

National  
Kidney  
Foundation®

## KIDNEY PATIENT SUMMIT

**Advocate Profiles**

**Mary Baliker**

*Middleton, WI*



Mary Baliker has gone through four kidney transplants since age nine, and she's making her hard-fought life count. A Wisconsin native, Mary has been a healthcare advocate and professional for more than 30 years. Her experiences have given her an opportunity to cherish her life and created within her a strong interest in improving healthcare. Mary has also written her story "Maria Never Gives Up" to help children and their families in their personal struggle with the emotional and physical rollercoaster that is brought on by a chronic illness. Mary has been a patient lobbyist and is actively involved in legislative work. She serves on the United Network for Organ Sharing Patient Affairs Committee, UW (University of Wisconsin-Madison) Health Patient and Family Advisory Committee, Friends of UW Health Board of Directors, Midwest Kidney Network Board of Directors, Midwest Kidney Network Consumer Committee and the National Patient/Family Engagement Learning & Action Network Health Services Advisory Group. She is a member of the National Kidney Foundation's Peers mentoring program, NKF's Kidney Advocacy Committee, NKF's Public Policy Committee and an American Association of Kidney Patients Field Ambassador. Mary is a graduate of the University of Wisconsin-LaCrosse and has worked professionally at the University of Wisconsin School of Medicine & Public Health, Department of Defense Congressionally Directed Medical Research Program, Astellas Pharmaceuticals and Long Beach Memorial Hospital. She enjoys spending time with her family and friends, and her husband, Jim, and their dog, Kona.

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**Melissa Bensouda**

*Lee's Summit, MO*



A 3 a.m. phone call from her doctor in spring 2012 awakened Melissa Bensouda from sleep into a new lease on life – at least for a while. That morning, after nearly a decade on dialysis, she learned she would receive a kidney matched from a deceased donor. Since her transplant, Melissa's kidney had been fully functioning, and she never had felt better – until early this year when the transplant rejected, forcing her to resume dialysis. Melissa was diagnosed with kidney disease at 24 after the birth of her second daughter and suffered complete kidney failure after having her third and last child, a son born 15 weeks early and legally blind. She underwent dialysis while maintaining motherhood and a full-time job. To be more self-sufficient, she also received training to manage her own home hemodialysis. Even amid her challenges, promoting awareness about kidney disease is her passion and a priority as an active member of National Kidney Foundation's Kidney Advocacy Committee and Advisory Board.

**Alex Berrios Jr.**

*Louisville, KY*



Alex Berrios believes it is important to look at all the signs of kidney disease. As a transplant recipient, Alex is committed to sharing his story with others. He received his kidney donation 10 years ago. Alex states that he doesn't believe that states provide enough funding for kidney disease education and treatment. He wants to be an advocate and bring information back to his local National Kidney Foundation chapter to continue to spread the word about issues surrounding kidney disease to his local community. His personal message to his representatives on Capitol Hill is that he wants them to know the importance of education so that people are aware of the symptoms of kidney disease. He also wants people to spread the message and have conversations with their local officials as well.

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**Joyce Bearman**

*Wheeling, WV*



Joyce Bearman is waiting to have a new kidney transplant at either Allegheny General Hospital in Pittsburgh or The Ohio State University in Columbus. Her story starts with a misdiagnosis in 1974 by a second-opinion doctor. It turned out that her first doctor was right, and 21 years later, her kidneys failed. In 1998, Joyce had a transplant, which failed in 2009, and she has been on dialysis since then. Yet, Joyce is an active volunteer with the National Kidney Foundation and other charitable organizations. Passionate about early detection of kidney disease leading to better outcomes, she is a member of NKF's Kidney Advocacy Committee and is certified to present the program *Your Kidneys and You*. Joyce also is a former board member at NKF Serving the Alleghenies. Retired in 2010 after working nearly 30 years in media and corporate communications for nationally-known companies, Joyce and her husband, Dennis, have two daughters and a grandson.

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**Gary Bodenheimer**

*Elwood, NE*



Several years ago at age 66, Gary Bodenheimer was diagnosed with membranous nephropathy, an incurable, autoimmune disease that affects kidney function by attacking and damaging the glomeruli, the tiny filtering units inside the kidney where blood is cleaned. This leads to the loss of a large amount of protein into the urine, which can result in kidney failure. Gary followed his doctor's advice to receive six months of chemotherapy as a possible way to prolong avoiding dialysis. He also lost more than 100 pounds and follows a special diet. "So, for a while, my kidneys have been functioning better, but . . . I may have to do chemo again," said Gary, a former NBC affiliate assistant director and teacher, both in Topeka, KS. He is married and has six children, 18 grandchildren and two great-grandchildren. Gary's third wife, Catherine Cole-Bodenheimer, has been his strongest support and advocates alongside him. "My husband and I continue in our fight to help others learn more about kidney disease," Catherine said. "I have been screened myself as both of my parents have had kidney issues, and I have a sister who has lost a kidney," she continued. "Screening is easy and painless and is something all should do!"

## **Kent Bressler**

*Kerrville, TX*



This is Kent Bressler's fourth year advocating in Washington D.C. with his wife of 48 years, Catherine. He was diagnosed in 1982 with focal segmental glomerulosclerosis, a disease that causes scarring in the kidney. This can lead to 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, a living donor. Still, for nearly 30 years, he has been on immunosuppressive drugs that can have harmful, long-term side effects. A registered nurse, Kent has represented National Kidney Foundation nationally and has participated in chronic kidney disease research reviews for the U.S. Department of Defense. He's also worked in Texas with NKF as a mentor for potential transplant recipients and donors. Last year, he received the Richard K. Salik Advocacy award for his outstanding commitment and work in patient advocacy. He is active in his church and has two daughters and four great-grandchildren.

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## **Ned Brooks**

*Rowayton, CT*



Founder and owner of Donor to Donor, an organization dedicated to helping create awareness of the need for living kidney donation, Ned Brooks is an advocate who wants to help potential donors understand the donation experience and how they can impact a life. Ned also has a very special connection to kidney donation and a unique perspective on its importance; he gave one of his kidneys as a non-directed donor in September 2015. His talks on this topic explore his experience and highlights numerous studies that have shown that there is a measurable improvement in the quality of life that occurs after living kidney donation – for the donor. Ned is passionate about organ donation and in the future hopes to continue collaborating with the National Kidney Foundation on advocating on the topic of kidney donation by delivering key messages to Capitol Hill.

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## **Kelly Cline**

*Glen Allen, VA*



Tireless National Kidney Foundation volunteer, fundraiser and Kidney Advocacy Committee member Kelly Cline looks forward to participating in the Kidney Patient Summit for her fourth time, but not without first looking back. Kelly's daughter Hannah was diagnosed as a toddler with kidney cancer, followed by kidney disease which led to the need for a transplant. Thanks to a living donor, her father, Hannah received her kidney in 2011 and is now doing well. Kelly's experiences with her daughter have fueled her passion to help others in similar situations and advocate on behalf of all living donors. Shortly after Hannah's father donated his kidney, he returned to work as he was fearful that he would lose his job even though he was not fully recovered. This is one reason Kelly advocates – for living donor protection. "I never thought I would go to D.C. and speak with our representatives about anything," she said, "but now I look forward to every opportunity I get to urge them to support legislation protecting living donors."

**Felicia Cde Vaca**

*Albuquerque, NM*



Early in 2014, Felicia Cde Vaca donated a kidney to her father, Leonard, who was on the transplant waiting list. Getting him to accept a kidney from his daughter, however, was a challenge and took nearly a year even as his health worsened. As time progressed after the transplant, Felicia relished in her father's recovery, healing and much-improved health. "It was priceless," she said. "I went from seeing him as very ill, to living life with a smile!" Felicia is the mother of one child, a son, in whom she instills the importance of appreciating life and health. She holds a Master of Business Administration and has worked many years in the financial industry. Felicia often volunteers for causes that improve the quality of life and well-being of others.

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**Lenora Coss**

*Elk Grove, CA*



A retired nurse and advocate from California, Lenora Coss knows the importance of quality healthcare. At the age of 61, Lenora was diagnosed with a rare disease, fibrillary glomerulonephritis, which causes kidney failure. There is no treatment or cure. Fortunately, Lenora was diagnosed early and was able to receive dialysis for two years, and then received a transplant five years ago.

She hopes that all patients with a chronic illness will someday have adequate care to allow them to have the highest possible quality of life. "It is my hope that the benefits we get for patients with chronic kidney disease will eventually be for everyone with a chronic disease." As part of her mission to advocate for patients, Lenora worked with the California Nursing Association to get nursing ratios

instituted in California. She passionately believes that "everyone should have the same quality healthcare that legislators have."

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**Andrea Cox**

*Fayetteville, NC*



Veteran teacher Andrea Cox abruptly became the student by having to learn how to stay alive after being diagnosed with end-stage renal disease in 2004. The mother, wife and caregiver to her own ill mother had to adjust to undergoing extensive treatment herself as she faced what she called the "frightening and unknown" prospect of hemodialysis. "The process was long and sometimes a little painful," said Andrea, who also recalled that noticeable changes in her physical appearance stirred personal fear, sadness and disbelief. Her faith, inspirational music and family would help her persevere, but physical restoration came when her oldest son, David, donated a kidney to her in 2006. This gift of life allowed

Andrea to resume teaching her beloved second graders for five more years before retiring after 32 years. A dedicated volunteer with NKF and other programs that help dialysis patients and the elderly, Andrea said she will continue to use her story to "inspire, motivate and empower others."

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## **Rahmeka Cox**

*New York, NY*



Rahmeka Cox's connection to kidney disease is two-fold: as the daughter of a transplant recipient and the sister of a donor. In 2006, her brother David donated a kidney to their mother, Andrea, who also is a member of the Kidney Advocacy Committee in North Carolina. Rahmeka and her family are creators of a platform to create awareness for organ donation, transplantation and kidney disease called "It Only Takes One."

Rahmeka is pursuing a Master's in Public Health with a focus in epidemiology at New York University, where she focuses on analyzing the incidences of kidney stones in patients with Cystinuria, a rare inherited genetic disease. She's also a research coordinator with the Narrows Institute for Biomedical Research and Education and the works with the Department of Veterans' Affairs New York Harbor Healthcare System. Among her personal missions is to gain more funding dedicated to kidney disease-related research.

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## **Megan Craig**

*Chicago, IL*



As a non-directed living kidney donor in 2011, Megan Craig has made a difference in the community and directly impacted someone's life. After she donated, Megan found out that her kidney was given to a little boy named Evan, who is 7 years old now. She also is passionately rooted as an advocate for kidney-related issues as the Director of Programs for the National Kidney Foundation of Illinois.

Megan is a constant supporter for kidney patients and loves the opportunity to represent living donors to the nation's legislators. At the summit, Megan wants to focus on advocacy goals for kidney patients but wants her representatives to be reminded that access to quality, affordable healthcare extends far beyond the renal space. She believes that our lawmakers need to "keep in mind the unquestionable impact legislators have on the ability of all Americans to gain such access."

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## **Carlos Cristi**

*Washington, D.C.*



For Carlos Cristi, the journey with kidney disease began more than three years ago, when a routine physical revealed his kidney function had dropped to 25 percent. Soon afterwards, his kidneys failed, and he underwent peritoneal dialysis and hemodialysis. Meanwhile, members of Carlos' family were tested to see if any of them could be a living kidney donor. His brother was found to be a match and the resulting transplant was successful. Both men are doing well, according to Carlos, a Tucson, AZ, native who moved to Washington D.C. to attend law school and pursue a career. "These experiences give me a lot of firsthand insight into many of the efforts being pushed by the National Kidney Foundation," said Carlos, emphasizing his personal reason for representing his home as an advocate at the Kidney Patient Summit. "I would like to encourage my representative to make preventative efforts a big part of her legislative mission," he added.

## **Erich Ditschman**

*East Lansing, MI*



Erich Ditschman inspires dialysis patients and others living with chronic illness to get outdoors everywhere he goes – and online through his blog and Facebook page titled, *Paddling on Dialysis for Kidney Health*. Erich's personal diagnosis came in high school and he knew, even at that point, that his diagnosis wouldn't prevent him from the activities he loves. His then-50-percent kidney function didn't stop him from skiing, backpacking or working full-time while pursuing his degrees, up to and including a doctorate in water resource economics and development. Still, he faced end-stage renal disease and later learned that focal segmental glomerulosclerosis, a disease that presents as scarring in the kidney, shut down his kidneys plus two transplanted kidneys – one donated by his wife, Andria. In 2006, he founded a small company that makes a home hemodialysis machine that he uses with his doctor's approval. Erich is a former senior project manager for Tetra Tech, an international engineering and construction management firm and was president/CEO of the Clinton River Watershed Council near Detroit, MI.

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## **Adam Doiron**

*Minneapolis, MN*



"Becoming a living donor doesn't stop someone from living a normal life." That's the message Adam Doiron wants others to know. He donated to his friend, Jenn, in November 2015. Adam also has undertaken the mission of donation, and the topic is very important to how he continues to live his life.

Doiron has competed in several marathons – and even an Ironman triathlon – since donating. Adam tells people that he has "indirectly" become healthier since donating. He believes that sharing his story will help others understand that donors are protected and given a stress-free path to donation.

Education is also important to Doiron. "Certain kidney diseases attack even healthy kidneys," he states. He stresses that it's critical to dedicate research and development funds to improving the lives of those with kidney disease beyond dialysis because being on dialysis should not be considered an acceptable way to live.

### **Christl Domina**

*Billings, MT*

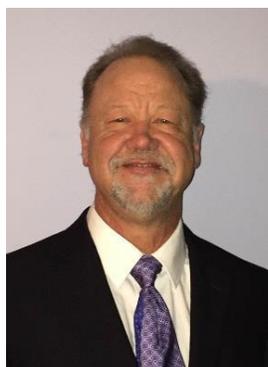


Christl Domina grew up in Idaho Falls, ID, but fell in love with the Big Sky Country while attending Montana State University. She was diagnosed with chronic kidney disease (CKD) due to lupus in 2007. After losing all kidney function, she started hemodialysis in late 2009, and later changed to peritoneal dialysis. Then after serious infections, Christl resumed hemodialysis upon her doctor's advice. After eight years and 28 surgeries, Christl remains on dialysis and has become a dedicated National Kidney Foundation volunteer. "When I received the invitation to join the Kidney Advocacy Committee, I jumped at the chance," she said. "I think it's an excellent opportunity to have my voice heard. Affordable healthcare and access for chronic kidney disease patients in rural areas and on reservations is very important to me. Early detection and prevention are crucial. If we can educate people about kidney disease, and their risk factors, we can reduce the rate of people going on dialysis." Christl, an animal lover with two cats and five birds, is married and has an adult.

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### **Derek Forfang**

*San Pablo, CA*



Derek Forfang, an end-stage renal disease (ESRD) patient since 1999, has undergone a kidney transplant, peritoneal dialysis and hemodialysis. His late grandfather, mother and father each had kidney disease. He is a member of the National Kidney Foundation's Kidney Advocacy Committee and Public Policy Committee and he is "grateful" to be selected for the Kidney Patient Summit. "I feel the issues and experiences we bring to the Hill are meaningful and support needed changes to protect and improve care for our kidney community in the U.S.," he said. He wants to share with his legislators why their help is needed and "what it's like in our shoes as a kidney patient." Derek is very active with HSAG ESRD Network #17 and The National Forum of ESRD Networks, which advocates for the organizations that monitor the quality of end-stage renal disease, dialysis and kidney transplant care in the U.S. and its territories. He chairs its Kidney Patient Advisory Council, which is just one of a handful of his leadership roles there. He also serves on the Patient Advisory Council of the Kidney Health Initiative.

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### **Alex Fox**

*Star, ID*



In October 2015, Alex Fox saw a Facebook post that would change his life. It was a picture of young Darienne, a girl with special needs whose mother wrote a heartfelt caption pleading for a kidney for her daughter. Alex, a husband and the father of a son with special needs, already had considered becoming a donor in prior years. Yet this time, with his son in mind, he eagerly answered the call, was tested and found to be a perfect match for Darienne, who received one of Alex's kidneys in May 2016. "It's been a huge success," Alex said. "Helping a stranger is pretty awesome. There are so many people out there that need a donor." Alex, former chairman of the board for Special Olympics Idaho, said he looks forward to advocating for future donors during the Kidney Patient Summit and beyond.

**Monica Fox**

*Flossmoor, IL*



In 2013, Monica Fox immediately became an advocate for kidney patients as she was diagnosed with kidney failure and immediately put on dialysis. For three years, she had to participate in hemodialysis until she received the gift of a kidney transplant. Because of this gift, Monica believes it is important to advocate for renal patients to improve outcomes as too many people are dying before they receive the life-saving transplant they require. Monica is glad she's been selected to participate in the Summit. She is grateful to the National Kidney Foundation and believes advocating for renal patients and transplant patients is something she is called to do. Monica wants to encourage representatives to be aware of the issues surrounding kidney disease and organ donation.

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**Cynthia M. Franklin**

*Fayetteville, NC*



Cynthia Franklin is an advocate. For more than 20 years, she dedicated her professional career mediating for displaced youth and worked with foster and adoptive parents to provide the necessary training and resources to help them succeed. She developed a mentor 24-hour hotline to support these parents and founded a parental training program to educate people to effectively parent minority children to ensure their safety and well-being. Not surprisingly, she continued her advocacy to support others who felt they didn't have a voice in their kidney health journey after her diagnosis, in December 2008, of end-stage renal disease due to polycystic kidney disease. She collaborated with her nephrologist to provide pre-dialysis information to patients to help alleviate fears. Franklin has been involved in several committees and councils such as the Southeastern ESRD Kidney Council and the ESRD National Coordinating Center, where she helped develop the mentor program for "Patients Helping Patients Learn about Kidney Care Choices." After receiving a kidney transplant in August 2015, Franklin remains actively involved with her previous dialysis center patients, providing current kidney and legislator information.

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## Ted R. Garding

*Eagan, MN*



In 2010, longtime medical supply business professional Ted R. Garding read an article on kidney donation. In that moment he knew it was his “calling” to give one of his kidneys to someone. Ted credits his parents providing him with “good health” and raising him with “good morals and values,” as the foundations for his immediate response to become a living kidney donor to a stranger. “I gave a kidney to a young man. That young man is now living a normal life and has quality to his life,” said Ted, who has since become a tireless National Kidney Foundation volunteer. “I know that the key to life is to ‘be kind to people, help those in need, and rewards will never cease to come,’” Ted said, citing a quote. It’s also important to note that being one of 11 children – six girls and five boys – taught Ted lifelong lessons about sharing and giving. He said he was very fortunate to have taken on caring for his ailing mother and father in the years preceding their deaths in 1999 and 2004, respectively. Ted notes that “being an advocate for the National Kidney Foundation and helping the people suffering with kidney disease brings me joy, and I will never stop.”

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## Patrick O. Gee, Sr., PhD

*North Chesterfield, VA*



National Kidney Foundation Kidney Advocacy Committee member Patrick Gee understands that repeated efforts are necessary to affect change in Washington, D.C. His dedication has taken him to Capitol Hill several times to meet with legislators and he strongly supports policies to improve healthcare and the quality of life for people who suffer from kidney disease. Patrick has end-stage renal disease and received a kidney transplant in April 2017. Prior to his transplant, he was a peritoneal dialysis patient since December 2013. He is a certified presenter for the foundation’s *Your Kidneys and You*, a vital public education talk, and has many leadership roles with other organizations within the kidney and healthcare communities. A recent ministry graduate, Patrick plans to create a church-based outreach program to visit his patient peers undergoing in-center hemodialysis to offer encouragement and support. In his spare time, he enjoys time with his grandchildren, listening to traditional jazz, reading non-fiction and assisting with authoring business plans.

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## Shannon Glynn

*St. Paul, MN*



Shannon Glynn is committed to having face-to-face conversations and dialogue to champion the issues central to the National Kidney Foundation mission. She received her life-saving kidney from her friend Molly in March of 2009 after being on peritoneal dialysis for seven months. And while Shannon thinks that petitions championing the issues are important, she wants to meet with representatives to discuss the concerns surrounding kidney issues today so that they can take action. Shannon believes that care and coverage are essential for transplant patients. Her personal message for representatives is that it is “critical to expand drug coverage beyond three years post-transplant.”

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## Sharon Goldhirsch

*Trevett, ME*



At 14, Sharon was told what her future was going to be like, and she said “no.” She was not going to accept that fate but was going to be a game changer. She had become ill with rheumatic fever, which left her with glomerular nephritis, a kidney disease. She was told there was no cure, the disease would advance to kidney failure, and she would need to go on dialysis or have a transplant by age 25. Sharon never went on dialysis and received a transplant from her husband long after that age. She started doing yoga 39 years ago to help improve her strength and energy while managing her kidney disease. As her disease advanced, her commitment grew. She became an instructor and has been teaching yoga for several years and is a certified health coach and therapist. Professionally, Sharon was an accounting and sales executive in several high-tech firms including Apple, IBM, and Hewlett Packard. She also owned her own voice/data cabling company, Dash Communications, in Denver. Sharon lives on an island on the coast of Maine with her husband, Doug, her son Rafael, and her toy poodle The General. Sharon is passionate about sharing her story with other kidney patients and families and educating people about early detection.

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## William Hahn

*Rockledge, FL*



William Hahn was diagnosed with diabetes at the age of 26, and exactly 26 years after that diagnosis, his kidneys failed. On New Year’s Day of 2009, William was given the gift of a new year – and a kidney-pancreas transplant. In his nine years post-transplant, he has drafted and advocated for legislation for the “gift of life” community, and regularly organizes fundraising events and health screenings for those in need. He has also written a book on the topic. William recognizes that he is not alone and appreciates the efforts of those who speak out and advocate for kidney donation legislation. He states that Florida District 8 Congressman, Bill Posey, “has been a very supportive part of outreach. He has co-sponsored all the legislation that will benefit patients, donors and recipients. He is a kidney warrior on the Hill and a member of the Kidney Board in Washington D.C.”

William wants to ask Posey and others to dedicate time, resources and their continued support in the ever-changing climate of the healthcare system.

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## Raymond Harris

Owings Mills, MD



"I just wanted to feel better. My family needed me and I didn't want to die," said Raymond Harris as he recalled the "dark, gloomy and lonely period" during which he said he felt worse than he ever had in his life. "My routine was no longer routine for me. This chronic kidney disease bully was barging in." It began in 1998. The physically active and enthusiastic father had just become a natural resources officer when doctor visits revealed suddenly that his kidneys were failing, he would require a transplant, and he needed to start dialysis right away to stay alive. Everything Raymond was hearing was unfamiliar and scary. He became a social hermit, avoiding family and friends. "My wife never gave up on me. She encouraged me not to hibernate from life," said Raymond, who later had two kidney transplants that lasted for eight years in total. Kidney disease returned in 2014, and he resumed dialysis. "This time, despite being told I would need a live donor, I refused to be bullied and just exist." He and his wife, Lauren, now "bully kidney disease" by getting as much education as possible, and, in turn, spreading awareness, promoting prevention, giving support and advocating for NKF.

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## Alexandra Harrison-Flaxman

Cambridge, MA



For people with chronic kidney disease, life can be like an obstacle course. It takes a great deal of persistence, skill and courage to overcome the complications. Alexandra Harrison-Flaxman embodies these traits. She was born with VATER Syndrome, a rare disease comes with many ailments, including chronic kidney disease. Because of her illness, Alexandra started dialysis when she was eight years old and received her first kidney transplant when she was 11. Her first transplant lasted until 2005 and then failed so she went back on dialysis. Her health was a rollercoaster during the next eight years and she attempted several times to get back on the transplant waiting list, but encountered numerous serious medical issues like high antibody levels and cancer. Finally in 2013, Alexandra received the call she had been waiting for and received her second transplant. The kidney was a perfect match, and although it didn't start working right away, it began to function. Now Alexandra is living free of dialysis. Because she experienced some unfortunate incidents on dialysis, such as medical teams not being patient-centric and false-alarm calls from transplant centers, Alexandra became motivated to take healthcare into her own hands to improve the lives of other kidney patients. She got involved with the National Kidney Foundation, both locally and on the national level, and has been attending the summit since 2014. She is pursuing a career in law with the end goal of lobbying Congress on renal issues. She has been able to remain strong and thanks to her loving and supportive family. This year Alexandra and "Nemo" (her kidney) will be celebrating their 5-year "Kidneyversary."

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**Charles N. Harvey Jr.**

*Lewes, DE*



Charles Harvey Jr., thinks it is very important to get the word out far and wide for people to consider becoming a donor. As a kidney transplant recipient in June 2014, Charles knows the impact of donation and wants to encourage others to consider how they can become a donor. Charles needed a transplant after he was diagnosed with membranous nephritis and the outer cells of his kidney slowly stopped performing. Because he was under a doctor's care, he was able to survive until he received a transplant from a very special donor – his wife. Charles believes kidney donation is a great thing and feels "wonderful" about life now that he has received a transplant.

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**Jessica Hood**

*Wilburton, OK*



"I was diagnosed with end-stage renal disease in 2009 out of the blue." Since then, Jessica Hood has received two kidney transplants as a result of her diagnosis - and she is grateful. She doesn't take her life for granted as she believes it is important to always make the best of her situation, no matter what it may be. Jessica is passionate about making a difference in the way kidney disease is viewed and wants to be a voice to bring about legislation that could benefit kidney patients. She believes that education and information can prevent someone from having to go through some of the hardships she's endured. She states that if her advocacy can help someone, it would make her feel like "everything that has happened to me, maybe happened for a reason." Jessica's personal message is that kidney disease needs more attention. She wants to increase awareness of warning signs and access to education and information.

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**Cynthia Infante**

*Laveen, AZ*



Arizona native Cynthia Infante is a two-time kidney transplant recipient. The first kidney she received as a young adult was from a deceased donor and lasted 20 years. The second gift came last summer from a living donor, her "loving and generous" cousin, Jacob. Cynthia was diagnosed with kidney disease at 15 and placed on hemodialysis at 19. She used the long hours of treatment to do homework in pursuit of a college degree in respiratory care she completed in 1997 before working at a local hospital. These experiences along with her positive outlook on life drive her to help others understand and cope with kidney disease while encouraging them to not give up hope. Family oriented and a lover of life, Cynthia enjoys vacationing – especially riding her bicycle along the Southern California coast. She and her husband of nearly 17 years, Domingo, have a teenage daughter, Hailey.

## Nichole Jefferson

*West Des Moines, IA*

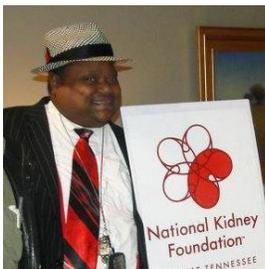


Sometimes kidney disease seems to come out of nowhere. In shock, people ask “Why?” and “How?” When this happened to Nichole Jefferson she set out to find answers and ways to stop this from happening to other people. Nichole always has been a personal healthcare advocate because she has asthma. Her life drastically changed in 2003 when she wound up in the emergency room with a sudden diagnosis of kidney failure. She immediately went on dialysis in the hospital and later alternated between peritoneal dialysis and hemodialysis. In 2008, Nichole received a kidney transplant from an unknown deceased donor. The cause of her kidney disease was never determined, but undiagnosed high blood pressure was suspected. Nichole realized that most people in her culture and community suffered from high blood pressure, unaware that it is a leading cause of kidney failure. This prompted her to seek out ways to educate others, so she volunteered with NKF in Dallas. When she moved to Des Moines for a job, she immediately volunteered with the local NKF. Nichole participated with NKF in the 2014 Kidney Patient Summit in Washington, DC, representing Iowa. She spoke with Members of Congress regarding the need for early detection of kidney disease. In 2015, Nichole was invited to join NKF’s Kidney Advocacy Committee. This is a way for her to “pay it forward” to her community.

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## Thomas Jones

*Memphis, TN*



Thomas Jones is in it for the long haul. The Memphis native has been on dialysis since 1993 and has refused to let kidney disease hold him back. When he’s not working toward his undergraduate degree at the National Business & Technology College, he’s busy advocating for dialysis patients with Kidney Care Partners and other organizations. “I have a strong desire to engage my counterparts in the renal industry in the local, state and federal government levels during the legislative process,” says Thomas. “I am very committed to advocacy.” Being on dialysis for so long, Thomas has accumulated invaluable experience that he puts to work benefitting his fellow kidney patients. “I’ve been on dialysis for 24 years and learn something new every day.”

## **Robin Kahn**

*Watertown, MA*



From Capitol Hill to Beacon Hill, Robin Kahn is on the job advocating for kidney patients and donors. And she backs up what she says—she’s a kidney donor. In 1986, when Robin was 12 years old, her mother received a diagnosis of kidney disease, the result of childhood diabetes. The nephrologist where they lived in Washington, DC, urged her parents to visit the University of Wisconsin in Madison and meet with one of two transplant surgeons in the U.S. performing kidney-pancreas transplants. Her mom was eventually accepted into the transplant program. In 1989 she received a kidney-pancreas transplant from a deceased donor. In 2001, her mom needed another kidney transplant and this time her father successfully donated. In 2012, at same the moment she learned that her mom’s second kidney transplant failed, Robin decided to be the next donor. The transplant was successful. Robin says if she could donate again, she would. She lives in the Boston area and is the director of education and teen engagement at a synagogue. She often speaks to Jewish groups about Judaism and live organ donation. She’s been active with NKF’s Kidney Action Committee for three years, regularly meeting with her representatives on Capitol Hill and Beacon Hill about kidney patients and live kidney donors. Her parents have been involved with NKF of the National Capital Area for the past 30 years.

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## **Angela Lattimore**

*Seneca, SC*



Angela Lattimore is a tremendously brave and caring person. When faced with the choice between her child’s life and the life of her kidneys, she chose the former. In 1999, Angela was diagnosed with kidney trauma during pregnancy. She also suffered from preeclampsia and toxemia. She was advised to terminate her pregnancy so her kidneys might be saved. She decided to have her baby. After delivering a healthy boy, it was determined Angela had end-stage renal disease (ESRD), and she was placed on dialysis in 2000. While dealing with and learning about ESRD, Angela decided to help other people. She started by becoming the village greeter at her clinic, then joined Dialysis Patients Citizens and National Kidney Foundation. She also became a subject matter expert on ESRD. She has been to her state capitol in South Carolina to lobby for Medigap coverage, as well as Washington D.C., 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.

**Kristie Lemmon**

*Anchorage, AK*



Kristie Lemmon has a deeply rooted connection to the work that is done by the National Kidney Foundation. Both of her parents died from kidney disease after years of dialysis and treatments, and her son was injured in an accident and lost both of his kidneys, endured peritoneal dialysis and received a kidney transplant when he was 10 years old. She also is a living kidney donor. Years ago, Kristie went to Washington D.C., to advocate for kidney disease patients and left feeling discouraged, but now she has hope as an advocate for the Fifth Annual Kidney Patient Summit. She wants to use this opportunity to communicate what she calls “the kidney message” with the Alaskan delegation in a manner they can hear and understand. Kristie’s personal request is that she’d like to see legislators sponsor and offer meaningful support to the Improvement in Research and Treatment Act of 2017 concerning chronic kidney disease and address comprehensive immunosuppressive drug coverage for kidney transplant patients.

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**Doris J. Lew**

*Oakland, CA*



Diagnosed with chronic kidney disease in 2013, Doris Lew first experienced peritoneal dialysis in 2015 and continued for a year before receiving a kidney transplant from a living donor in 2016. Through her experience with late diagnosis and subsequent dialysis and transplant, she became passionate about sharing her story. As a patient advocate, she wants to raise awareness about the importance of getting tested for chronic kidney disease, encourage legislators to fund research and programs and educate others about organ donation. Doris believes it is important for high-risk populations to have access to testing and care and wants to promote programs to work with physicians to test patients and provide health screenings. She thinks this should be top priority for legislators. “CKD kills more people than breast cancer and prostate cancer combined, yet 90% of patients go undiagnosed. This should not happen when early detection is easy, provides better outcomes for patients and is less-costly in the long run.” She also believes that early-detection and prevention costs will significantly and positively impact healthcare costs in America, as dialysis and treatment costs put too great of a burden on Medicare. Doris also wants to continue to spread the word on kidney-related issues so that others can be educated and opt-in to both living donation and posthumous organ-donation.

**Corinne Loftus**

*Chicago, IL*



Corinne Loftus knows what it's like to have a family member with kidney-related health issues. Corinne's mother has been battling kidney stones and cysts for decades. And, as the current Programs Associate at the National Kidney Foundation of Illinois, she also works closely with kidney disease patients. Because of her close connections, Corinne believes that kidney patients – along with everyone in the United States – need to have access to healthcare that is protected by our lawmakers. She is grateful to attend the Summit to support the National Kidney Foundation on their advocacy initiatives to ensure that strategies and methods to complete care are implemented in all locations. She wants to “show legislators the face of kidney disease and give our patients a voice.”

Her personal message to representatives is to keep in mind that the right to affordable, accessible healthcare is of vital importance to ensure the health of our nation.

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**Dolores A. McGrath**

*Raleigh, NC*



“Without warning of declining kidney function, my husband was diagnosed with end-stage renal disease (ESRD).” These words from Dolores McGrath show why she believes that time is running out for so many people, and she wants to help. Dolores has seen firsthand the damaging effects of ESRD and of chronic kidney disease (CKD). She has seen what the patient experiences and profoundly knows what it's like to be the home caregiver and care partner. As a Certified Health Education Specialist, Dolores understands the importance of professional support in addition to personal support. From a holistic perspective, Dolores wants to help people to not be so negatively impacted on a physical, emotional, social and financial level. She wants to encourage her local and national representatives to remove barriers that keep people from getting the proper care they need to treat and prevent

kidney-related illnesses.

## **Christopher Melz**

*Huntington Station, NY*



It was summer 2008 when Christopher Melz – a printing business owner and celebrated HipHop DJ – received word from a close childhood friend that he was battling end-stage renal failure and had begun dialysis. Christopher immediately contacted Stony Brook Hospital to ask about becoming a living donor for him. Christopher was a match. By spring, he underwent a successful surgery to remove one of his kidneys, which his friend received, prolonging his life. The experience also was life-changing and an “eye-opener” for Christopher who soon developed a relationship with the National Kidney Foundation by attending workshops and accepting every opportunity possible to speak about being a donor. He also continued what he called the “reward of giving” by becoming a registered nurse, inspired by the role this profession played in his own recovery. In April of 2017, Christopher accepted a position working at LiveOnNY in New York City, a non-profit organ and tissue procurement organization. As a member of the donor center, Christopher assesses patients to determine their viability for donation. He also speaks with donor families to discuss and fulfill the donation process of eligible tissue from the patients. Christopher, native of Huntington Station, NY, lives with his wife and two children.

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## **June Monroe**

*Las Vegas, NV*



June Monroe is a living kidney donor who gave to her younger brother, Brian, in March 2009. His kidneys failed when they were children, and their father donated a kidney to him in the 80s. June is a volunteer with the National Kidney Foundation and the Nevada Donor Network. She passionately believes that with the number of people waiting for a lifesaving kidney transplant, it is important to educate and encourage people to register as organ/tissue donors. She is a strong supporter of Nevada Governor Brian Sandoval’s recent legislation requiring Nevada high schools to provide organ and tissue donation information in educational programming for high school health and science classes. She wants the mission of the bill of “understanding the life-giving benefits of organ and tissue donation” and “conversations within families and communities, ultimately saving and healing more lives” to be realized. Her personal message to legislators is that it should be mandatory for all high schools across the nation to provide organ and tissue donation information in science and health classes. “As an educator myself, I believe that education is the key for advocating for kidney and organ/tissue donation.” Monroe also is an author of a children’s book, “A Little Yellow Cap.”

**Lynne Morin**

*North Andover, MA*



For most people affected, dealing with kidney disease is enough. Facing a combination of kidney disease *and* cancer is almost unbearable. Lynne Morin's incredible strength and courage have moved her past managing these terrible diseases to doing more—helping others. Lynne is a childhood cancer survivor living with chronic kidney disease. She also worked in the nonprofit health industry for 25 years. She was the director of survivorship for the American Cancer Society, New England, until 2003, then worked at the Leukemia & Lymphoma Society until 2015 before retiring. Lynne was diagnosed in 2011 with stage 4 chronic kidney disease and is waiting for a transplant. As an advocate, Lynne is a founding member of the Mass General Hospital (MGH) Cancer Center's Patient and Family Advisory Council and a member of the MGH Network for Patients and Families. Lynne co-chairs the Department of Public Health's Mass Comprehensive Cancer Control Network Survivorship Workgroup and is a member of the steering committee. She has testified and advocated for legislation related to access issues for cancer patients and other chronic health diseases. In 2016, she joined the NKF Kidney Advocacy Committee and serves as a liaison in Massachusetts.

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**Bill Murray**

*Wilmington, DE*



A diagnosis of end-stage renal disease (ESRD) forced Bill Murray to close his plumbing company business which he started in 1987. His retirement in 1996 was due to IgA nephropathy, an autoimmune and kidney disease that damages the glomeruli, the tiny filtering units inside the kidney where blood is cleaned. From the time of his diagnosis until 17 years later, Bill battled kidney disease while carefully following his doctor's orders. He went on peritoneal dialysis for 10 months but switched to home hemodialysis, because peritoneal dialysis was causing him to gain weight and increased his body-mass index above acceptable transplant levels. Finally, after many difficulties, Bill received his transplant. Bill didn't let anything stop him, however. His difficulties living with end-stage renal disease and his time spent patiently waiting for a transplant has led him to be a kidney activist, educator and tireless volunteer with the National Kidney Foundation and other kidney-focused organizations. He is a certified presenter for the Foundation's *Your Kidneys and You*, a vital public education talk. Bill also is involved in the Knights of Columbus and the Ancient Order of the Hibernians.

### **James W. Myers, III**

*Hammond, IN*



James W. Myers, III received a diagnosis of kidney disease in 1979 and in 2012, he began dialysis. This extraordinary length of time not only is a testament to his personal strength but indicates the amount of knowledge he has about the difficulties of managing this disease. James' personal experience ignited his passion for patient and donor support and education. He is a former trial attorney and college professor who taught law, political science, and English to undergraduate students at Westwood College and DeVry University, as well as graduate students at Keller Graduate School of Management. He became an advocate for and was honored by National Kidney Foundation of Indiana and belongs to several other kidney advocacy organizations. James has been to Washington D.C. three times, meeting with members of the House and Senate, and meets with representatives in Northwest Indiana. He has created online petitions for kidney legislation, drawing more than 50,000 signatures, and was given the Robert Felter Award by the Renal Network. In 2015, he was awarded the National Social Media Education & Advocacy Award by the American Association of Kidney Patients. In 2017 he was successful in getting the governor of the State of Indiana to sign a Proclamation for Living Kidney Donors Day. He is a blogger on kidney issues on more than a dozen sites and has been published in the Northwest Indiana Times, Post-Tribune and Chicago Sun Times. He runs the Kidney Stories page on Facebook, which has been called a "kidney information warehouse." In addition, James runs a dozen pages for kidney patients, belongs to more than 100 kidney patient groups, and is active on Twitter for kidney issues. He is very proud to be a Member of NKF's Kidney Advocacy Committee.

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### **Haley Newkirk**

*Evergreen, Colorado*



Ms. Newkirk is program evaluation analyst in child welfare with the City and County of Denver. Her work focuses on providing effective and efficient services to children and families in need. Haley went on dialysis at age 14 following sudden acute renal failure. Without an eligible living donor, Haley was blessed to receive a kidney from the U.S. national waiting list after only six months on dialysis. While the cause of her kidney failure remains unknown, her experiences on dialysis and post-transplant inspired her passion for promoting early detection, encouraging organ donation and preservation, and supporting extensive living donor protections to reduce dangerously long transplant wait times. Haley has been involved with the National Kidney Foundation (NKF) since 2015. Haley is a trained patient educator through NKF's Your Kidneys and You program and a patient mentor through the NKF Peers program.

### **Cynthia Nichols-Jackson**

*Belleville, MI*



Retired registered nurse Cynthia Nichols-Jackson has 30 years of experience working in the University of Michigan Health System and is passionate when it comes to teaching about kidney health. She is a program coordinator in patient services at NKF of Michigan, where she trains and educates peer mentors, coordinates an internship, recruits for the annual scholarship program, and organizes community health fairs. "I also am an African-American nurse working as an educator for kidney health. The prevalence of end-stage renal disease is highest in the African-American population" said Cynthia, who holds a Master of Science in Nursing. She also is a dedicated member of the NKF's Kidney Advocacy

Committee, attended the Kidney Patient Summit last year, and has continued to follow up with her elected officials to push NKF legislative priorities. Cynthia was diagnosed in 1986 with systemic lupus, which gradually led to kidney failure during an 18-year span. She began hemodialysis in 2004, and two years later, received a kidney from a girlfriend, a living donor. The transplant recently failed, however, and Cynthia has returned to home hemodialysis and to the kidney transplant waiting list. She and her husband have two adult sons and three grandsons.

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### **Jason A. Nothdurft**

*Clarksboro, NJ*



Jason Nothdurft knows his life's purpose and is passionately advocating for it on a daily basis. He states, "I donated my kidney to the step-father of one of my close friends on January 14, 2014. Since then, my life's purpose has been to advocate for organ transplantation and against kidney disease." Jason considers it a significant part of his life to have been chosen to participate in the National Kidney Foundation Patient Summit in Washington D.C. His education and close experience with the process serve as the foundation for his personal message to advance care for current patients. He also wants to pass this message along to his representatives. Jason believes it is important for all to work to expand the kidney

and transplant community in South Jersey and bring to the forefront the medical and educational resources available to help patients get efficient care and support.

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### **Dave Oberembt**

*Little Rock, AR*



In May of 2016, Dave Oberembt was diagnosed with stage 5 kidney disease and immediately started dialysis. His kidney failure is due to a rare disease called IgA Nephropathy, an autoimmune disorder that attacks the kidneys. After some time on dialysis, Dave received a second chance on life and received a donor kidney. After working two legislative sessions in Montana lobbying on behalf of higher education, Dave realized his passion was in politics and public policy. He spent the next eight years working on various political and policy efforts across the country; including congressional, senatorial, and presidential elections. Dave has his Bachelor of Arts in

Political Science and a Master of Higher Education, both from Montana State University. He currently works as Government Relations Director for the America Heart Association in Arkansas and married his wife Emory in 2014. They happily spend their time spoiling their two dogs.

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## **Devon Osborne**

*Hurst, TX*



Devon Osborne, a well-traveled and proud son of a WWII pilot, joined National Kidney Foundation's Kidney Advocacy Committee because he said, "it is uniquely suited to achieve the common goal of bettering the lives of kidney patients through legislation." He has visited Capitol Hill often to meet with legislators to lobby for others – and himself. Devon suffers from end-stage renal disease, was on dialysis for over nine years and recently received a kidney transplant. "During my process, there was so much I was unaware of when it came to treatment, and I feel there are so many patients like myself who are uninformed regarding what they should know and expect even before starting dialysis," said Devon, who writes a blog about his experiences. "My aim in life is to make a major, positive impact and

help improve the lives of kidney patients now and forever!" Devon said. "It's a slow process, however, I fully believe someday we will get the legislation we need. Now, let's get to work!"

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## **Andreas R. Price**

*Louisville, KY*



Andreas Price is a native of Kentucky and has dealt with Chronic Kidney Disease and end-stage renal disease for 35-plus years. He has personal experience with most of the options available for the treatment of ESRD, including all forms of dialysis and his transplant, which he received in 2008. After 16 years working in finance in the corporate arena, Andreas pursued full-time ministry work and now uses experience in organ and tissue donation/ transplantation and pastoral care in his role as a Family Support Liaison with the Kentucky Organ Donor Affiliates. He is also privileged to serve as Senior Pastor at the Oakland Missionary Baptist Church in Louisville, KY. Andreas is passionate about various organizations connected to kidney disease and transplantation and continues to be involved with the National Kidney Foundation Advocacy committee, patient summits and has served on the Board of Directors for NKF of Kentucky. Andreas wants to continue to build

awareness for kidney related issues, much like when he helped institute a "Donate Life" license plate in his home state, and when he traveled to communities with the Kentucky Organ Donor Affiliates to help educate about organ donation.

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## **Paul Rakoski**

*Newmarket, NH*



At 31, Paul Rakoski was diagnosed with a rare genetic lysosomal storage disorder known as Fabry Disease, which is inherited and affects about one in 117,000 people. In his quest to find out why his kidneys were failing, Paul became interested in helping other kidney patients. He is a volunteer for New England Donor Services and is a patient advocate for a pharmaceutical company working on bringing additional treatment options to market for patients with Fabry Disease.

A Massachusetts native who lives in New Hampshire, Paul received a Bachelor of Facilities and Plant Engineering degree from Massachusetts Maritime Academy and a Master of Business Administration from Franklin Pierce College. He works as a

program manager with the federal government. Paul also follows his passion to volunteer as an advocate for the American Society of Transplantation and the American Association of Kidney Patients. He has participated and medaled at The Transplant Games of America and the World Transplant Summer Games. He joined the Kidney Advocacy Committee in 2017 and is someone who is “working the problem” as he says, for himself and others.

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### **Bobbie Reed**

*Wexford, PA*



Bobbie Reed is on a mission – for her son and for the millions of others living with chronic kidney disease. A graduate of Indiana University of Pennsylvania with a Bachelor of Consumer Services degree, Bobbie is the office manager at her family's insurance business. The eldest of her two children, Alex, was graduating from Penn State with a degree in business administration and getting ready to join the family business when he became extremely ill with skyrocketing blood pressure. He was hospitalized for 14 days as baffled doctors tried to figure out what was happening. They never did, but they discovered that his kidney function had been badly damaged. He progressed to end-stage renal disease, began home hemodialysis and got on the kidney transplant waiting list. And then Bobbie stepped in. Through her efforts a living non-related donor came forward, and Alex received his life saving transplant. She wants to pay it forward by helping others with their struggles in dealing with kidney disease. Bobbie became active in the Kidney Health Initiative with the American Society of Nephrology. She also became a member of the American Association of Kidney Patients, contributed to the Academy of Science Engineering and Medicine workshop on Prescription Medications and currently sits on the Society to Improve Diagnosis in Medicine panel where she is a contributor to the Patients Improving Research in Diagnosis Project. As part of NKF's Kidney Advocacy Committee, she hopes to help her son and, in addition, use her experience to benefit the many others afflicted with kidney disease.

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### **David Rodriguez**

*San Antonio, TX*



When lobbying on behalf of kidney patients and organ donors, it's never “politics as usual” for David Rodriguez. As a kidney transplant recipient, he knows what's at stake. David serves as a patient advocate and spokesperson for organ, tissue and eye donation and leads 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 the National Kidney Foundation, American Association of Kidney Patients (AAKP), Texas Kidney Foundation, Texas Organ Sharing Alliance and University Health System. David has lobbied for the Foundation as a member of the Advocacy Committee in Washington, D.C. and the Texas State legislature on behalf of the Texas Kidney Foundation. He is currently a field ambassador and director-at-large board member for AAKP. Professionally, David works as a patient relationship specialist for the University Transplant Center in San Antonio, TX. He also has served in several leadership positions in local, state and national political campaigns.

## Judy Rosenstein

Edison, NJ



Judy Rosenstein made a “big ask” for her husband, Abe, and got back a miracle for an answer. Abe was diagnosed with end-stage renal disease and focal segmental glomerulosclerosis, a disease that causes scarring in the kidney. He was listed for a transplant five years ago. Abe is the only child of sole survivors of the Holocaust, and therefore, had no blood relatives. Judy became Abe’s advocate. With the help of social media, newspaper ads, flyers, and contacts to radio and television, a selfless donor came forth in 2016. Judy was a special education teacher in Brooklyn, NY at a large high school. She is no stranger to altruistic activities, having served as a union representative for many years and organizing many school-wide events for charities. She has been involved in several National Kidney Foundation Kidney Walks in New York City. Judy and Abe’s family are thrilled that Abe has been given a second chance at life, and support Judy’s efforts with the Kidney Advocacy Committee in the hope that others will be helped.

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## Leilah Sampson

Chicago, IL



Leilah has always known her passion for helping others and service was her purpose. During her freshmen year at college, she volunteered on President (then Senator) Barack Obama’s Presidential campaign and met the entire First Family at his first Iowa Caucus. Leilah then transferred to the historic Tuskegee University in Alabama where, at 19, she was diagnosed with FSGS and told the disease would progress to end-stage renal failure and she would need dialysis and ultimately, a kidney transplant. After years of denial, complications and seizures, she experienced severe anxiety and depression but decided she wasn’t going to let kidney disease win. Through meditation, yoga, work and volunteering, Leilah persevered and received her life-saving call on December 15, 2015 and recently completed her memoir. She is a patient editor of *Kidney Living Magazine* (NKF), a Peer Mentor (NKF) and a member of the Associate Board of the National Kidney Foundation of Illinois. Her mission is to improve patient compliance by sharing her story so the importance of mental health isn’t overlooked in renal patients.

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## **Chardae Sanders**

*Decatur, GA*



As a founder and advocate for kidney related health, Chardae Sanders has found her calling. In 2008, she was diagnosed with end-stage renal disease and began dialysis shortly after. Sanders received a kidney transplant in 2009; however, her transplanted kidney rejected, and she had to go back on dialysis in the summer of 2010. However, this set back did not stop her and she co-founded Kidney for Prima, LLC in May 2010 to help empower those affected by kidney disease and provide education to help prevent end-stage renal disease. Since her increased activity in her kidney advocacy campaign, she has been featured in articles on CNN and Al Jazeera America and uses her social media platforms to bring awareness to kidney disease. Sanders believes that being an advocate for the National Kidney

Foundation is a necessity to ensure that we are dedicated to the promotion of health and wellness, in addition to prevention and treatment of kidney disease. Sanders is a recent graduate of Kennesaw State University, where she held many community and communications related positions.

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## **Matthew Scroggy, PharmD**

*Columbus, OH*



Declaring he is “thankful for another chance at life,” Matthew Scroggy is celebrating six years since he received a kidney from his older sister, Sarah, a living donor. The native Ohioan was diagnosed with end-stage renal disease at age 22 in early 2009, his first year of pharmacy school, after having no previous signs, symptoms or family history of kidney disease. Yet, he was grateful to have the transplant barely six months after the illness “caught everyone off guard.” Since then, the avid runner competed in his first of three Transplant Games, ran 10 half marathons, and ran a 5K event just nine weeks after his transplant. Matthew, now a pharmacy manager, earned a Doctor of Pharmacy in 2012 preceded by a degree in chemical

engineering.

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## **David Seldner**

*San Antonio, TX*



David Seldner received a kidney transplant from his former exercise trainer, Ellen, in August 2013. Post-transplant, he joined the board of his local National Kidney Foundation office in 2013. While active in various areas, his principal interest is in community education, in which he educates people and encourages them to assess and advocate for their own kidney health. “Being able to share my personal knowledge of the transplant experience to corporations, local consulates, non-profits, YMCAs and others is especially gratifying,” Seldner said. He believes that so much of chronic kidney disease is not known to the public and it puts people in jeopardy with their health. Seldner earned his Masters of Public Administration from The American University and law degree from the University Of Toledo

College Of Law. He’s worked as a lobbyist and for corporations in the state regulatory and legislative areas, and as a development director for the Jewish Community Center and at the World War I Museum at Liberty Memorial. He also serves on several boards in the Kansas City area. He and his wife, Jeanne, look forward to deepening their involvement with the National Kidney Foundation.

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**Julie Siegel**

*St. Louis, MO*



Julie fights for people with kidney disease with the same passion she brings to legal cases at her firm. She received a diagnosis of chronic kidney disease in 1980 and had her first transplant in 1987 at age 16. During the next 12 years, she was able to complete high school, attend college, and graduate from Saint Louis University School of Law, earning her Juris Doctorate, cum laude. In 1999, her transplanted kidney began to lose function. She was again listed for a transplant, surviving on hemodialysis and peritoneal dialysis. She received her second transplant in 2001 and was privileged to meet Dean and Paula Henkel, the parents of her deceased donor. She then joined the board at NKF of Eastern Missouri and became chair of the Public Policy Committee. In addition to testifying in government, she helped establish the Take Action Committee (formerly called People Like Us). Julie was chosen in 2009 to be a keynote speaker for the United Network for Organ Sharing (UNOS) kidney committee open forum concerning the kidney allocation policy and specific changes that, since, have become practice. As a result of her speech, she was asked to join the board of directors for UNOS, and, upon finishing her term, she joined NKF's Kidney Advocacy Committee.

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**Mary Ann Starick**

*Cleveland, OH*



After a diagnosis of IgA nephropathy in 2008 and years of peritoneal dialysis and treatment, Mary Ann Starick received a kidney transplant in June 2015 from a living-donor – her generous sister, Mary. Mary Ann is devoted to continuing to educate legislators about kidney disease. She wants to promote legislation to increase organ donation, advocate for early detection of chronic kidney disease and support increased federal funding for kidney disease research and other programs. She'd also love to see extended immunosuppressive coverage beyond the 36-month, post-transplant limit to help patients maintain their transplanted kidneys. Mary Ann also is a wife and mother of two adult children. She works part-time since her transplant. She says her dog – a large lab – has helped her stay active during her dialysis and post-transplant.

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**Jack Tomlin, III**

*Alexandria, LA*



"Home hemodialysis allows my family and me to lead a more normal life," Jack Tomlin said. Jack inherited the gene for polycystic kidney disease from his father and started home hemodialysis in 2012. His wife, Patty, helps him manage his care. Jack wants to advocate for governmental involvement to help people get care earlier for chronic kidney disease and other kidney related medical issues. He believes that earlier care could help prevent or lessen the severity of some of the related issues that go along with kidney issues, such as high blood pressure and diabetes. Jack and his wife are thankful to be involved with the Kidney Patient Summit and plan to pass along first-hand knowledge both at the conference, and upon their return.

## Patricia Tomlin

Alexandria, LA

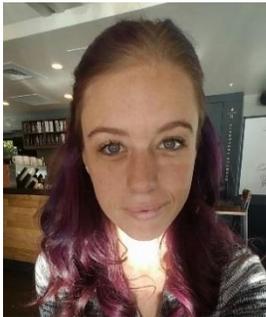


Patricia Tomlin believes that “life is given to be lived to the fullest.” She and her husband are doing just that. Tomlin is a care partner to her husband who is on dialysis due to polycystic kidney disease, an inherited disorder in which clusters of cysts develop and cause kidneys to enlarge and lose function over time. She helps him do home hemodialysis three times per week, and they are both passionate about the benefits of hemodialysis. Tomlin and her husband are looking forward to sharing their thoughts and experiences with their local representatives as part of the summit. Tomlin is grateful for hemodialysis and believes that the option of doing dialysis at home allows her and her husband to have comfort and peace in the sanctuary for care and healing. “Without dialysis, there is no life for us.”

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## Melissa Tuff

Cape Coral, FL



Melissa Tuff was a “drop-out” who “dropped back in” when she was challenged by kidney disease. She was just turning 17 when she was diagnosed with rapidly progressive glomerulonephritis and began a nine-year journey on kidney dialysis before finally receiving a kidney transplant. While she was on dialysis, Melissa, who had dropped out of high school in the ninth grade, decided to get a high school equivalency diploma. She then continued to college and graduated with Associate of Applied Science (*magna cum laude*) and Bachelor of Health Service Administration degrees, all while working full-time and serving as a peer mentor and patient representative for her dialysis unit. These days, she manages her own personal consulting business and online craft store while studying to become a counselor. A big multitasker, she also creates organ donation awareness accessories, advocates for patients, and volunteers for Meals on Wheels. She has been an active NKF Peers patient mentor since the beginning of the program and has participated in more than 15 NKF Kidney Walks. Today, Melissa needs a second kidney transplant, but like before, she’s answering the challenge with action. She has established her own website to spread organ donation awareness and hopes to start a nonprofit organization to assist her peers with transplantation costs. She’s probably heard this before, but Melissa *Tuff* has made a great comeback from some *tough* times.

**Curtis Warfield**

*Indianapolis, IN*



In 2005, Curtis Warfield had a kidney biopsy after a routine checkup found protein in his urine. After four months of treatment, doctors gave the all-clear but warned something worse still could develop. In 2012, he was diagnosed with stage 3 kidney disease and soon began peritoneal dialysis. His daughter was excluded as a suitable donor, but her college roommate and sorority sister decided to get tested “just because” she wanted to help. She was a match – and Curtis entered 2016 with a new kidney. That spring, his young donor graduated with a master’s degree in public health. Since being given the gift of life, Curtis has become a passionate

National Kidney Foundation volunteer and advocate for kidney disease awareness and organ donation. He has provided counseling to patients with end-stage renal failure and those on the transplant waiting list. With a master’s degree in management, Curtis is a senior quality analyst for the State of Indiana. He is active in his church and community, has been married for more than 30 years, and has four children, a daughter-in-law and one grandchild.

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**Brandy Webster**

*Sandy, Utah*



At age 14, Brandy was diagnosed with IgA Nephropathy, an autoimmune and kidney disease that damages the glomeruli, the tiny filtering units inside the kidney where blood is cleaned. A biopsy revealed the disease soon after she visited the emergency room for an unrelated reason. For years, Brandy avoided any major health crises. Recently, however, Brandy’s estimated glomerular filtration rate (eGFR), which doctors monitor to assess kidney function, worsened and she was told she needed a kidney transplant. In October of 2017, Brandy received a kidney transplant from her wife, Lyndzie. Both are doing well, and they are looking forward

to all the future holds!

## David White

*Hillcrest Heights, MD*



David M. (Dave) White is a healthcare consultant with expertise in patient-centered care, patient engagement and kidney-disease awareness and prevention. As a grateful kidney transplant recipient and a veteran of in-center dialysis (nocturnal and peritoneal), Dave's mission is to promote health through advocacy. He serves on the boards of directors of the American Association of Kidney Patients, the Kidney Health Initiative, and the Veterans Transplantation Association and chairs the Kidney Health Initiative Patient and Family Partnership Council. He also co-chairs the Patient-Centered Outcomes Research Institute's Advisory Panel on Patient Engagement.

Dave's advocacy doesn't stop with the Boards on which he serves. He is a member of the American Society of Transplantation Transplant Community Advisory Council, the End Stage Renal Disease National Coordinating Center Health Services Advisory Group, the National Kidney Foundation Kidney Advocacy Committee, and the Quality Insights Mid-Atlantic Renal Coalition Patient Advisory Committee. He enjoys public speaking, writing and exercise, and has made regional and national television appearances as a patient advocate. A United States Army veteran, Dave lives in Hillcrest Heights, Maryland, with his wife and "hero," Hilva.

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