story. She is now passionate about spreading awareness, knowledge, and providing mentorship for those want to develop and maintain resiliency to face and overcome the challenges that kidney disease and the rest of life brings. She is the Founder of Gen Resilient, a community devoted to resiliency, personal development, well-being, and self-actualization. Jennifer is available for speaking engagements, patient perspective, interviews, workshops, and conferences. She currently resides in Virginia with her partner LaSean and their 3 fur kids: Frankie, Obie, and Ovinnik.

### Charles Reaves



Biography coming soon!

### Anthony Reed

Biography coming soon!

### Cheryl Ross



As the former patient advocate at the National Kidney Foundation of the Delaware Valley, Cheryl testified before the Pennsylvania Department of Public Welfare Pharmacy & Therapeutics Committee regarding a proposed Medicaid preferred drug list; lobbied in support of issues concerning people with diabetes and kidney disease, including pre-dialysis education and the expansion of the Chronic Kidney Disease Control Program at the Centers for Disease Control and Prevention; and she has rallied support in New Jersey and Pennsylvania to require clinical laboratories to calculate glomerular filtration rate (GFR), resulting in the passage of the GFR law in both states.

In addition to her federal and state public policy work, Cheryl has spoken at various events about diabetes, hypertension and kidney disease and its financial and human impact in the minority community. She has appeared on the cable TV show *Comcast Newsmakers*, and health radio shows broadcasted in Philadelphia.

## Meet AAKP's Ambassadors!

Updated 12.09.19

Born and raised in Seattle, WA, Cheryl received a kidney transplant from a deceased donor in 1997. She relocated to northern Virginia where she continues to lobby for federal policies positively impacting kidney patients, living organ donors, and moving efforts forward in kidney research and innovation.

---

### 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 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

## Meet AAKP's Ambassadors!

Updated 12.09.19

corporate leadership and patient experience and views herself as being uniquely positioned to be a positive force for advocacy, advancement and awareness.

---

### WEST VIRGINIA

#### Charles Cranford



Charles is a retired former Director of the Eastern Management Development Center in Shepherdstown, WV. His struggles with kidney disease began in his early 30's when after a routine physical exam some protein was detected in his urine. Since that early detection, he has had a clinical diagnosis of FSGS and along with it, chronic kidney failure. As he spoke with doctors and assessed his options while on the waiting list, which at the time suggested a five plus year wait, he learned of a program called the Shared Kidney Exchange at Johns Hopkins. Charles was very fortunate to have a loving wife, Amy, who volunteered to be a living donor to expedite the process for him to more quickly receive a transplant. The unlucky part was that they were not a "Match."

On February 3rd, 2011, a miracle occurred whereby a match had been found for Charles and he had managed to barely avoid the need for dialysis. Hopkins arranged to have three donors provide three kidney recipients with life-saving kidney transplants. His wife's kidney was removed first and sent on a chartered jet to Barnes Jewish Hospital near St. Louis and the wonderful chain reaction commenced.

As a result of his successful transplant of more than eight years, Charles is passionate about giving back to the Transplant Community. He often says, "for those who much is given, much is required!" He volunteers for many different organizations including two OPO's; the Living Legacy Foundation and LifeNetHealth. He speaks at many different venues to promote eye, organ, and tissue donation. Finally, since his wife, Amy, is a living donor, he is especially interested in promoting legislation regarding the Living Donor Protection Act.

#### 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,



## Meet AAKP's Ambassadors!

Updated 12.09.19

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!

---

### 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.

#### Terry Foust Litchfield



A dedicated patient advocate; her husband Bill prior to his death a few years ago, celebrated 46 years of renal replacement therapy. He was one of the 4 patients who testified for House Ways and Means with one of them dialyzing before members of congress to pass Medicare legislation for ESRD. She serves on the KHI Patient and Family Partnership Council and AAKP to name a few of her patient advocacy roles. As the care partner during home dialysis or supportive of in center care, she well

knows the impact of kidney disease on a family.

She also spent more than 30 years in the health care field, with an emphasis on dialysis related care. Until recently, Terry headed up clinical operations at Lifeline Vascular Access. She has a unique insight into the changes of the current healthcare environment related endovascular disease treatments, particularly those involving renal patients. Twenty years ago, Terry was one of 4 founders of Lifeline Vascular Access and was an early leader in dialysis access care outside of hospitals. Best known for her outcomes research and disease management for renal disease

## Meet AAKP's Ambassadors!

Updated 12.09.19

and chronic kidney disease patients, she is the author of a number of publications in the field in addition to multiple publications and presentations related to Patient Engagement and Satisfaction with care.

---

### WYOMING

#### Shane Pierce



Shane is a married father of 4 and was diagnosed in 2014 with IGA nephropathy, shortly after the birth of his 4<sup>th</sup> child. He was in stage 4 when he learned of his diagnosis. Shane has been in law enforcement for 12 years and has held many positions including Field Training Officer and Homicide Detective. He is a few credits shy of a bachelor's in criminal justice. Shane did peritoneal dialysis at home and because of that he was able to continue working full-time. He was graciously given a live donor kidney and transplanted at Barnes Jewish, St. Louis in 2017 at the age of 43. He and his donor happily shared their story with the media and anyone that would listen. Shane recently moved to Wyoming and learned they did not have an advocate here. He wants to share his story with others and help them understand how important kidney health is.

---

### ARGENTINA

#### Maria Eugenia Vivado Duran



Maria Eugenia was diagnosed with kidney disease in 1979 during the screening tests of her second pregnancy. She remembers her doctor wanted to give her a corticosteroid shot to stop the disease, but she did not accept it and her son was born healthy. Then a biopsy found FSGS. For 10 years, Maria Eugenia followed a conservative treatment to take care of her kidneys. She finished studying Medicine with a specialty of Pediatrics and enjoyed the growth of her two children. She was involved in so many activities and wanted to do everything before starting dialysis, as if the world would be ending.

In 1989, Maria Eugenia began hemodialysis. As a doctor, she knew how and what the treatment was, but as a patient she had many questions. She learned that she was starting a new way of life that depended on one's attitude and good medical care. In conversations with her dialysis partners, she noticed that they lacked a lot of information. She looked for different organizations of patients and professionals. In 1991, she found information from INCUCAI, an organization dedicated to the distribution of donated organs, tissues and cells, for transplantation throughout the country. There she met other patients with different pathologies but similar needs who also needed a transplant. They met to defend the rights of patients, then

## Meet AAKP's Ambassadors!

Updated 12.09.19

the Transplant Law was created in 1993 and included patients and medical professionals, each as an Advisory Council.

Maria Eugenia started participating in the Asociacion Solidaria de Insuficientes Renales (ASIR) in 1996, consisting of kidney patients, family and friends. They talked about alternative dialysis treatments, especially about peritoneal dialysis, and she later promoted transplant information. Since then, she has participated with different groups of patients, both national and international. Over the years they have created several organizations that protect the rights of patients, information, education, participation and support for new laws that benefit and protect patients.

After 13 years on the waiting list while doing hemodialysis, Maria Eugenia received the long-awaited transplant from a deceased donor on October 29<sup>th</sup>, 2001, which gave her the ability to continue working voluntarily for patients, educating the community, enjoying her family and grandchildren, to explore new places – in short, to live life. She does everything in gratitude to that anonymous donor who gave her once more in life, the great joy and honor of meeting patients, family and friends of AAKP and participate in their 50th anniversary.

Maria Eugenia is currently the president of the ASIR, for the fourth consecutive period. With the impulse of patient organizations and the National Congress, they achieved current laws such as the Patient Rights and Duties Law in 2012, Law on Comprehensive Protection of Transplanted People and Waiting List in 2015, and a new Transplant Law in 2017. She is a member of organizations of transplant and kidney patients, also of medical organizations of pediatrics, nephrology and transplants. She is always willing to help and work for the patient, family and community. On October 29, she will celebrate 18 years of transplant, which is like a second life for her. Maria Eugenia says: *"I LOVE WONDERFUL LIFE, it is beautiful to live it."*

---

### CANADA

#### **Nate Boutcher**

Biography coming soon!

#### **Rozelle Callangan**



Rozelle is from Vancouver, BC Canada and was born with kidney disease. The doctor told her mom that she either had one small kidney or no kidneys at all but Rozelle found out later that she had 2 small kidneys. At the age of 3 years old, she was diagnosed with Stage 3 CKD and her kidney function started to go down, with one of her kidneys not working. In 2011, she was transferred to Adult care and the doctor said she was border line end-stage renal failure and started talking about dialysis.

## Meet AAKP's Ambassadors!

Updated 12.09.19

In July 2015, Rozelle started hemodialysis and it was one of the toughest things she had to deal with. She struggled with a lot of infections, dialysis access issues, and other complications. It started to feel like she was living at the hospital, and it was a lot to handle for a 22-year-old. On June 18, 2018, she got the call from the hospital that they had a potential kidney, and the next day she received a kidney transplant from a deceased donor.

Rozelle is a Peer Support Worker helping youth transition from Children's Hospital into Adult Care, and she supports and helps new hemodialysis patients understand dialysis. She has also helped with The Kidney Foundation of Canada British Columbia and Yukon Branch with their events like Kidney Walks and Kidney Gala. Her current volunteer position is an Online Ambassador. While she may be the youngest, she is very passionate about helping others who are going through similar situations.

Kidney disease is part of Rozelle's life, and she chooses to raise awareness and advocate for other kidney patients, especially for the younger generation. She is also working on going back to school to become a social worker. Her goal is to make a Transition Clinic at Children's Hospital to prepare and educate them before they transition to Adult care. She is also a Get Loud for Kidneys Advocate helping spreading awareness about kidney disease and organ donations. Rozelle is trying to help her community because they have been such a big support for her. She is excited for what's to come as an AAKP Ambassador!

---

### IRELAND

#### Colm Clifford



Colm is a three-time kidney transplant recipient. Born with only one functioning kidney, Colm suffered reflux as a child which damaged this kidney. He went on CAPD at the age of 11 and was transplanted in March 1990, which was not a success as the kidney never functioned. In November 1990, he received his second transplant which gave him a great quality of life for over 22 years. He found himself back on dialysis (CAPD) for two and a half years but due to complications had to move to haemodialysis for a year and a half until his recent transplant in March 2017.

For over 20 years, ironically, Colm works for a pharmaceutical company which produces the immunosuppressant he currently takes. He is actively involved in the Kerry Branch of the Irish Kidney Association and has recently set up a patient support group meeting for people on a similar journey. His passion is to promote awareness and educate people on the importance of organ donation through one-on-one talks and group talks in schools and communities.

---

## Meet AAKP's Ambassadors!

Updated 12.09.19

---

### PUERTO RICO

#### Orlando Torres



Orlando is originally from Puerto Rico where he lives with his wife Jenny. He earned his bachelor's degree in Business Administration at the University of Puerto Rico, and later earned graduate studies at Wharton. Upon graduation he initiated his professional career working with Gillette Company and later with pharmaceutical, health insurance and international banking entities.

In 2015, Orlando was diagnosed with end stage kidney disease and he kept out of dialysis for more than one year due his discipline with the renal diet program. Unadornedly, Hurricane Maria hit his country and due to the limitations after the hurricane, he started dialysis in December 2017. Orlando is waiting for his transplant at Methodist Hospital in Dallas Texas, and he is part of the paired program for kidney transplant.

---