

AAKP SPEAKER'S BUREAU - REGIONAL AND STATE SPEAKERS

ARIZONA

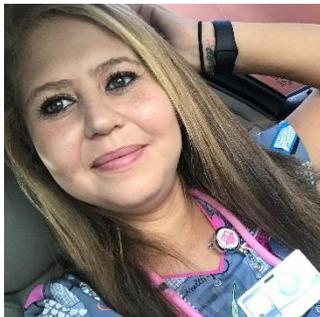
Risa Simon



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

FLORIDA

Gabi Morales



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

GEORGIA

Edward Drake II



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

Edward received a kidney transplant from a deceased donor in October of 2008, and continues to spread the word about organ donation and early detection through his own charity, the YNOTT? Foundation (Youth Needing Organ & Tissue Transplants), and as a field ambassador for the American Association of Kidney Patients. He frequently visits kidney

disease and dialysis patients of all ages, especially young ones like him, mentoring and comforting them with his own story and positive outcome. He also advocates for policies that improve the lives and treatments of those with kidney disease and expand patient choices.

IDAHO

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.

ILLINOIS

Lana Schmidt, MBA



Ms. Schmidt is a kidney transplant recipient after being on dialysis for over 13 years from Liberty, IL, with a MBA – Masters 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.

MARYLAND

Austin Lee



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

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

Sharron Rouse



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

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

MISSOURI

Melissa Bensouda



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

NEVADA

Maile Robb



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

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.

OHIO

Ashley Martin



Ashley, age 22, is a kidney patient and caregiver advocate. She is currently entering her junior year at The University of Cincinnati. After a recent change in majors she is now studying Biological sciences with a concentration in Biomedicine and a minor in Chemistry. In addition to a Pre-Med fast track. She hopes to go on to become a pediatric transplant surgeon at Cincinnati Children's Hospital. She has been a caregiver for her mom since 7 years of age. She has also been attending AAKP's national patient since she was 8 years old. In her downtime, she enjoys shadowing Dr. Gregory Tiao (Pediatric transplant surgeon and Chief of

General Surgery) at Cincinnati Children's Hospital. She also enjoys participating in a club at The University of Cincinnati called CRU and spending time with her boyfriend Miguel and her dog Bailey. Notable achievements include invited member by the FDA to the 1st Kidney Health Initiative meeting, panelist on Amgen-sponsored webinar for the American Association of Kidney Patients, invited advocate by The American Kidney Fund to Advocacy on the Hill, RenaLife contributor, and AAKP Ambassador.

OKLAHOMA

Brian Hess



Mr. Hess is a home hemodialysis patient from Edmond, OK. He is a graduate of the University of Central Oklahoma with a major in Biology and a minor in English. Mr. Hess authored the book "Kidney Failure Won't Stop Me", published in July 2012. He is a former member of the ESRD Network 13 Patient Advisory Committee & the Medical Review Board. Mr. Hess has been a member of AAKP since 2010.

TEXAS

Kent Bressler



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

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

David Rodriguez



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

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

WASHINGTON

Glenda Roberts



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

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

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