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# NATIONAL AMBASSADORS

## ALABAMA

### Katina Lang-Lindsey



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

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

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## ALASKA

### Yalonda & Gary Moore



On April 18, 2012, Gary was diagnosed with ESRD. He started his treatment as an in-center dialysis patient. He did ICHD for four 4 months before changing over to peritoneal dialysis (PD). In early 2013, while Gary was at a conference, he was asked to join the ESRD National Coordinating Center (NCC) National Patient and Family Engagement Learning and Action Network (NPFE-LAN) as a patient subject matter expert (SME) because of his upbeat spirit and not letting the kidney diseases get him down attitude. Gary has also participated with the ESRD Network 16 organization as a Medical

Review Board member for 10 years.

In February 2018, Yalonda was asked to join the NPFE-LAN Team. She has been a member as a SME for Caregivers/Care Partners.

Both Gary and Yalonda have participated in several podcasts as well as educational review panels. They love talking about the benefits of doing PD and traveling while on PD as well as

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talking to people about how to involve your children in your treatment and being your own first defense during your treatment.

For Gary's birthday on April 15, 2023, he received that long-awaited call saying they had a kidney. They both have full intentions on continuing their work with the multiple kidney organizations they participate in and are looking forward to the work they can do with AAKP now that he has a transplant.

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### ARIZONA

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

#### Risa Simon



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

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### ARKANSAS

#### **Ericka Downey**



Ericka felt called to act when she saw a story about a college basketball coach needing a kidney. Being the wife of a college basketball coach herself, she felt a real connection and reached out to begin the process of getting tested to be a donor. In 2018, Ericka donated a kidney to Coach Billy Gillispie.

#### **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.

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### 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 20<sup>th</sup> District Circuit Court in Faulkner County. A strong advocate for education, he holds a master's degree in Higher Education Administration and a bachelor's degree in Communication/Sociology, both from Arkansas Tech University. He is currently pursuing a Juris Doctorate at UALR-Bowen School of Law. Jimmy has held leadership positions at Hewlett-Packard, Apple, and the Conway Area Chamber of

Commerce. He is a member of the Arkansas Tech University Young Alumni Board, City of Conway Safe Routes to School Board Member, and a Junior Achievement classroom volunteer.

In 2008, he also served as a communication strategist volunteer during President Barack Obama's National Day of Service. In his spare time, Jimmy enjoys reading, completing community service projects, and advocating for youth. Jimmy and his wife, Shakira, have 2 daughters, Amaya and Alivia. In January 2017, at a yearly Dr's appointment Jimmy was diagnosed with ESRD. He started dialysis immediately. In December of that year Jimmy received a kidney transplant through a living donor.

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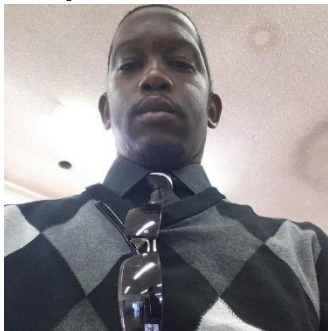
### CALIFORNIA

#### Susie Dantzig



While studying the kidneys as part of her biology major, it wasn't until Susie met her fiancé in 2008 that she was introduced to what kidney disease really meant. Born with IgA Nephropathy, Susie has witnessed her fiancé endure peritoneal dialysis, a transplant, and a return to hemodialysis. Despite the challenges of dialysis, Susie and her fiancé continue to do what they love to do most - eat their way around Los Angeles, take weekend trips to somewhere surrounded by nature, and ride their bikes to as many coffee shops as possible. He is her motivation to fight for change, educate others, and contribute to the AAKP mission.

#### Philip Jones, Jr. – IN MEMORIAM



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 his goals and to receive another kidney.

Philip lived a life of purpose in sharing his journey with others. He passed away July 19, 2023. We will continue to advocate in his memory.

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### 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 would go on dialysis at the age of 42. Currently, he is 4 years post-transplant. 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?

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### Chelsea Roman



Chelsea was born in complete kidney failure two months early, weighing only 3lbs. She never had more than 25% kidney function growing up. She was able to maintain her kidney function through diet for 32 years until she started on home hemodialysis in 2017. She was a solo home hemodialysis patient for 2 years and received her transplant in November 2019 after being on the list for 7 years.

Chelsea is married and a pet mom. She works as a Patient Consultant and Patient Advocate with NxStage Medical. She is a member of the Home Dialyzors United Patient Advisory Board. She enjoys educating patients and their family of the benefits of home dialysis, which she was able to experience. Chelsea has shared her life living with kidney disease, dialysis, and transplant on various social media platforms to show that life does not have to slow down when dealing with a chronic illness. She is passionate about home dialysis and is looking forward to continuing to inspire others through her journey.

### Aaron Slaven



Aaron is an airline pilot based out of San Francisco who lives in Fresno California. He is married to his wife Kristine and their three young children.

At the age of twenty, Aaron was diagnosed with end stage renal disease and consequently was placed on dialysis. He received a kidney transplant in April of 2003 from his father at St. Vincent's medical center located in Los Angeles California.

He is forever grateful for this gift allowing him to continue living his life mostly unrestricted. He learned to fly and began his pursuit of becoming an airline pilot. He also took up technical rock climbing and became an avid climber in the Sierra Nevada mountain range.

Presently, Aaron volunteers with his local credit union in a mentorship position to the board of directors. He also serves as a new-hire pilot mentor for the union in which is part of.

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### Nnamdi Uyalor



Nnamdi is a third-year law at Irvine University College of Law. He also graduated from California State University, Fullerton and earned his Bachelor's Degree in Political Science. Given his current circumstances, his propriety is graduating from law school and earning his Juris Doctorate Degree. Nnamdi's desire to become a Kidney Ambassador, to create legislative and policy changes on his mother's behalf.

Nnamdi's mother is essentially the driving force behind him wanting to become a California Kidney Ambassador as his mother has Chronic Kidney Disease and is currently on Peritoneal Dialysis. Given his work ethic, commitment to legislative policy change, and excellent writing skills, he contends that he has the capability of becoming an Ambassador of the highest caliber.

Nnamdi's second motivation for becoming a Kidney Ambassador is because the program will provide an excellent learning experience for himself and his future career as a Healthcare attorney. For instance, it is his contention that the AAKP Ambassadors Initiative and its extensive network of government agencies, such as the United States Department Health and Human Services will provide him with the best foundation for exceling as a future Healthcare attorney. As a future Healthcare attorney, he will be able to represent kidney patients and other clients who have experienced mistreatment by the Healthcare industry in an official capacity similar to the Ambassador program.

### Mihi Wickramasinghe



Mihi is 19 years old and living with Polycystic Kidney Disease. She is on dialysis and looking for a living donor. Mihi just graduated from high school and is attending Chaffey college. Her hobbies include reading mystery books, watching movies, swimming and painting her nails. She hopes to help the kidney community to the best of her abilities.



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### COLORADO

#### Denise Steininger



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

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### CONNECTICUT

#### Stephanie Shabanowitz



Stephanie was diagnosed with ESRD in 2001 at the age of 15. Despite this, she graduated from high school and attended the University of Connecticut where she earned Bachelor of Arts degrees in History and English. While at UConn, Stephanie had to begin dialysis, choosing to begin on PD so she could do treatments in her dorm while she slept. After graduating from UConn, Stephanie attended the University of New Haven to earn her 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!

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### 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.

#### 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

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years by promoting awareness, helping with fundraising for education and research and participating in events that help promote awareness and education of renal disease. She is also a Patient Advocate for the National Kidney Foundation.

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### DISTRICT OF COLUMBIA

#### 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.

#### Krystal McLear



Krystal L. McLear is a passionate advocate for individuals living with and affected by kidney disease. As a living kidney donor for 16 years, she credits her decision to donate to her cousin, which ignited her commitment to empower and educate others.

Professionally, Ms. McLear is an award-winning healthcare sales professional dedicated to education and advocacy.

Ms McLear has volunteered for various organizations and has worked to shape policies that directly impact organ donors and recipients. Additionally, Ms. McLear has served on several speaker's bureaus and takes pride in her role as an ambassador for organizations that promote kidney health and organ donation education.

A proud resident of Washington, D.C., Ms. McLear is also the loving mother of two sons. She is a graduate of Spelman College. She is excited to make a difference by sharing her story and raising awareness about kidney disease within the community.

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### FLORIDA

#### Shameka Ausborn



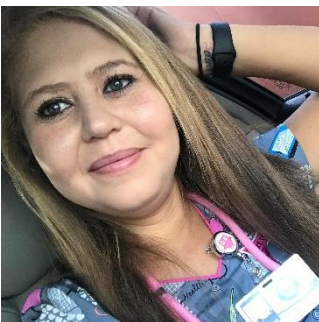
Shameka has been on dialysis for 19 years, starting in-center at the age of 15. She has had 2 kidney transplants, in 1999 and in 2005. It lasted 10 years until it failed due to Nephrotic Syndrome and FSGS. She returned to in-center hemodialysis until she started home hemodialysis in 2016. She has two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

#### Nia Lugo-Koch



Nia was living with undiagnosed CKD for years until she went into failure in 2020 and started emergency dialysis. Her formal diagnosis is FSGS. She did in-center hemo-dialysis for almost three years and received a transplant on 1/4/23 via paired kidney exchange. Her husband is a living donor. Nia says this experience has shown her what the power of awareness and education can do, and how much more change the community needs.

#### 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.

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### 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. She is working in Boca Raton as a CPA, in business valuation and transaction services and is continuing to help with the UM Life Alliance Organization in Miami.

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 an 18-year kidney transplant recipient from a good Samaritan donor 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 an adorable grandson.

### Terre M. Perez



Terre currently works as a Teacher of Deaf and Hard of Hearing students in Duval County, Florida. Her journey with kidney disease began even before she understood what it all meant. Around 1995, she was told by a doctor that she had protein in her urine. Afterwards, there was no further explanation or recommendations offered. In 2004, her primary care physician referred her to a nephrologist. Within four years, she had been placed on the transplant list and started peritoneal dialysis. In 2009, she received a precious gift of a kidney from a cousin; however, due to various circumstances, the kidney failed, and she began hemodialysis in 2014. Since being diagnosed, Terre has become increasingly more proactive about kidney disease by advocating for herself, sharing information with other dialysis patients, and

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organizing a team to participate in the Jacksonville Kidney Walk for the last three years. After attending the 2019 AAKP National Patient Meeting in Washington, D.C., her drive and passion for sharing information with patients, their families, and others in her community has increased.

She strives to help others become more proactive in their care and about their health to help others reduce the probability of advancing or acquiring kidney disease.

### 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!

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 it's 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.

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Together, they enjoy traveling the globe, boating, checking out surrounding islands/beaches, fitness and eating good eats!

### Janice Starling



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 Disease (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.

### Sherri D. Thomas



Sherri is the proud mother of two children, Carrie and Ross. Their family resides in both Georgia and Florida. The family pastimes include traveling, bowling, school sports and promotion of Kidney Awareness.

Sherri considers herself a kidney advocate for a lifetime. Her purpose from God, and passion inspired from her daughter, Carrie Sivania. With being born with a kidney disorder called hydronephrosis, their infant would undergo corrective surgery. However, the surgery was successful; however, a nephrectomy (kidney removal) was required to sustain proper health.

In 2010, Sherri became the founder of Caring4Carrie. The community outreach promotes kidney awareness throughout the year. One of their annual events is the Carrie Kidney Awareness Bowling Event. It's a "party with a purpose," with a focus on hypertension and kidney health. All guests receive a complimentary free blood pressure check from licensed nurses to know their health stats. The emphasis is learning about the second leading cause of kidney disease – uncontrolled hypertension. Then, the Bowling Bonanza starts! We provide trophies, prizes & awards for top bowlers. In 2016, Sherri established the ManaSota Kidney Support Group, for those affected by kidney disease or their love needing support and interacting with other renal patients. Sherri also volunteers with the National Kidney Foundation and has participated in Capitol Hill Days.

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### Jazmyn Torres



Jazmyn is a recent high school graduate and graduate of an EKG certification class with a EKG technician license. She wants to continue her education to ultimately be an ultrasound technician. Jazmyn was born with bilateral renal dysplasia and Pulmonary stenosis. She was on medication her entire life, but it wasn't until she was 15 in 2016 that she was put on dialysis. She had multiple surgeries over the next 2 years and tons of complications, until she recovered from her transplant in 2018! Getting her education as a 19-year-old was a huge accomplishment for her since her treatment held her back so much, and she can't wait to

continue on!

### Julie Vatel



Julie has been a Registered Nurse (RN) for over 30 years, from the acute care setting to a telehealth coach for a major pharma company. Her compassionate efforts were acknowledged with the "Patient Outreach Passion Award." Julie now serves as a remote RN teleworker, a subject matter expert, and Co-Chair of a Highly Reliable Organizational Interdisciplinary Committee. As a caregiver of a parent with renal disease, she is now passionate about supporting initiatives to raise awareness on kidney disease- the underrecognized determinant of health.

Julie was raised in Montreal and speaks French fluently. She loves the beach and has developed a passion for growing her own organic food and loves to entertain over delicious meals at home. She enjoys a relationship with God, her family, salsa, and nut-covered chocolate.

### 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.



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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.

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### GEORGIA

#### Carlos Copeland



Carlos is an Atlanta native. He was diagnosed with end stage renal failure in February 2013. As a result, he did peritoneal dialysis at home for over four years. After seeing a social media post expressing his need for a new kidney, an altruistic donor was moved to donate one of her kidneys to him. In September of 2017, Carlos was given a kidney from his donor.

Carlos has spoken on local news programs, radio stations, and community events sharing his story. In 2018, he appeared on the national TV game show, "Beat Shazam" with Jamie Foxx to further share his kidney story and journey. He also has a Facebook page called "The Journey: My Road to a New Kidney".

He is very excited about being an Ambassador with AAKP. He hopes to use this opportunity to inspire others and serve as an advocate for fellow "kidney warriors."

#### Edward Drake II



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

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

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### Cyrelle George – IN MEMORIAM



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.

Cyrelle passed away in March 2021. She was a brave and strong advocate, and we continue to fight and advocate in her memory.

### Kathy Manis Findley



After graduating from seminary, Rev. Kathy's ministry took her from the villages of Uganda, East Africa to places across the U.S. where she served as a hospital chaplain, a parish minister, an advocate for victims of violence and abuse, a child forensic interviewer and a certified trauma specialist — sometimes all at once. So when a routine blood test prompted her doctor to call her one night during dinner to tell her to go immediately to the hospital emergency room, she was not prepared to hear the diagnosis of end stage renal disease. She was busy! Her work was important and fulfilling! She had no time to be sick! After ten hours, the emergency room doctor admitted her to the nephrology unit, and dialysis began that very day. For a full year, it seemed as if the hospital was her second home, and she spent more than 100 days hospitalized that year, almost losing her life three different times. She did home peritoneal dialysis for the next 5 years.

Kathy's life changed in an instant in that hospital ER — changed into something she never wanted, as *she* changed into someone she never was. Her life changed again after five years on dialysis when a long-time work colleague emailed to say he wanted to donate his kidney. Not being a match for Kathy, they entered the paired donation program at Mayo Clinic. From that donation, eight living donors and eight transplant recipients experienced the beginning of a life-changing, life-giving story. Predictably, Kathy's life changed again, and today she is, in some ways, just as she has always been — busy, involved, creative and joyful. After all the unexpected changes kidney disease brought her, Kathy is still a minister, as that is a lifelong calling. She is also a writer, artist, graphic designer, gardener, chef, blogger, public speaker, teacher, preacher, trauma counselor, spiritual director, AAKP mentor, political and social justice activist, victim advocate, wife, mother, and grandmother of five. Kathy can attest to one real and certain truth: that her creativity, contentment, passion, peace, joy, and hope remained, even after kidney

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disease!

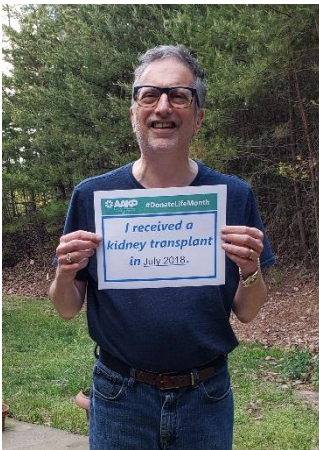
### Dammeon Marshall



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.

### Stuart Miller



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

kidney disease.

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### Jade Osborne



Jade was diagnosed with ESRD with FSGS in 2012 at the age of 21. Although it was a shock to be seemingly healthy then diagnosed, she was no stranger to kidney failure. Growing up, Jade witnessed her mother go to dialysis, yet still have a hot meal on the table for her kids and whoever else needed anything. This is what gave her the strength to be strong for others.

Jade is still waiting for a transplant after almost 9 years, but until that day comes and beyond, she will make sure kidney patients have a voice.

### Wills Porter



Wills is a liver transplant recipient of twenty-one years. He grew up as a liver transplant recipient and can personally attest to the life transforming power of organ/tissue donation and transplantation. His transplant journey has not always been easy. However, he states that it is through the challenges of his transplant journey that he has gained a deeper appreciation for the second chance at life he was so graciously given. After having received second chance at life, he now considers his life calling to inform, inspire, empower, and speak life to those impacted by organ failure and transplant. It is in seeking to achieve this mission that he chose to become involved with AAKP.

Of the challenges facing communities in America, Wills believes one of the greatest is that of kidney health and organ failure. During his graduate studies at the University of Georgia, he designed and implemented a kidney health and organ donation awareness webinar series called Operation Impact. The program was implemented in four states and was recognized by LifeLink of Georgia as a Lifelink Workplace Partner for Life. In implementing this project, he came to discover his passion for public health education and community empowerment. Through blog writings, podcasts (The Joy in the Journey podcast), and involvement with AAKP, he hopes to empower communities through organ health and donation education. Wills is thankful for the opportunity to work with AAKP in advancing their mission to put patients first and make an impact.

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### Chardae Sanders – IN MEMORIAM



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!

Chardae passed away in February 2021. Despite her own health challenges, Chardae always offered guidance to others battling kidney diseases. Her mother, Regina, continues to work alongside AAKP to fight and advocate in her memory.

### Crystal King



Crystal is a devoted mother and a proud kidney transplant survivor who is passionate about spreading awareness about kidney disease and educating those who may be at risk for or living with the disease. After going into kidney failure following the birth of her son, Crystal began documenting her life with him because she didn't know how long she would be living. Through sharing her journey online, she educated thousands about kidney disease and became a Kidney Influencer.

With over 15 years of experience developing and implementing marketing campaigns for iconic brands, Crystal brings a unique and innovative approach to engaging with her followers online.

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As a social media content creator and strategist, she is able to use her expertise to educate people about kidney disease in a way that is engaging and accessible.

In addition to her work as a Kidney Health Coach, Crystal is also the founder of the Kidney Champion Foundation, a nonprofit organization that supports individuals and families affected by kidney disease. Through her foundation, Crystal is dedicated to educating historically marginalized and underserved communities while fighting for inclusive and equitable access to care.

Crystal's mission is to celebrate the resilience of women and to help people feel empowered to live their best possible life despite the challenges of kidney disease. She believes that through advocacy and education, we can create a more compassionate and supportive community for those affected by this chronic illness.

With her passion for spreading awareness and her unwavering commitment to making a difference, Crystal is a valuable addition to the AAKP Ambassador team. She is excited to use her skills and experience to help shape the future of kidney disease care and advocacy.

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### IDAHO

#### Gloria Peninger



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

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

Gloria has learned so much about caregiving and has been through numerous life-changing experiences. One of the most intense challenges has been a kidney transplant. The whole experience makes you appreciate the little things in life and leads to an awareness that you should enjoy every minute of every day. During that time, Gloria met other caregivers who were enduring the same thoughts and emotions she was struggling with, and so they were supportive and empathetic to one another. Talking about their individual experiences offered a sense of comfort. The caregiver's role is a very important one, and Gloria believes they need as much support as their loved ones.

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### Dale Rogers



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

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

### Christy Stutzke



Biography coming soon!

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## ILLINOIS

### Gail Glasser



Gail has lived with kidney disease since she was 18 years old when an undiagnosed strep throat impacted her kidney. Gail's nephrologist was ahead of his time and believed in a treatment plan that was supplemented with specific diets and vitamins. This made it possible for Gail to go 30+ years without requiring dialysis or a transplant. She ultimately received her kidney transplant in November 2015 from a deceased donor and has since been actively involved in awareness building for kidney patients. In addition to her business, Gail works actively with kidney transplant patients to ensure they feel as though they have the tools necessary to take control and live healthy,

long lives.

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### Christine Hernandez, RN, BSN



Christine has dedicated her life to helping others and has been a Registered Nurse for over nine years. In 2016 she found out she had kidney disease that was incurable and, along with her siblings and other family members, discovered they have a genetic condition that attacks different people at different stages of life, with everyone in the family having a 50/50 chance of getting it. Christine believes more funding needs to be acquired for kidney disease research and treatments. Her purpose here at AAKP will be to make sure that kidney warriors have rights and legislation that help them live better lives and not have to worry about things that are irrelevant. Christine also wants to help make a difference by using her experience as a nurse and as a warrior.

### 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. Della received a kidney transplant in August 2018! 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



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### 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 – IN MEMORIAM



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.

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The kidney world lost a fierce kidney advocate in May 2024. Lana was an AAKP Board Member for many years and a beloved friend to many. We will continue to advocate and educate in her memory.

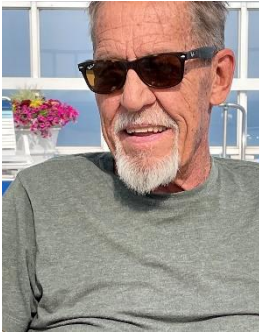
### Mike Smith



Mike is 1993 graduate of the University of Illinois and lives in Jerseyville, IL, a small town an hour northeast of St. Louis. After 3-years of teaching high school math & physics and coaching golf, he has spent the past 25 years in IT, primarily in business analytics. In July of 2020, Mike donated his kidney to his 22-year-old son, Brett. Brett received a pre-emptive transplant after managing his IgA Nephropathy since his sophomore year in high school. Brett is now in his first year of Physical Therapy school at Rockhurst University in

Kansas City, MO.

### Richard Stacewicz



Richard is a retired professor who has been living with kidney disease and treatments since he was 22. Between then and now, he has been on in-center hemodialysis twice for a total of 2 years and received 2 kidney transplants which lasted a combined 37 years. His second transplanted kidney developed a cancerous tumor which had to be removed in the summer of 2022. He is currently on home hemodialysis. During the past forty years, Richard and his wife were fortunate to have two children and deeply fulfilling careers. At present, he is on the Patient Advisory Council for the Kidney Project, a potentially revolutionary development in treating

ESRD. Richard is excited about representing AAKP as an ambassador.

### 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 hemodialysis, 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. 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."

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### Quin Taylor



Quin Taylor is a Chronic Illness Warrior, Patient Advocate and Speaker. She was diagnosed with chronic kidney disease at the age of 20. She had dreams of becoming a psychologist, getting married and having two and a half kids with a dog and white picket fence and was working her way towards that. At the age of 27, her kidneys failed and she started dialysis, it felt like her dreams were gone...at least that's what she thought.

While on dialysis, Quin began patient advocacy. Being a voice to speak and help other patients was one of the tools that helped her to accept and navigate a life that was now about living with chronic illnesses. The other tool that helped her was gratitude. Quin was grateful that God equipped her for this journey. That no matter how defeated she felt or discouraged she was, she knew God had a purpose for her and she would get through it.

Quin dreamed of going around the world sharing her story to uplift and encourage others, but with a life of managing chronic invisible illnesses she didn't see how that would happen. She decided to get out of her own way, exercise her faith and trust the Lord. She has birthed Tayloring Gratitude, the manifestation of her passion and purpose aligning. Quin knows that her voice is necessary and valuable and is dedicated to using it make a positive impact in the world.

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## INDIANA

### Kelly McGee

Photo and bio coming soon!

### 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 Directors 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

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Members of Congress. Jim helped to initiate Kidney Pals, AAKP's pediatric kidney patient initiative, and is part of the initiative for kidneys and veterans.

### Niesha Neal



Since beginning her journey in 2015, Niesha has been a passionate kidney and dialysis patient advocate. As a patient subject matter expert with the ESRD National Coordinating Center's Patient and Family Engagement Network (NPFE-LAN), she amplifies patient voices and experiences. Her dedication led to roles on the IPRO ESRD Network 9 Medical Review Board (2017) and Board of Directors (2022-2024). After seven unsuccessful transplant calls, Niesha received her kidney and pancreas transplant in June 2021, lovingly naming her new organs "Ren & Stimpy."

Her advocacy continued as she joined Dialysis Patient Citizens (DPC) in 2023, where she and her husband Christopher advocate on Capitol Hill to improve ESRD care. In 2024, at the AAKP National Patient Meeting, the IPRO ESRD Network 9 team and Niesha were honored with the Dominick Gentile, MD Memorial Award for developing the Kidney Compare application, a tool helping patients navigate transplant options.

### 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 worse later in time. In 2012 he was diagnosed with Stage 3 CKD disease due to FSGS and by December 2014 he started peritoneal dialysis. In June 2015 his daughter went to be tested to be a living donor. During the last stages of the testing, it was determined that she would not be the best suitable match. His daughter's roommate and a college

sorority sister decided to get tested in October of 2015, "just because" she wanted to help someone. After completing her 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 an advocate on Capitol Hill and in Indiana with his Members of Congress.

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### IOWA

#### Adam Akers



Adam 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 his nephrology team and staying active, he was able to slow the progression of the disease for about 10 years before he was told it was time to either look into dialysis or a transplant. After being put on the list, Adam's younger brother came forward and volunteered to donate one of his kidneys. Adam is fortunate enough this was done before having to be on dialysis. He says he is glad he didn't pick on him any more than he did when they were younger, and his brother likes to say he doesn't have to get Adam Christmas gifts any longer.

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

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

#### Dawn and Jimmie Bates



Jimmie started his journey with end-stage renal disease (ESRD) back in May 2008 when he had to suddenly begin dialysis because of uncontrolled hypertension. He did in-center dialysis for a year before reconnecting with his childhood sweetheart, Dawn, after 25 years. They dated for five months, got married, and were then introduced to the idea of home hemodialysis (HHD) by a nurse. They started training for HHD and never looked back.

In 2012, Jimmie received a kidney transplant, which gave him an amazing year before the kidney started rejecting. Despite the challenges, Jimmie is an extracorporeal membrane oxygenation (ECMO) survivor and has a newfound appreciation for life. Dawn has fully embraced her role as a care partner. Together, they are actively involved in the kidney community, co-facilitating support groups for men and care partners. They are always open to sharing their experiences and providing support to anyone in need.

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They love to travel in their RV, visiting dialysis centers to demonstrate how HHD works. They invite patients, care partners, staff, and doctors to see their setup, ask questions, and learn more about home dialysis. Their passion for helping others shines through in everything they do.

### Shane Blanchard



Shane Blanchard is from Oskaloosa, Iowa and was born with a rare disorder called Eagle Barrett Syndrome. As a result, Shane has always battled kidney disease. His older brother donated to Shane, and he had his first kidney transplant at the age of 22. That kidney lasted him 24 years. Now at 47, Shane is again battling kidney disease while waiting on his next transplant. Through the years, Shane has been very involved within his community and state. Shane was elected to two terms as a Council Member in Waukee, IA. The fastest growing city in the state of Iowa, and the county was the 7th fastest growing in the nation. He also served on many Nation Campaigns for

Congressional and Senate races as well as served as a Committee Member within his respective State party. Today, Shane works as a Sales Director for 3 new car dealer Franchises and he also runs his own non-profit organization. Shane is also on the Advisory Council, Regional representative, Peers in Action Representative and advocate for other CKD 501c3 organizations across the country.

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## KANSAS

### Anja Schlagel



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

was barely 30. Anja offered to be a living donor, but that plan was foiled when Anja received her own diagnosis in her mid-thirties. Anja's dad, now in his mid-seventies is over 20 post

kidney/liver transplant; her sister had been on dialysis (PD and in-center hemo) for over 6 years and finally received her transplant in early 2020 transplant; and after 1 year and 9 months on PD Anja received her transplant in 2019. Everyone is back to living life at its fullest, thanks to functioning organ transplants.

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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. Also, after having talked to other kidney patients she is always saddened by how much many kidney transplant patients worry about finances, with Medicare only covering medication for 36 months post-transplant, but then once again paying when one needs to go back on dialysis because a transplant failed due to

insufficient or no immunosuppressants. And what about living donor protection? In her native of Germany living donation is limited to family members and close friends only, so she was impressed when discovering the different rules in the United States. Yet, the lack of living donor protection prevents many potentially donors from donating, a fact that needs to be remedied. Naturally, Anja knows how important awareness of your risk (and early detection) of CKD is. It allows for proper patient education and a well-informed decision making of treatment modalities, as well as understanding insurance coverage when the kidneys finally fail. After researching opportunities to become involved in the world of kidney advocacy Anja believes she has found a great match in AAKP.

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### KENTUCKY

#### Alex Berrios



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

Alex's professional background is in ten years in the nonprofit world of working with individuals with intellectual disabilities and helping them get their voice and help them be the best versions of themselves. He would like to now work with patients with chronic kidney disease and help them to see that from diagnosis to dialysis to possible transplant that a quality life can be achieved. Alex wants to be a voice at the table and be involved with research and education. Alex has a blended but beautiful family. His partner Tamiera, son Zander and daughter Abigail from his previous marriage, all help Alex to be the best advocate for kidney patients and their families.

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### 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 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.

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### LOUISIANA

#### Brandi Nunez



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

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.



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### Leigh-Ann Williams



Leigh-Ann is a lifelong resident of the greater New Orleans area. Her educational background includes a B.S. in toxicology from Univ. of Louisiana Monroe, a M.S. in toxicology from the Univ. of Florida, and a Master of Public Health from LSU Health Sciences Center New. She is the program coordinator for the federal 340B drug pricing program at West Jefferson Medical Center. In addition to the work she does with AAKP, she is a certified Kidney Health Coach and an ambassador with the American Kidney Fund. Leigh-Ann is also a board member of the Kidney Health Initiative Patient and Family Partnership Council (PFPC).

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 was officially diagnosed with lupus. In April 2016, one month before she was set 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 was elected and 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 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.

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## Meet AAKP's Ambassadors!

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### MAINE

#### Genevieve Morgan



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

She is currently in Stage 4 with the expectation of undergoing a pre-emptive transplant. She has two children, to whom she is dedicating her advocacy for funding for research into a cure for PKD, better choice for kidney patients, and continued focus on quality of life and protections for all kidney patients. Genevieve received a pre-emptive kidney transplant in December 2018.

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### MARYLAND

#### Daronta L. Briggs



Daronta is Founder & CEO of the Veterans Transplantation Association. He is Deputy Vice President of Alpha Lambda Psi Military Fraternity Inc. as well as a highly decorated Honorable Discharge Desert Storm/Shield Veteran.

Daronta is a former hemodialysis patient who received a kidney transplant October 23, 2012 at Walter Reed National Military Medical Center. Daronta serves as Ambassador for America Association of Kidney Patients, United Organ Sharing Network, Living Legacy Foundation, Donate Life Maryland and a member of Team Maryland Transplant Team.

As a kidney patient, Daronta advocates throughout communities by sharing his story about the importance of kidney health, proper care while on dialysis, pre-transplant and post-transplant. He shares the importance of the 3 E's: Educate, Empower and Encourage on his advocating journey.

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### 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.

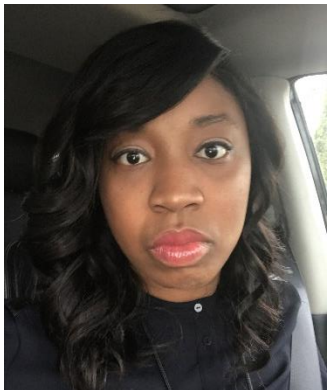
### Ray Harris



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,

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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.

### Taylor Kriss



I was diagnosed with Alport Syndrome at 18 months old and have been battling chronic kidney disease my entire life. At age 22, I went into kidney failure and started my dialysis journey on in-center hemodialysis. Shortly after, I chose to transition to at-home peritoneal dialysis. This gave me autonomy over my body and health again. I began sharing my kidney disease journey on social media where I found the most loving kidney disease community. I found myself to be incredibly passionate about advocacy and education and hope to continue working with kidney patients.

### 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.

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### 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 is an active AAKP Ambassador and served as Co-Chair of AAKP's 45<sup>th</sup> National Patient Meeting. Sharron lives in Maryland with her husband Shawn and daughter Kyla.

### Abdou Simon Senghor



Dr. Abdou Simon Senghor received a kidney transplant in 2010. This prompted him to engage in research to better understand his disease but also to do research on kidney failure by doing a thesis in sociology on the participation of patients with chronic renal failure in the process of therapeutic decisions. He is currently s a postdoctoral fellow with the PATIENTS program to address bioethical issues related to community-engaged research. He is working on the COMMunity Mistrust and Institutional Trustworthiness to Advance Health EQUity Research (COMMIT-EQ) project to conduct qualitative data analysis to identify bioethical issues during clinical phases. Previously, he worked as a postdoctoral fellow with the Pragmatic Health Ethics Research Unit based at the Clinical Research Institute of Montreal (IRCM) to enrich pragmatic ethics by developing a model for assessing the quality of ethical deliberation. Dr. Abdou Simon Senghor recently obtained a grant offered by the Mid-Atlantic Center for Cardiometabolic Health Equity (MACCHE), to lead a project entitled Using an ethical deliberation approach to address the ethical challenges related to the enrollment of African Americans with chronic kidney disease in US health registries. This project, involving the participation of patients living with kidney disease, is part of his commitment to patients suffering from kidney disease.

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### David M. White



Dave White endured six years of dialysis before receiving a kidney transplant from a deceased donor in 2015. Having learned the importance of self-management as well as advocating for better care during his arduous battle with kidney disease, Dave is a tireless advocate for advancing health equity.

Dave serves as the Dreyfus Health Policy and Research Center's Community Outreach Specialist and Policy Director. Dreyfus Health promotes and supports community-driven movements to prevent serious illnesses, promote wellness, and create a better quality of life.

Dave serves or has served on the boards of directors of the American Association of Kidney Patients, the Kidney Health Initiative, the Patient Advocate Foundation, Quality Insights Renal Network 5, and the Veterans Transplantation Association. He is an inaugural member of the FDA Patient Engagement Collaborative, an advancement in the FDA's efforts to strengthen its relationship with patient communities. Dave also chairs the Kidney Health Initiative Patient and Family Partnership Council and is past chair of PCORI's Advisory Panel on Patient Engagement and Quality Insights Renal Network 5's Patient Advisory Council. Dave believes that the best way to reduce disparities in health outcomes is to empower communities to take collective responsibility for improving their own well-being. Dave lives in Hillcrest Heights, Maryland with his wife Hilva.

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## MASSACHUSETTS

### Iya Bekondo-Granatella – IN MEMORIAM



Iya Bekondo-Granatella is an in-center hemodialysis patient and former 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.

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### MICHIGAN

#### Lori Cooper



Lori's interest in kidney disease and transplantation began in the late 1980's when a close relative was diagnosed with kidney disease. She was not a suitable match for her relative but decided to sign up with her State's donor registry as she saw the agony of waiting for an organ first hand.

In 2003, Lori's Mother was diagnosed with kidney disease, and without hesitation she wanted to be her donor. Fortunately, she was a viable donor for her. Unfortunately, the kidney only lasted 3 years. Adding injury to insult, Lori was diagnosed with kidney disease in March of 2015 and received a transplant later that year. Her experience led her to do more research about the prevalence of kidney disease, especially for persons like herself who didn't have any known precursors. It is Lori's mission to educate and share knowledge about kidney disease and transplantation.

#### 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.

#### Oliver Hale



Oliver, or Chef O as he is more widely known, is a two-time kidney transplant recipient, with over 32 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 that loves to travel to teach

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dialysis patients on how to cook healthier. He has served twice on the 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, the UNITED STATES CULINARY EXCELLENCE AWARD, to be a representative on TEAM USA and TEAM MICHIGAN at 9 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.

### 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.

### Karen Solomon Edwards



Karen lives in Michigan where she worked as a public health official for the local health department in Detroit. Karen has a master's degree in Public Administration and a bachelor's degree in Business Administration. She was recently readmitted as a doctoral student to complete her dissertation. As an Ambassador for the American Association of Kidney Patients, Karen emphasizes the importance of devoting her energy toward the advancement of legislation that can enhance the quality of life among kidney patients. As an Ambassador, she believes this is an opportunity to serve to ensure assurance, policy development, and assessment for kidney patients.

Karen's kidney failure was a result of polycystic kidney disease. She became more aware and realized that it was imperative that she learn more about her illness, health options, and access to quality kidney health care. Therefore, this awakening came much later when she was on hemodialysis during her seventh year as a kidney patient. Karen began to take control of her kidney health instead of "totally" relying on her health care team. Subsequently, she received her kidney transplant and decided that she would devote her expertise as a public health official in her role as an Ambassador to advance policy development to ensure legislation is passed to



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enhance the quality of life for kidney patients. Lastly, Karen serves as a peer mentor for the Polycystic Kidney Disease Foundation and a Kidney Health Coach for the American Kidney Fund.

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### MINNESOTA

#### Jessica Bates



At a young age, Jessica was diagnosed with hereditary focal segmental glomerulosclerosis and is currently considered to have end-stage renal disease. She is working toward being on the transplant wait list and finding a new kidney. Jessica is an Air Force Veteran and graduated Cum Laude with a Bachelor of Science in Urban and Regional Planning with a minor in geographic information systems from Eastern Michigan University. She is just one graduate class away from achieving a Master of Sustainable Tourism at Arizona State University and planning to attend Penn State to add a Bachelor of Arts in Digital Journalism and Media. Jessica is one of those who loves to learn and do new things. She also loves being an advocate for kidney disease and helping to run a kidney support group. Jessica is co-founder of the Phoenix Area Kidney Warriors which is an in-person support group that happens the second Sunday of each month in Phoenix, AZ.

#### Charles Rice



In 1998, Charles was diagnosed with kidney disease, and in 2003, he found himself in the hospital for 45 days after crashing into dialysis. During his hospital stay, he was formally diagnosed with nephrotic syndrome and congestive heart failure. He had to endure 4.5 hours of dialysis treatment three days a week. But something remarkable happened during this time - Charles became inspired. He wanted to learn more about his illness, the medications he was taking, and even the dialysis machine. He became an advocate for himself and others. In pursuit of this passion, he decided to pursue a degree in Pharmacy, with a focus on medication therapy management.

In 2007, Charles received a kidney transplant from a deceased donor, which brought him hope. However, by 2008, his body started rejecting the donated kidney. Despite this setback, Charles didn't give up. He continued to pursue another degree in Business Management, showing his determination and resilience.

Throughout his journey, Charles has worked with various organizations, including ESRD Network 11, AAKP, National Kidney Foundation, American Kidney Fund, United Network for Organ Sharing, ESRD NCC National Patient and Family Engagement Learning and Action Network, and many more.

When Charles isn't busy making a difference in the kidney disease community, he enjoys working on home construction projects. He believes that creating something with your own

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hands can be a true masterpiece. He also loves watching sports and spending quality time with his grandchildren.

This year, Charles will be celebrating his 16th Kidney-anniversary, a significant milestone in his life. He is determined to continue helping patients achieve their goals.

Charles's motto is "Participate in your care, be your own advocate, your voice is powerful."

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### MISSISSIPPI

#### Brenda Dyson



Brenda started dialysis in 1987 choosing to do home hemodialysis. One year later, she began working for ESRD Network 8 as the Medical Review Coordinator. In December 1990, she received a kidney for her sister Lynda. The transplant functioned for 11 1/2 years before she re-started dialysis in 2001. At that time, she was serving as President of AAKP along with continuing to work full-time. She was chosen to be the first person in the U.S. to use the NxStage machine as part of the clinical trial. In June 2002, she received her 2nd transplant from her sister Lisa. The transplant

lasted 12 1/2 years and in February of 2015 she re-started dialysis choosing to do in center hemodialysis. In December 2015, she retired from Network 8 as their Community Engagement Coordinator after working in several positions during her 28 years. During this time, she served on numerous committees, boards and TEPs serving as AAKP's president for 6 years and as President of the Board of the Mississippi Kidney Foundation (previously NKF of Mississippi). She is currently serving on the Network 8 PAC and represents Network 8 on the national PAC (KPAC).

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### MISSOURI

#### Margaret Baggett – IN MEMORIAM



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 participated in Kidney Day at the Missouri state capitol in Jefferson City a has attended several AAKP National Patient Meetings.

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Margaret passed away on August 3, 2023. We continue to advocate in her memory.

### 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.

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## 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.

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.

### Tiffini Gallant

Photo and bio coming soon!

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### NEBRASKA

#### Gary Bodenheimer



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

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

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### NEVADA

#### Maile Robb – IN MEMORIAM



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 in improving the lives of fellow dialysis patients through knowledge, education, projects and programs.

Maile passed away in March 2020 and has left a huge void in the kidney community. We all strive to continue her legacy.

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### NEW HAMPSHIRE

#### Paul Rakoski



Paul was diagnosed with Fabry Disease in 2007 after undergoing a series of tests to determine the cause of his kidney disease. He was the first in his family diagnosed followed by 4 other family members. At the time, he and his family didn't foresee the road and hurdles that go along with Fabry Disease and kidney failure. He was fortunate enough to undergo a pre-emptive transplant in 2009, receiving the gift of life from a very special college friend. As a result, he has taken an active role in the Fabry Disease, Kidney, and Transplant communities as a way of paying it forward to others who may benefit from improved treatment options.

Paul serves on the patient advisory board for a pharmaceutical company, volunteers for Fabry Disease support organizations, and has worked with patient advocacy groups on Capitol Hill. He has also participated in the Transplant Games of America and the World Transplant Games multiple times, winning medals in swimming, track and field, and golf events.

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### NEW JERSEY

#### 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.

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### 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.

### 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.

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## NEW MEXICO

### Susan Brown – IN MEMORIAM



Susan has been living with a chronic autoimmune disease called focal glomerulonephritis for a remarkable 75 years. This condition was a genetic condition. Her great grandfather succumbed to Bright's Disease in 1921. Over time, focal glomerulonephritis has become the recognized term for this ailment. Surprisingly, she remained unaware of her condition until her kidneys failed in 2002, leading her to undergo dialysis for a grueling 3.5 years. However, a glimmer of hope emerged when she received a life-changing call from the esteemed Mayo Clinic in Arizona. They informed her that a deceased donor kidney was available for transplantation, and on June 5, 2005, Susan gratefully received this gift of life.

Remarkably, 18 years have passed since the transplant, and Susan's kidney continues to function well without any signs of rejection. As a Vietnam era U.S. Army Veteran, she is fortunate to receive all her necessary medications from the VA Hospital in Albuquerque, NM, ensuring her ongoing well-being.

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In 2008, Susan had the privilege of co-founding a non-profit organization known as the Las Cruces Transplant Group. Their primary initiative involves organizing the annual Las Cruces Donate Life Car Show, a fundraising event held every July. For the past 14 years, this event has served as their main source of financial support, attracting participants and enthusiasts to Young Park in the city of Las Cruces and surrounding areas.

Susan was featured in the [November/December 2023 issue of aakpRENALIFE](#).

Susan passed away in May 2024 from COVID complications. She loved advocating for her community, and she was always quick to reach out to her elected leaders about policy issues impacting kidney patients. AAKP will continue to advocate for veterans and those who are immunosuppressed/immunocompromised in her memory.

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### NEW YORK

#### Lisa Baxter



Lisa is known for being the Dialysis Whisperer, Advocate, PAC Rep, Author, and Mentor. Lisa has worked as a Social Worker in New York for 24 years with Catholic Charities. She is a Health Ambassador with Rogosin Institute/Dialysis Centers Incorporated, the CEO and Founder of Blessed Kidney Connections, Producer and Host of "The Lisa Baxter Dialysis Reality Transplant Show." Lisa has the passion and drive to encourage dialysis and transplant patients to view better choices and tools on their journey. After 12 years of dialysis and 4 years transplanted, being

diagnosed with polycystic kidney disease, it was in her heart to spread kidney awareness in every way possible. Lisa travels all over for health fairs, street fairs, speaking engagements, etc. She also volunteers with hospital youths and prison juvenile justice from city to city. As of February 2021, Lisa works as a HealthCare Pain Manager with Dreyfus Health Policy and Research Center's "Rise Up East New York" campaign.

#### 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

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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 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 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



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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.

### **Dawn P. Edwards**



Self-described 30 Year Chronic Kidney Disease Warrior, Dawn P. Edwards has experienced first-hand every renal replacement modality including a kidney transplant and rejection. She is currently a Nocturnal Home Hemodialysis patient and pursuing a second transplant. As a result, she has a plethora of insight into the needs of people with Chronic Kidney Disease, always keeping in mind that patients need different things at different times in their lives. Dawn is dedicated to improving the quality of life of people with kidney disease, and is also a resource to her community, sharing her story and educating people about the relationship between hypertension, diabetes and kidney disease, especially among the underserved and communities of color.

Dawn has served the community for over 25 years through the IPRO ESRD Network of New York as a communicator, mentor and educator, she serves on many kidney disease related boards and has reinvented herself by working as a Patient Advocate for Fresenius/NxStage and a Wellness Ambassador for the Rogosin Institute. Dawn is also the Co- Chairperson of the Forum of ESRD Networks Patient Advisory Council (KPAC), Board of Directors member for Home Dialyzors United (HDU), is actively involved with the National Kidney Foundation , American Kidney Fund and American Association of Kidney Patients, serves as Patient Advisor for the HOPE study, as well as the Community Advisory Board in the HEAL study with the NIH/NIDDK, is a member of the Health Equity/Health Disparities Workgroup, serves on the NIH-NIDDK Advisory Council, and is the CEO of her own Advocacy and Education Organization, the New York State CKD Champions, whose motto is to Educate, Encourage and Empower. She believes that Faith Family and Education are the keys to her longevity, and every day is an opportunity to thrive, not just survive.

Dawn recently co-authored an article in the January 2021 issue of Clinical Journal of the American Society of Nephrology (CJASN) titled, *Personal Experiences of Patients in the Interaction of Culture and Kidney Disease*.

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### Robert "Bob" Friedman



Bob managed Type 1 diabetes for 30 years before being diagnosed with End Stage Renal Disease in 2010 and spending 7 years in center-based hemodialysis with numerous complications, before receiving a successful kidney transplant from a living donor in 2018.

A lifetime in progressive social activism, and with a graduate degree in social work, policy and planning; and a career directing major nonprofit organizations, Bob brings his personal experience as a kidney patient fighting to survive, supported by a loving family and close community; a skill set well-suited to working with fellow patients, government and healthcare professionals; and a commitment to working to insure that others avoid the crises that he has known, and are empowered to preserve their identity and the things they cherish, and triumph over kidney disease.

### 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.

### 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.

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### 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.

### Cecilia Santana



Cecilia serves as a Wellness Ambassador for The Rogosin Institute to educate kidney patients on improving their quality of life, the different modalities of dialysis and the benefits of transplantation. Her mission as an advocate is fueled by her own chronic kidney disease journey, combined with her more than 20 years of experience as a public relations professional promoting specialty healthcare initiatives to inform communities on gaining better access to information, resources and care.

As a Kidney Warrior and breast cancer survivor over the past 15 years, Cecilia has advocated for herself as a dialysis patient and since becoming a kidney transplant recipient in 2013. She has engaged with ESRD patients and served as a speaker at several events. More than a decade ago, she joined a group of other CKD patients in Washington, DC, where they successfully encouraged House Representatives to sponsor a bill ensuring Medicare coverage of patients' education on dialysis modality options.

Since 2014, Cecilia has also volunteered as a Patient-Teacher to first-year med students of New York Presbyterian/Weill Cornell, as part of its LEAP program (*Longitudinal Educational Experience Advancing Patient Partnerships*), helping them to understand the patient experience of navigating the healthcare system, especially as someone handling multiple chronic conditions.

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### Leesa Thompson



Learning that you need a kidney to live can be overwhelming. Leesa works with kidney patients showing them the way to a living kidney transplant by making the experience empowering, instead of discouraging, just as her Earth Angel did for her.

Since her kidney transplant in 2019, Leesa has been paying it forward by helping patients with failing kidneys to find a living kidney donor, thereby helping them to live a more normal life.

Leesa's journey started with a diagnosis of chronic kidney failure, which left her bewildered and in search of a lifeline. She found help when a friend contacted his colleague who had recently received a kidney transplant. That colleague suggested writing a compelling story about her life and the positive impact her contributions have had on the environment and children with speaking difficulties. Leesa's story was posted to Facebook in a concerted effort to get her message out—that she had much more work to do for the benefit of others and that she needed a kidney to live.

Her story went viral and attracted more than 32,000 views in merely six weeks. Eventually, her need for a living kidney donor came to the attention of a friend whose kidney was not a match but who agreed to become a swap donor for Leesa. Then, through the National Kidney Registry's kidney matching program, she received a matching kidney from a non-directed donor across the country whose goal was to donate her kidney to start a chain of kidney transplants to help as many people as possible.

Leesa earned a B.A. in Psychology and a B.S. in Speech and Hearing Sciences with honors from Boston University. She also holds an M.A. in Speech Pathology with honors from Ohio State University. For more than 40 years, Leesa practiced as a Speech/Language Pathologist, primarily with early intervention and preschoolers.

Leesa enjoys writing and loves public speaking through Toastmasters. She is a lifelong environmental activist and participates in several political action groups focused on cleaning up our planet. Sailing and improvisational theatre are high on the list of things she likes to do.

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### NORTH CAROLINA

#### Scott Burton



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

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

#### 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."

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### 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 help.

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### NORTH DAKOTA

#### Becky Ronkowski



Becky is a transplant recipient. She received a kidney from her husband Keith 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 a retired educator, and the mother of three children.

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### 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 became 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

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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. He received a kidney transplant from a deceased donor in February 2020 at UAB in Alabama.

### 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.

### Ashley Martin



Ashley is a caregiver advocate and serves as a project manager for Kroger Prescription Plans. She currently holds a bachelor's from The University of Cincinnati in Public Relations and Health Care Communications. In her downtime Ashley enjoys assisting with compounding antineoplastic medications at Cincinnati Children's Hospital, spoiling her dog Bailey and spending time with family/friends. She is very passionate about empowering the patient voice and driving change in health care through communication. Ashley hopes to go on to get her masters in the coming years and become a Physician Assistant. Notable achievements include attendee to the 1st

Kidney Health Initiative meeting, panelist on Amgen-sponsored webinar for the American Association of Kidney Patients, American Kidney Fund Advocacy on the Hill advocate,

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aakpRENALIFE contributor, AAKP Field Ambassador and Coauthor on Identifying Major Barriers to Home Dialysis (The IM-HOME Study): Findings from a National Survey of Patients, Care Partners, and Providers.

### Toni Martin



Toni is a patient advocate for kidney disease awareness for the State of Ohio. She is a 2x kidney transplant recipient and has been treated with all modalities of dialysis over the past 21 years. She has had to endure the loss of one kidney transplant and a return to dialysis during that timeframe. She has had to advocate for herself and daughter to search for resources in order to live with kidney disease setbacks while raising her young daughter.

She has been on The Christ Hospital Patient and Family Advisory Council for over 10 years. Her daughter and she have hosted a kidney diet webinar for AAKP in 2016. She is an advocate for The American Kidney Fund and represented Ohio on Capitol Hill in March 2018. In 2015, she was engaged in the first patient and caregiver FDA conference to streamline many kidney disease initiatives. She has raised money for AAKP, AKF, NIH, ASN, Kidney Project, KidneyX, and the National Kidney Foundation for several years. For the past 4 years, she has been employed part-time by the United States Census Bureau as a Data Analyst/Field Representative. She previously worked in clinical research for 5 years. Kidney disease has changed her life in so many ways. She is always learning about new opportunities to help other kidney warriors and caregivers learn the complexities of living with kidney disease in order to live life to our fullest capabilities.

### Jason Miller



Jason serves as a Constituent Liaison for United States Congressman Tim Ryan and the founder of the first non-profit philanthropic fund in honor of his late mother to address financial barriers to education with interest-free loans. To date, the Juanita Access to Education Fund has awarded or inspired over 1.3 million in private and federal grants removing over \$900,000 in barriers to education. In addition, he is the principal at The JCM Group, the director of an inspiring travel YouTube channel, an ambassador of AAKP, and a proud Vigil Honor Gold Psalm Eagle Scout.

Jason holds a bachelor's degree with honors from the University of Akron. Completing his degree as an adult learner, he earned the Rising Star Student of the year as an incredibly engaged and productive student, holding five leadership positions in nine of the organizations. Jason works with Social Security, Medicare, IRS, and Education concerns for the thirteenth district of Ohio. He sits on the several education committees, holds several board seats, including serving as a patient advocate ambassador for AAKP. Jason is very active in the community to help humanity with increasing access to education, empowerment, and championing energy through healthy lifestyles and mindsets, especially those with kidney health



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issues. Outside of work and volunteering, Jason is a world traveler, an alpine ski instructor, a professional orator, and a passionate and experienced collaborator for change and a connector to help others step into their purpose.

### Elizabeth Oldham



Elizabeth was born in Cleveland, Ohio to parents that did the very best for her. Her parents taught her to give back to the community. She graduated from Wilberforce University with a degree in business. Elizabeth has spent her career involved in community service projects and working for inner city development corporations.

She became involved with the kidney community when she became a caregiver for a brother diagnosed with end-stage renal failure. Elizabeth became a kidney patient in 2018 after being diagnosed with stage 3 CKD. She is also a member of the National Kidney Foundation and participated in the 2021 Virtual Patient Summit.

### Victoria Schmalstig



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

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### Brenda Williams, PhD, MBA, RN



Brenda was a caregiver and managed her husband's medical care for 26 years until his death in September 2019 – not related to his dialysis. He had been on PD for three years prior. Brenda is active in the Ohio River Valley (District 9) ESRD network on the Patient Advisory Committee, an SME, and a Patient Ambassador. She was also active in the NPFE-LAN (National Patient and Family Engagement-Learning and Action Network) as an SME for peritoneal dialysis and blood stream infection affinity groups.

Brenda has two passions regarding ESRD. Her first passion is to see that 3-D printer kidneys become the norm in curing ESRD. Her second passion is to get legislation passed that will force CMS and doctors to recognize and offer education to patients about their dialysis choices when they are at CKD Stage2 and to require yearly BUN and creatinine testing as part of the wellness exam beginning at age 40. Most patients never know they have choices or even that they have ESRD until the doctor tells them that they must start dialysis today. This is so unsettling and unfair. To that end, Brenda will advocate vigorously for those patients.

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### 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

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2017, she was diagnosed with breast cancer and was told she may lose her transplanted kidney due to chemo and meds.

Sonya passed away in 2019. We will continue to educate and advocate in her memory.

### 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.

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## OREGON

### Lisa Custer



Lisa is a National Patient Advocate with a personal mission to share her journey with kidney disease, provide encouragement to fellow kidney patients, and offer insightful firsthand knowledge about dialysis. Over the past nine years, she has undergone in-center, peritoneal, and at-home hemodialysis, gaining valuable experience in managing this condition. Her primary focus is to be a voice for kidney patients and Native Americans, advocating for access to quality healthcare and striving to bring equality to this vulnerable population.

As a National Patient Advocate, Lisa actively participates in policymaking with the State of Oregon Legislature. This involves assessing and analyzing issues related to kidney policies and seeking funding to support the needs of kidney patients. Her advocacy work revolves around ensuring quality patient care for all, with a particular emphasis on improving access to healthcare for Native American and Alaskan Indian kidney patients.

Lisa is deeply involved in the kidney community, collaborating with various organizations such as Comagine Health – ESRD Network 16, ESRD National Coordinating Center, The Forum of ESRD Networks, National Kidney Foundation Region 9, and Dialysis Patient Citizens. These partnerships allow her to contribute her expertise and insights to the development of effective strategies and initiatives.

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Prior to her kidney failure diagnosis, Lisa enjoyed a successful 30-year career in the banking industry as a Collections/Recovery Senior Asset Specialist in Seattle, Washington.

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### PENNSYLVANIA

#### Candie Gagne



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

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

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

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### 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.

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## 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.

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### SOUTH CAROLINA

#### Angela Lattimore – IN MEMORIAM



Angela 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.

The world lost brave kidney warrior Angela in August 2020. Her lessons and example will accelerate our fight for more innovation and life-saving treatments for those impacted by kidney disease. We will greatly miss Angela who was frequently advocating on Capitol Hill with her loving son Trey always by her side.

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### TENNESSEE

#### Tessa Byars



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

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### AK & Orrie Diefenbach



Orrie was diagnosed with ESRD after experiencing flu like symptoms in January of 2019. After a year on nocturnal peritoneal home dialysis Orrie received a kidney transplant from his brother on January 23, 2020.

Orrie and his wife AK live in Nashville, TN with their three cats and one dog. They enjoy traveling, watching live music and binging tv shows with their fur babies.

### 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!"

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## 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

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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, MA, RN**



In 1982 after undergoing a renal biopsy, Kent was diagnosed with focal segmental glomerulosclerosis (FSGS), a disease that causes scarring in the glomerulus of the kidney. In 1987, after two days of dialysis via central line, he received a kidney transplant from his brother Kip. He has been on Sandimmune (150 mg daily) and (5 mg Prednisone daily) since transplant.

Kent is a Veteran of the US Army and a retired RN with work experience in the Veterans Administration and the private sector for over 40 years. Kent is on the AAKP board of Directors and is an active advocate and ambassador. He is an NKF peer mentor and advocate and is the leader of the NKF KAC region 7. He is an active consumer Peer Reviewer for PCORI and DoD. He has written articles relating to preemptive renal transplant and immunosuppressive drug coverage. He has been an active member of Nephcure International an agency seeking a cure for FSGS.

Kent and his wife Catherine celebrated their 50<sup>th</sup> wedding anniversary in 2019. Kent is co-founder of Kidney Solutions a 501c that helps patients find a kidney donor without fees or charges. Kent is committed to assisting and aiding those who have Kidney disease.

### **Catherine Campbell**



Catherine is a Doctor of Nursing Practice. She is a Professor at Southeastern Oklahoma State University and an Assistant Professor at Mount Saint Mary's University. Kidney disease has made a significant impact on her life for over 5 years. Her wait for a donor continues. Her deep commitment for assisting kidney disease patients began when she was invited to participate in the National Institutes of Health (NIH) Kidney Precision Medicine Project (KPMP). Through the semi-annual meetings and phone conferences she has gained further incites to patient experiences participating in dialysis, transplant, and waiting for a transplant. Additional activities in the KPMP includes Patient Engagement and Return of Results committees. Local volunteer contribution includes membership on the Community Advisory Board strategizing community outreach engagement and education. She has also served on a hospital grant committee securing research funds advancing treatments in chronic disease. Transition of care is vital to the stability of kidney disease patients following hospitalization into the community. As a Board of Director for Case Management Society of America, educating case managers has become a priority. Her role in healthcare and community engagement will maintain priority.



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### **Andrea Fattal**

Photo & bio coming soon!

### **Tiffany Fisher**

Photo & bio coming soon!

### **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.

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### Bill Gottfried



Bill's Father, a WW II and Korean War Veteran, suffered from kidney disease during the last five years of his life and died from kidney failure at the age of 65. Bill helped his Father with his dialysis treatments and saw first-hand the difficulty, pain, and suffering of dialysis patients. Bill and his wife, Danielle, have additional Family members who suffer from kidney disease and kidney failure. They are committed to supporting the kidney patient community by working to accelerate investment in kidney disease prevention and kidney disease research and the acceleration of dialysis technology innovation and renal replacement therapies, including the development of an artificial kidney. Bill and Danielle Gottfried formed The Kidney Research Institute of Texas, a non-profit, in 2018 focused on supporting the kidney patient community.

Bill earned a B.S. from The University of Tulsa, Tulsa, Oklahoma; a M.B.A. from The George Washington University, Washington, D.C.; and he was commissioned a U.S. Naval Officer at Officer Candidate School, Newport, R.I., serving on active duty in the Middle East. Bill is a member of The Army and Navy Club in Washington, D.C. Bill and Danielle are partners in a management consulting and real estate company in Houston.

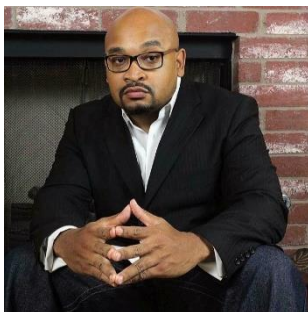
### Nichole Jefferson



Nichole is a two-time kidney transplant recipient. When diagnosed with end-stage renal disease in 2003, not only was she unaware of what meant, she had no idea she was at high-risk for developing kidney disease due to her race. On June 12, 2008, she received her first gift of life, a kidney transplant. Due to the many obstacles faced following her transplant, Nichole realized that a transplant was simply another form of treatment and not a cure. This realization sparked her quest for knowledge, which later initiated her enthusiasm for advocacy. Nichole received her recent transplant on April 24, 2020 during the midst of the

COVID pandemic. She is President of Home Dialyzors United and sits on several patient advisory boards, including the Steering Committee for the APOLLO Study.

### 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

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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.

### **Precious McCowan, MS**



Precious is a remarkable person from Dallas, TX who has faced the challenges of kidney disease head-on. Her kidney journey began in 2010 when she received her first kidney and pancreas transplant. Unfortunately, the kidney failed after just seven months, leading Precious to undergo in-center hemodialysis (ICHD) for the next eight years.

In April 2019, Precious was fortunate enough to receive a second transplant. However, the second kidney also failed, forcing her to return to dialysis. Despite these setbacks, Precious has remained resilient and dedicated to advocating for better care not only for herself but also for patients worldwide.

For over a decade, Precious has actively served on various boards and committees, demonstrating her commitment to improving the lives of those affected by kidney disease. Her roles have included being a Dialysis Facility Patient Representative, a member of the ESRD Network 14 Patient Advisory Council, and a Patient Subject Matter Expert for the ESRD National Coordinating Center. Additionally, Precious has contributed her expertise to organizations such as the Kidney Community Emergency Response Program (KCER), the National Kidney Foundation's (NKF) Public Policy Committee, the United Network for Organ Sharing (UNOS), and the Kidney Health Initiative (KHI) Patient and Family Partnership Council (PFPC).

One of Precious' proudest accomplishments was her involvement in the UNOS eGFR committee. She helped amplify the patient voice, ensuring that kidney transplantation wait time policies are fair and just for all individuals affected using the eGFR Black race variable. Precious's commitment to advocating for equitable treatment is truly commendable.

Beyond her advocacy work, Precious finds joy in mentoring individuals who are also battling kidney disease. She understands the importance of providing support and guidance to those in need, and she willingly takes on the role of a mentor. In her free time, Precious also serves as a coach for a little league dance team for girls aged 7-12.

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### David Rodriguez



David lived in Austin, TX, when he was diagnosed with focal segmental glomerulosclerosis (FSGS). Three years after his diagnosis, David received his kidney transplant through the Pair-Exchange Donation Program at University Health Transplant Institute in San Antonio, TX.

Originally a native of 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 State of Texas.

David is a Field Ambassador, Public Policy Committee Member, and Member of the Executive Committee for the American Association of Kidney Patients (AAKP). David is a former member of the National Kidney Foundation, Texas Kidney Foundation, Texas Organ Sharing Alliance (TOSA), and a volunteer for the University Health System. As a member of the Advocacy Committee for the National Kidney Foundation (NKF) and an Ambassador of the American Kidney Fund (AKF), he lobbied at our Nation's Capital in Washington, D.C. He also lobbied at the Texas State Legislature at the Texas Capitol on behalf of the Texas Kidney Foundation.

David has served with AAKP/Vertex ICF Patient Advisory Committee and the SRTR Review Patient and Family Affairs Subcommittee.

David published a Patient Voice article in the Clinical Journal of the American Society of Nephrology titled "Kidney Disease Burden and Kidney Transplantation: A True Story."

In 2017, David established Kidney Solutions – A Network of Transplant Experience, a non-profit organization with its mission to help guide those with chronic kidney disease, dialysis patients and assist families in finding living kidney donors through their registered Kidney Transplant Hospitals.

David received the 2017 NKF Rita Littlefield Patient Spirit Award, 2017 TOSA Joan Wish Award for the Central Region, 2018 Texas Kidney Foundation Volunteer Year Award, and 2020 AAKP Presidential Volunteer Service Award.

David is a former Patient Navigator and Patient Relationship Specialist at University Health Transplant Institute, where he visited inpatients at the Hospital and dialysis patients at dialysis treatment centers throughout Texas. David uses effective marketing and community outreach programs designed for patients with chronic kidney disease.

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### Donna and Isabella Tovalin



A mother and daughter fighting kidney disease-together. Pennsylvania native, Donna, made the journey of a lifetime to Torreon, Coahuila Mexico to teach. There, she met her husband Jaime and had two healthy children. Everything was good until she began to feel sick and the doctors in Mexico determined that both kidneys were failing. As her health worsened, Donna and her husband made the decision to move to Houston, Texas, where she received a kidney transplant from her sister Cecelia in 2004. Five years later, her daughter's kidneys also began to fail. Donna began to fight for kidney awareness and became an active NKF volunteer. Donna and her daughter, Isabella, advocate for kidney disease awareness and are ambassadors for kidney health.

### Jonathan Traylor



Jonathan is a husband, father, and friend to all. He has a strong supporting family in his wife Melissa and children Jett and Mackenzie.

Jonathan has worked in technology, computer/printer diagnostics & hardware repair as well as website design and social media.

On July 8, 2019, Jonathan went into kidney failure (Stage 5 ESRD) and woke up in the ICU on dialysis. He was about 30 minutes from death according to doctors. Jonathan went from the hospital after a 2-week stay to in-center hemodialysis treatments. After around 10 months of being in-center, he progressed to home hemodialysis with Melissa as his caretaker. Jonathan only did home hemodialysis for 3-4 months and on August 11, 2020, he received his miracle Gift of Life and was transplanted in San Antonio, Texas at Methodist Specialty and Transplant.

Jonathan has a passion for all things kidney and now uses his personal story to give encouragement & hope to those that are suffering with kidney disease. He now advocates for organ donation for kidney patients and is grateful and blessed to share his messages of hope with others.

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### UTAH

#### Dax Francis



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

Dax, determined to take advantage of the gift he was given, stayed enrolled in school and achieved his goal of attaining his bachelor's degree in Social Work all while undergoing treatment. It was not easy, and poor decisions in life made it even harder, but Dax has always learned from his mistakes, and today is the proud founder and manager of Ivye Wear, LLC. Dax's company specializes in apparel for people who are chronically ill and need a way to stay warm and comfortable during, oftentimes grueling, treatments. He did all this while he was on dialysis and is a testament to the warrior's attitude many dialysis patients have. Dax tries to travel as much as he can to speak and visit with other warriors to encourage them to stay strong and stay positive in the face of adversity. He also makes inspirational and motivational videos for anyone to view, and frequently gives presentations to medical device companies on the patient's perspective to improve care. He very much hopes to be an advocate for organ donation, rare disease research, bringing awareness to vital causes related to chronic kidney disease and chronic illness at the highest level, and first and foremost, is committed to helping others.

#### Michael & Christina Gilchrist



In her early teens, Christina ("BLIND CHICK LIVING") was diagnosed with kidney disease. She became pregnant in her early 20's and the doctor missed toxemia, resulting in seizures which caused her retina and optic nerve to implode, causing blindness. She also had high blood pressure which led to total kidney failure. Christina's oldest brother donated a kidney but unfortunately it was rejected within 2 years. She asked if she could do home dialysis and was told she could not because she was blind. She did in-center dialysis for 5+ years all while doing the tasks of a young, single mother. She received the call and received a deceased donor kidney and decided she was going to start LIVING and having fun. Christina started having the time of her life with Michael ("THE CARETAKER") but started rejecting her donated kidney within 2 years again. She insisted on doing peritoneal dialysis and

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would not take no for an answer. She kept living on PD, doing dialysis all over – from dry camping with solar panels to vacations, got married and did PD on her honeymoon and even on the back of a motorcycle! Peritoneal dialysis stopped being effective, so transitioned to home hemodialysis with Michael's help. Michael felt he needed support and not being able to find a support group that fit his needs, he started his own. That was the start of LIVING on dialysis!! Christina and Michael, along with Christina's service dog Moose ("THE POMSKY SERVICE DOG"), have traveled all over the country advocating for dialysis and sharing how they are LIVING! Christina says: "I don't live to do dialysis, I DO DIALYSIS TO LIVE" and "Don't tell me I can't, show me how I can!"

### **Bruce Tippets**



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 Tippets 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.

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### VIRGINIA

#### Meshia Adams



At an early age, Meshia remembers being different from most kids. She never considered herself to be sick or not able to do the things that other kids could do; she just knew she wasn't the same. As Meshia grew older, she realized that she *was* different. She didn't think the same or see things the same way as other teens her age did. Having to deal with a chronic illness at an early age has a way of shaping who you become. Meshia was diagnosed with end stage renal disease (ESRD) at the age of seventeen. Although her life changed dramatically, she continued to be positive and endured several challenges that a seventeen-year-old shouldn't have to experience.

Meshia was placed on peritoneal dialysis in October of 1995 and was blessed to receive a kidney transplant five months later. Meshia bounced back quickly and continued on living her life. With the nudge from her nephrologist, Meshia educated and spoke to kidney patients about her experiences on dialysis and being transplanted. Meshia has always been strong, patient, caring, compassionate and willing to help others. This is part of why she has been able to face the challenges and frustrations that comes with being a kidney patient. Meshia would need to pull from all these traits when her kidney began to fail fifteen years later in July of 2010. Meshia was placed back on peritoneal dialysis and later transitioned to hemodialysis. Meshia faced challenges, frustrations and breaking points that were new to her. She almost lost her life to pneumonia, went through months of rehabilitation, and experienced double feet fractures in addition to two total hip replacements. It is Meshia's strong faith, support circle and outlook on life that has gotten her through these challenges. Meshia was on dialysis for almost two years before receiving her second miracle. On July 6, 2012 Meshia received a kidney transplant from a living donor which happened to be her husband! What a special gift that is.

Meshia has dealt with chronic kidney disease for over eighteen years. During her journey she has been fortunate to have people placed in her life who have taken excellent care of her and have given her a lot of support. Meshia learned a lot about herself and kidney disease over the years. Unfortunately, she has also witnessed a lot of misinformation and poor treatment of dialysis and kidney patients. There are many professionals in the health care industry who don't have much experience in dealing with dialysis or patients with kidney disease, which in turn increases the safety risk of the individual. Meshia has experienced firsthand the impact a lack of knowledge can have and ended up having minor surgery to have a catheter replaced shortly after her transplant in July. Meshia believes that as a patient, you should be your best advocate and be well informed. Meshia says instead of always relying on your healthcare team to tell you what or how you should feel, it should be a more of collaborative effort. There is no better advantage than having another kidney patient who has experienced similar things as you to get help and



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advice from.

Meshia wants to use her experiences, compassion and knowledge to help others living with kidney disease by starting her own organization. Meshia's Hope aims to educate, empower and raise awareness about kidney disease. Meshia enjoys volunteering with various organizations such as Dialysis Patient Citizens, RAE Youth Services, The National Kidney Foundation, Kamisol Imaging & Accessories and The American Society of Nephrology. Meshia's "can do" attitude, ability to engage people along with her desire to help others makes her the perfect candidate for this role. Meshia currently resides in Northern Virginia with her husband Rodney.

### Dean Armandroff



Dean is a public affairs advocate and activist. Most recently, Dean has worked in health care advocacy and organizing. Previously, he advised political and public affairs clients on media strategy, messaging and voter outreach tactics.

A kidney patient, Dean is on hemodialysis while awaiting a transplant. He is passionate about improving outcomes and quality of care for all kidney patients. Dean and his family live in McLean, Virginia.

### Kelly Cline and Hannah Shelton



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

been thriving ever since.

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

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### 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.

### Patrick Gee



Patrick Gee is a former Peritoneal Dialysis Patient and two and a half years into a kidney transplant that he affectionately named, "Lazarus." As a Healthcare Consultant/Consumer Advocate, he is very passionate about advocating on behalf of the underserved, undervalued, disenfranchised communities of fellow kidney. Patrick's advocacy focus is for a more comprehensive and universal healthcare, effective and realistic patient engagement, health educational tool kits being dispensed in low-income communities, social, moral and ethical injustices and perspectives concerning genetic differences and research and a better quality of life for

kidney patients. Patrick is an AAKP Ambassador, in addition to serving in a number of other capacities.

Patrick retired from the Virginia Department of Corrections as a Major/Chief of Security. Patrick has a bachelor's degree and a master's in Criminal Justice, with an emphasis in Public Administration from the University of Richmond, in Richmond, VA. He also has a Doctorate of Philosophy in Justice, Law and Criminology from a American University, Washington, DC. Patrick is the Founder & CEO of iAdvocate, Inc., non-profit Health & Wellness organization. Patrick is also a licensed Minister at Mountain Movers Ministry Church, Richmond, VA. His ministry is working with those suffering from kidney disease. Patrick's motto is, "I am the "Voice for the Voiceless and the Face of the Faceless in the fight against kidney disease."

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### Jennifer Jones



Jennifer Jones is a two-time kidney transplant recipient (first from an altruistic living donor in 4/2015 and second deceased donor 11/ 2021). In 2011 while serving in the United States Marines as a Combat Camera Videographer, her kidneys declined while forward deployed to Afghanistan. After being medically evacuated back to the states, she was diagnosed with Membranoproliferative Glomerulonephritis, Type 1 Idiopathic (MPGN).

Jennifer admits in the beginning she was considered a "challenging patient" because at first, she couldn't accept what was happening to her. She realized when she began in-center hemodialysis that she had to accept her current situation and focus on what was within her control, which was becoming her own advocate and taking charge of her health and well-being. Once approved for a kidney transplant Jennifer began an active pursuit for an altruistic living 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.

For the next five years, Jennifer focused on rebuilding her life by completing a BA in Organizational Leadership from Penn State, becoming engaged in chronic kidney disease advocacy work with the American Association of Kidney Patients, and launching a business until MPGN reappeared and caused rapid acute kidney injury to her transplanted kidney. She returned to dialysis at the beginning of January 2021.

Despite choosing peritoneal dialysis as a way to remain safe during COVID-19, because of her severely compromised immune system, she spent a significant amount of time in and out of the hospital for other ailments. Despite those challenges, Jennifer was determined to find a donor and be placed on the transplant list again.

She was fortunate enough in the same year to find another altruistic donor who was willing to be in a kidney-paired exchange, but in November a deceased donor match was found and she received her second transplant on the 28th. Her donor went on to donate their kidney to someone else who was in need. If it wasn't for the support of her family, friends, and fellow kidney warriors she wouldn't be here today.

Jennifer is currently the Vice President of AAKP, a member of the Center for Dialysis Innovation Patient Advisory Board, the Patient and Family Advisory Council of Quality Insights Renal Network 5, the National KCER Patient and Family Engagement Learning and Action Network, the Veterans Transplantation Association, and Kindness for Kidneys. She is passionate about advocacy for policies that improve the quality of life for the kidney patient and their families, patient-centered education, community building, and removing barriers to living organ donation and innovation.

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### Anthony Reed



In December 1990, Anthony was adopted by two wonderful parents that brought him back to the USA. Little did they know that Anthony had been born with a horseshoe kidney. In 2013 Anthony was diagnosed with ESRD due to high blood pressure caused by the horseshoe kidney. He started the exciting journey of dialysis not long after being diagnosed, and that journey lasted for close 4 years. In April 2017, he had a kidney transplant and since then he has been sharing not only the story of his journey but the lessons that life taught him throughout that time. He currently works as a biomedical Equipment Technician in dialysis and volunteers his time to the kidney field by speaking and being a patient advocate.

### Harald Stellwag, Jr.

Photo and bio coming soon!

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## WASHINGTON

### Laura Ellsworth



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

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

### Glenda Roberts



Glenda 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

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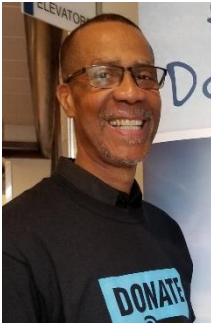
exercise and enjoyed a stellar career in the corporate world, evolving from a software developer to a senior business executive managing multi-million-dollar business units for top-caliber corporations, including General Electric and Microsoft. Simultaneously, she has been a passionate advocate for kidney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

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

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### WEST VIRGINIA

#### 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.

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### Nieltje Gedney – IN MEMORIAM



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

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

The kidney community lost Nieltje on September 21, 2023. She was a passionate advocate and her absence will be felt by the entire kidney community and beyond.

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### WISCONSIN

#### Clifton Agee

Photo & bio coming soon!

#### Mary Baliker



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

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

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### 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

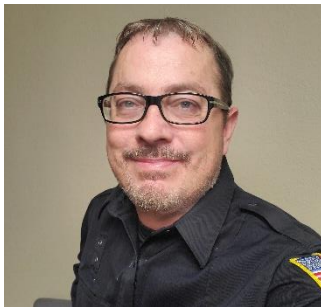
knows the impact of kidney disease on a family.

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 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.

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## 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.

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# GLOBAL AMBASSADORS

## 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 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.



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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."*

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### AUSTRALIA

#### Carl Juresic



Carl is an Australian / British kidney transplant patient with 15 years of experience working in Business Strategy and Marketing. He currently works as a Strategist at Meta in Sydney, Australia. Driven by his passion for helping fellow kidney patients around the world live a better quality of life he co-founded Kidney Ally which is an innovative patient driven start-up that helps kidney patients make personalised healthy food choices. Kidney Ally includes one of the biggest Kidney communities on [Facebook](#) with 16k members, a strongly followed podcast on [YouTube](#) and [Spotify](#) and a soon to launch [website](#) with advice and tips on following a personalised healthy kidney diet. He joined the AAKP global patient ambassador programme to find out new and innovative ways that he can help the kidney health community.

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### CANADA

#### Nate Boutcher



Nate lives in Ontario, Canada and is 28 years old. He received a kidney transplant on May 12<sup>th</sup>, 2020 after spending over 6 years on hemodialysis. Near the beginning of his experiences as a patient, he had a rough time, both physically and mentally. However, after his crisis period he came to realize that he had only one of two choices: to sink, or to swim. To sink, all he had to do was concede to his situation and be victimized by my circumstances. However, he clung to hope and decided to believe in a life where he was able. He refused to concede.

The years that followed have been the best years of Nate's life. He went back to college, graduated, and became a diligent and passionate volunteer in his renal community. He has pursued many different types of movement and activities, ranging from karate to kayaking. He became a certified yoga instructor, and last year, he ran the Detroit Free Press Marathon, and

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made the news in the process! Most importantly though, Nate has discovered strategies as a dialysis patient that have provided him with a meaningful, able, and joyous life. He feels privileged in his involvement as an ambassador with the AAKP and looks forward to future opportunities to share his message with the renal world – a message of hope and ability in the face of this adversity.

### 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.

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!

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### GERMANY

#### Rosi Brack



Rosi was diagnosed with ADPKD in 2010. Her mom had ADPKD and died in 1986. Rosi's doctor always told her that her kidneys have several bigger cysts, but that is not the same illness that her mom had. Now Rosi knows that this was not true. But she also knows the good intention, because her doctor knew that there was no treatment for ADPKD. Rosi's doctor was very dedicated to watching her blood pressure, the most important thing that could be done in early stage. Creatinine and other bloodwork was controlled every year.

In 2014 Rosi's doctor said, like every year, 'Creatinine is ok'. But there was a small pause when she was speaking, so Rosi Googled at home and saw that this result was a bit too high.

Then Rosi made an appointment at a nephrologist and had been told that her GFR was only 54. She was shocked. But Rosi got good explanations and in 2015, at the next appointment, her doctor spoke about Tolvaptan.

There were some tests, and she went to a university hospital in Ulm. She has taken Tolvaptan since January of 2016 and gets along with the public side effects, as drinking a lot of water and tea, and to go to the toilet every 1 – 1.5 hours. At night she needs to get up 2-3 times and will go to sleep again soon.

Rosi's aim is to share her experiences. That is why she is active in the German society for patients, 'PKD e.V.'. In summer of 2016 there was a request from Prof. Andreas Serra, Zurich, Switzerland. It was planned to make Tolvaptan available there in the following months and the professor asked if somebody from Germany would share experiences with the medication at the next meeting of the Switzerland patients' group 'SuissePKD'.

Rosi answered and had been to Switzerland at the competence center for ADPKD for several times. In the time between the meetings, she had a lot of questions, which Prof. Serra answered timely and competently.

One day Rosi asked him to recommend her a book about ADPKD, so she would not have to ask so often. His answer was 'there is no such book available - that would be a task for us.'

That was the beginning of them writing a book together, the first in German language about ADPKD, that is easy to understand also for patients and related persons with no or only little medical knowledge.

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The book has been published by 'Hogrefe Verlag' in November 2020 and had been presented at the international book fair 'Buchmesse Frankfurt' in October 2021 as a new publication. Their aim is to get it translated in English. The company Hogrefe works on offering the license for a translation to companies in the US.

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### INDIA

#### Vasundhara Raghavan



In 2005 Vasundhara retired as Secretary General to the Media Research Users Council, ending her corporate career to further her interests in understanding kidney disease.

Her personal experience with CKD began in 1996, when her son Aditya was diagnosed with Reflux Nephropathy. His two kidney transplants and experiences on dialysis became the basis for Vasundhara's book "Shades of Life, Sublime Joy is in Living", with US based Dr Mohammad Akmal as co-author. Her other literary works include "The Kidney Warriors," as an author and

"Who Lives, Who Dies with Kidney Disease" as co-author while living in Dubai. In December 2020, she returned to India to develop new strategies for improving impact in patient care programmes as CEO of Kidney Warriors Foundation's, India's largest on-line support group.

In 2021, International Society of Nephrology invited her to represent India's representative on the Patient Liaison Advisory Group. She was also appointed by The Government of India to represent the patient group in the Reconstitution of National Oversight Committee (NatCom) for National Dialysis Programme in 2019.

Kidney Warriors Foundation has been engaged in helping kidney patients with support and funding for medical expenses.

#### VG Chandrasekharan – IN MEMORIAM



In January 1988, V.G. was diagnosed with end stage renal disease (ESRD) - his kidneys were failing. In order to survive he had two choices undergo periodic dialysis or have transplant.

His nephrologist informed him that kidney transplant is considered the treatment of choice for many ESRD Patients. Quality of life and survival are better in kidney transplant recipients than in patients who are treated with dialysis. However, getting a donor was a challenge in KERALA. Fortunately, V.G.'s 60-year-old mother, Smt.Sarvamangala, decided to give the Gift of Life by donating one of her kidneys to her son on March 30, 1988. 32 years later, V.G. stood before fellow kidney transplant recipients and advocates to share his inspiring story through his foundation, Kidney Foundation (Kerala), and going to launch his book, "UNsung HEROES."

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"After my kidney transplant, each day has been a blessing. When people ask what secret enabled me to survive and thrive as a kidney transplant recipient for more than 32 years, I tell them there is no secret formula. The key to success is to be a compliant patient. Follow your doctor's orders regarding maintenance medications, diet and lifestyle and everything in moderation."

V.G. is the Founder & Chairman of Kidney Foundation & Director of Kidney Warriors Foundation. He served as General Manager of a Multi-Specialty Hospital. He was the 1st Indian Transplant Recipient and Medalist in Special World Olympics Games held in UAE in March 2019 & he was the organizer of the 1st Transplant Games in India in 2018 March 8th. He is the 1st Indian transplant recipient to summit Colorado's Spring Mountain (15 thousand feet altitude -in minus 24 degree Celsius) without supplemented oxygen in 2018 December 31st. His story was featured in many local & international newspapers & media channels. V.G. is loving father of two children and grandfather for one grandchild.

V.G. passed away in 2020. We will continue to advocate in his memory for all impacted by kidney disease.

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### IRAN

#### Hamidreza Zalpoor



Hamidreza is a medical researcher and medical Immunologist at Shiraz University of Medical Sciences. He is an ADPKD patient, diagnosed three years ago by an abdominal sonography when he had a renal infection. Hamidreza takes drugs for hypertension but is not on any specific drugs for ADPKD.

Hamidreza loves pediatric ADPKD patients because he can understand them, having ADPKD himself, and one of his most valuable goals in his research is designing a new specific drug for the treatment of ADPKD with low side effects for these patients. He says that having a low-salt food diet and checking the blood pressure for pediatric ADPKD patients can save them from some events of ADPKD. Nowadays, because of the SARS-CoV-2 pandemic, pediatric ADPKD patients are at high risk of COVID-19, because they have a very sensitive immune system versus SARS-CoV-2, and one of the target organs of SARS-CoV-2 is the kidney, therefore we must teach pediatric patients and their caregivers about the health protocols and importance of vaccines like for influenza.

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### KENYA

#### Moses Osino



Moses was diagnosed with ESKD in 2017 and has been on dialysis since, taking two sessions a week. This was a turning point, and he has had to adjust with so many realities, especially diet and fluids. After a year, Moses started searching for information regarding his condition to the extent fellow patients were asking more about this condition. Moses decided to put his voice to educate communities and thus the FIGO INITIATIVE was born. Moses would like to join other Ambassadors globally.

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### 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 received a kidney transplant at Methodist Hospital in Dallas Texas in 2020.

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