

# **AAKP** **RENALIFE**

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March 2019



## **COVER STORY:** **National Kidney Month** **Patient Profiles**

### **INNOVATOR SERIES:** **Dr. Robert Star**

### **The Mediterranean Diet:** **A Must-Have for 2019**

### **Special Feature:** **Medal of Excellence Honorees**



*A Publication of the American Association of Kidney Patients*



# **AAKP** **RENALIFE**

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American Association of Kidney Patients, Inc.  
14440 Bruce B. Downs Blvd., Tampa, FL 33613  
(813) 636-8100 • (800) 749-AAKP

Visit our Website [www.aakp.org](http://www.aakp.org) • [info@aakp.org](mailto:info@aakp.org)  
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Understanding kidney disease is a critical first step to improving your health. The American Association of Kidney Patients is the leader in kidney patient centered education. For 50 years, AAKP has provided patients and families the educational tools they need to understand kidney disease and take a more active and informed role in their health care.

Our efforts across the country to speak on behalf of patients and their families have improved their lives and well-being - benefiting all of America's kidney patients. Building communities among kidney patients and their families, health care professionals, and other support groups is an important goal of AAKP.

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The Independent Voice of Kidney Patients Since 1969™



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*By Jennifer Rose Parker, RDN, CSR, LDN*

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Get to know the 2019 AAKP Medal of Excellence award honorees! This program recognizes healthcare professionals who have made impactful contributions over the course of their career. This prestigious award is AAKP's highest honor for kidney healthcare professionals in categories including Physician, Transplant Surgeon, Transplant Professional, Nursing, Social Work, Dietetics and Dialysis Technician.

# MESSAGE FROM AAKP



*HHS Secretary Azar listens as AAKP President Richard Knight and Chair of Policy & Global Affairs Paul T. Conway discuss patient care choice and HHS efforts to improve kidney care. Secretary Azar has a father who lived on dialysis and was transplanted three years ago.*

Dear Friends and Allies!

I hope your winter season is finding you in good cheer – here in the Washington, D.C. area we are in the midst of our typical random snow and ice – but spring and the annual Cherry Blossom Festival are already on the horizon.

In celebration of [National Kidney Month](#), in this issue of *aakpRENALIFE* you will find several terrific articles. First, there is a nice piece on the professionals AAKP selected for the 2019 Medal of Excellence. This award program is distinct within the kidney community since they are the only awards presented to healthcare professionals by the largest independent patient organization in America – AAKP! The award symbolizes what no other group in America can say – these individuals meet the highest standard of excellence, as DEFINED by patients.

This year, as an extension of the AAKP National Strategy which includes the active promotion of policies that draw greater attention to, access to and use of pre-emptive transplantation as a treatment, we expanded our Medal of Excellence to recognize transplant professionals. You will read about Dr. Sherilyn Gordon,

recognized posthumously, of the American Society of Transplant Surgeons (ASTS) and Dr. Ronald Gill of the American Society of Transplantation (AST).

In our Innovator Series, you will read about an outstanding medical professional and public servant – Dr. Robert Star of the National Institutes of Health/ National Institute of Diabetes and Digestive and Kidney Diseases (NIH/NIDDK). Dr. Star, a recipient of the 2018 AAKP U.S. Public Servant Award, leads one of the most ground-breaking initiatives in kidney disease that your Federal government has undertaken in over a decade, the Kidney Precision Medicine Project (KPMP). The KPMP is hard science – and focused on the genetic underpinnings of kidney disease and unlocks the power of individualized medicine to begin what many believe will be a new generation of treatments. Central to this entire scientific endeavor are kidney patients and they have been involved since day one shaping consent agreements, protocols to protect patients and other aspects of KPMP. AAKP has been involved since the beginning of KPMP and I have had the pleasure of serving on the Community Engagement Committee to ensure patients

have an active and ongoing impact on the initiative. Former AAKP President, Paul T. Conway, currently serves on the External Evaluation Panel to monitor progress and ethics of this project.

Additionally, you will read about courageous fellow patients. I hope you are as inspired as I am when you read their profiles. They are just like you and together our daily lives send a powerful message to friends, families and policy-makers. That message is simple – kidney disease impacts people from all walks of life and all beliefs – but we are strong, we persevere, and we are committed to the ideal of serving others who too have been impacted by this disease.

Nationally, AAKP continues to have a significant impact as we channel your voice through far more sophisticated advocacy tools and under the expert work of our professional team. Diana Clynes, AAKP Executive Director, executed the AAKP National Strategy so well in 2018 that we broke all previous metrics and records for in-person and online advocacy and engagement. And, thanks to our active patient members, our 2019 performance metrics are running ahead of last year! AAKP conducted over 600 meetings on Capitol Hill and



across the Executive Branch last year alone – as well as highly sophisticated and highly targeted educational campaigns among key lawmakers that involved YOUR phone calls, YOUR letters and YOUR posts on their individual social media pages. On social media, we have more fans, more shares and more likes than ever before – but while that matters, the more important point is who follows AAKP on social media? The answer, as we have found, are key elected and appointed officials - along with their staffs - interested in kidney diseases and related conditions along with thousands of patients!

In 2018, AAKP patients and our kidney allies played a significant role in educating Congress on the importance of defeating – for the third year in a row – the highly controversial Dialysis PATIENTS Demonstration Act (DPDA). This bill, written by large corporate dialysis lobbyists, would have placed dialysis corporations in control of your healthcare, including access to kidney transplantation. The bill would have forced you into a care plan without your consent, and then given you a very limited time to “opt-out” of the plan if you no longer wanted to participate. AAKP vigorously OPPOSED any legislation that would deny patients and their caregivers true consumer choice in their own care – and we will continue to do so. Not surprisingly, when the bill was first proposed to Congress, dialysis lobbyists told lawmakers that it was not controversial

among patients, despite the fact AAKP had warned that was not accurate. After thousands of calls, letters and hundreds of thousands of targeted social media exchanges from kidney patients and caregivers like you, the Dialysis PATIENTS Demonstration Act failed to pass in Congress. AAKP will continue to monitor this legislation and other bills that promise patient-centered care but, in reality, treat the patients as a secondary concern to special interests. As a part of our 50th Anniversary, AAKP will be conducting multiple non-partisan voter registration drives, similar to our “I am a Kidney Voter” campaign hosted in 2018. AAKP is highly effective at raising your independent patient voice and we know that we are equally effective at mobilizing patients like you to register and exercise your right to vote for laws and lawmakers that protect full consumer choice. Our recent social media voter registration efforts on President’s Day weekend produced stunning results. Thank you, your family and your friends for registering and becoming KIDNEY VOTERS.

Looking ahead, please mark your calendars and plan to join us! Follow AAKP on social media (Facebook: **@kidneypatient** and Twitter/Instagram: **@kidneypatients**) visit **www.AAKP.org**, or call us at **800-749-2257** for more information on these important events. During our 50th Anniversary Celebration, AAKP is FULLY committed to our legacy

of educating patients, caregivers and policy-makers on the issues that are impacting our lives and our ability to achieve our dreams and aspirations.

AAKP is hosting a number of major events in Washington, D.C. through the year; plan to join us for all or some!

- **Global Summit on Innovations in Patient-Centered Kidney Care** - event in partnership with George Washington University School of Medicine & Health Sciences (May 21-23). Learn more: [www.aakp.org/global-summit](http://www.aakp.org/global-summit)
- **Second Annual AAKP Policy Summit** (June 19-20). Learn more: [www.aakp.org/public-policy-summit](http://www.aakp.org/public-policy-summit)
- **44th Annual AAKP National Patient Meeting: Driving Innovation & Changing the Status Quo** (September 6-8). Learn more: [www.aakp.org/national-patient-meeting](http://www.aakp.org/national-patient-meeting)

Please enjoy this issue of *aakpRENALIFE* – and make certain that you encourage your family and friends to follow us on social media for great educational updates!



Richard Knight,  
President of AAKP



# Patient Profile: National Kidney Month

By Deborah Pelaez, AAKP Marketing and Communications Manager



*In honor of National Kidney Month, AAKP is sharing stories from patients, a caregiver and a healthcare professional on their unique outlook on life and kidney disease awareness.*

*You can help spread the word about kidney disease this month by sharing your personal story and perspective with friends, family and the kidney community – kidney disease is a silent killer – let's end the silence.*



**David Rodríguez**  
*Transplant Recipient*

David was at the peak of his career as a legal assistant investigator in Austin, Texas when his life took

a drastic turn. At the young age of 36, David was diagnosed with kidney failure. The contributing factor leading to his diagnosis was high blood pressure; an ailment David mentioned is hereditary in his family. David knew his next steps would be difficult but necessary. He moved back home with family in Brownsville, Texas to begin dialysis treatment.

David was not aware at the time that high blood pressure could cause devastating effects. He took every opportunity during each of his treatments to learn about the disease. His eagerness and newly developed knowledge led him to become an advocate for others experiencing kidney failure, such as his father, who also underwent dialysis treatment at the same time as his youngest son.

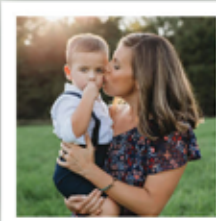
David frequently drove 300 miles to University Transplant Center (UTC) in San Antonio, Texas to attend support groups. He also sat in the clinic lobby building relationships with patients and caregivers going through the same emotionally challenging journey. His visits to the hospital proved beneficial as he followed all requirements and was added to the transplant wait list. David knew the importance of compliance and continued to go above and beyond for nearly three years before another life-changing moment.

David received a call in 2011 informing him an altruistic living donor had come forward. Thanks to

the Living Donor Exchange Program at UTC, David was an identical match to receive a kidney from a gentleman involved in a donor chain started by this Good Samaritan. The chain was made up of three people he never met. David's transplant was made possible by a generous stranger. As excited as David was to hear there was a donor for him, he was humbly intrigued to learn about the multiple lives saved through the living donor exchange, something he had never heard of before.

David is currently the Patient Relationship Specialist at UTC. He dedicates all his work in his career and advocacy role in memory of his late father. This year, for National Kidney Month, David wants to focus on raising awareness about kidney disease, diabetes and high blood pressure. Early detection is key in the prevention of kidney disease. David will also continue to educate families on living donation.

Kidney disease is a silent killer, and David hopes to help save lives by not being silent about the disease.

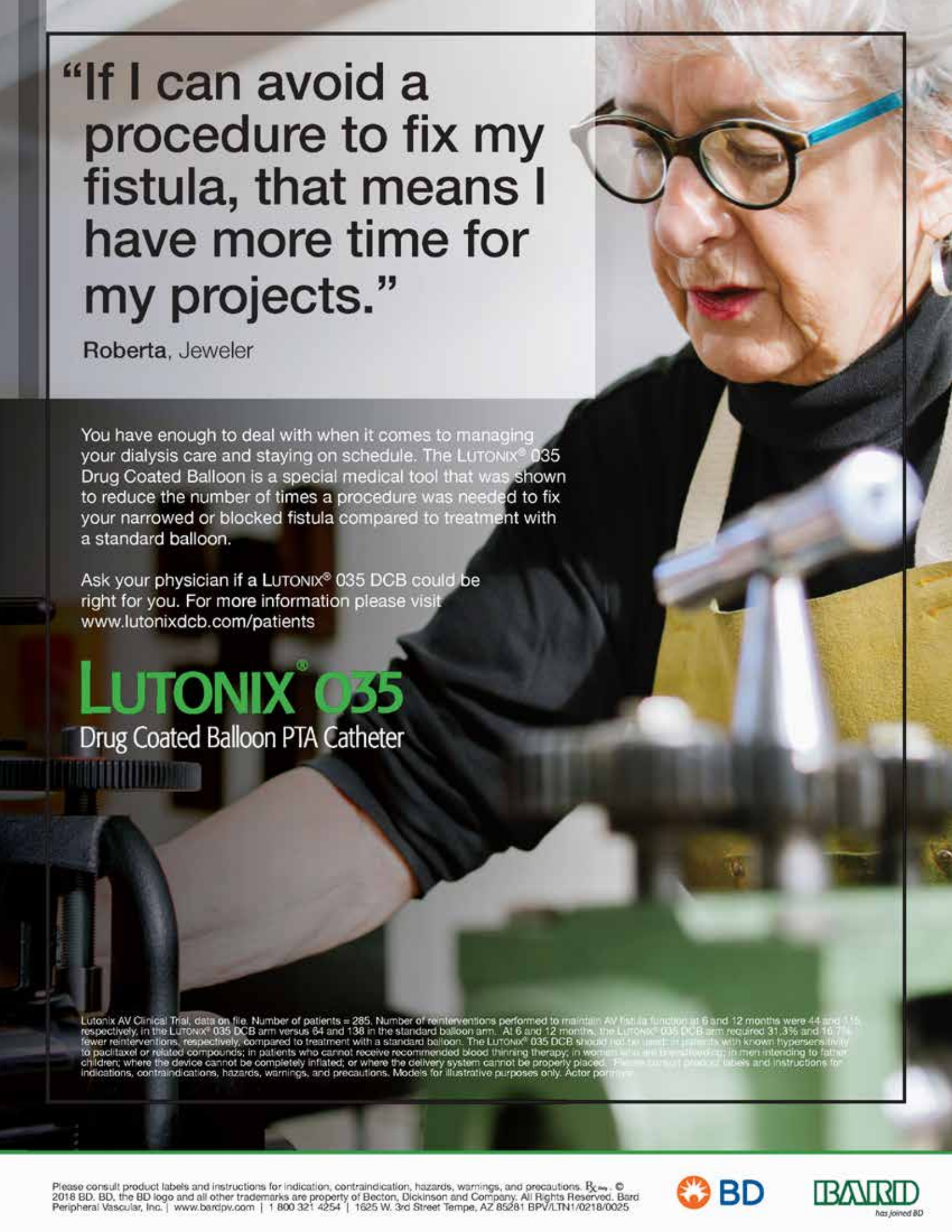


**Katie Bain**  
*Caregiver to her son Kellan, pediatric CKD patient with Atypical Hemolytic Uremic Syndrome (non-genetic)*

Katie's son Kellan was just seven months old when he contracted a virus that would change his life forever. He was in and out of the hospital for an entire summer. Then in August 2016, at just 10 months old, Kellan had a kidney biopsy and was diagnosed with stage 4 Chronic Kidney Disease. A rare viral

*Cover Story continued on page 8*





**“If I can avoid a procedure to fix my fistula, that means I have more time for my projects.”**

Roberta, Jeweler

You have enough to deal with when it comes to managing your dialysis care and staying on schedule. The LUTONIX® 035 Drug Coated Balloon is a special medical tool that was shown to reduce the number of times a procedure was needed to fix your narrowed or blocked fistula compared to treatment with a standard balloon.

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Lutonix AV Clinical Trial, data on file. Number of patients = 285. Number of reinterventions performed to maintain AV fistula function at 6 and 12 months were 44 and 115, respectively, in the LUTONIX® 035 DCB arm versus 64 and 138 in the standard balloon arm. At 6 and 12 months, the LUTONIX® 035 DCB arm required 31.3% and 16.7% fewer reinterventions, respectively, compared to treatment with a standard balloon. The LUTONIX® 035 DCB should not be used in patients with known hypersensitivity to paclitaxel or related compounds; in patients who cannot receive recommended blood thinning therapy; in women who are breastfeeding; in men intending to father children; where the device cannot be completely inflated; or where the delivery system cannot be properly placed. Please consult product labels and instructions for indications, contraindications, hazards, warnings, and precautions. Models for illustrative purposes only. Actor portrait.



induced disorder, called Atypical Hemolytic Uremic Syndrome, had caused kidney damage.

Katie says that Kellan's diagnosis was life changing. She has now adapted to having kidney disease as part of her world and this life is her new norm. Even though she is a nurse by trade, she had no idea how much the kidney controls – Kellan's feeding, blood pressure, heart, growth, speech, etc. have all been affected. Katie says she can't just leave the house for a few hours – every aspect of any small outing needs to be planned out. Kellan has a port that is used for medication infusions, he takes multiple blood pressure medications and he also uses a feeding tube. The Bain Family recently took a vacation to Clearwater Beach. Katie says that she was amazed by the amount of planning that was involved into just getting permission to have medical supplies on an airplane.

Katie is also wife and a mother to Logan and her step-daughter Hannah, Kellan's older siblings. She says that older brother Logan, who is eight years old now, was just five years old when Kellan was in the hospital a lot and it was difficult being away for extended periods. As Katie has adapted, so has the entire Bain family. Logan is a caring brother and will often offer to help with Kellan's G tube feeds.

In honor of National Kidney Month, Katie wants other caregivers to know that it will get better. She encourages other caregivers to find out all the resources that are available, and to not be afraid to reach out and use them. She also says that it is ok, not to be ok. You will have down times – Katie says she certainly does, but the important part is to remember to pick yourself up because life will get easier. Katie says she speaks to many groups in Iowa where she lives and offers to be a resource for other caregivers because she knows how tough it can be.

Katie's favorite quote that she often shares is: You never know how strong you are until being strong is the only choice you have.

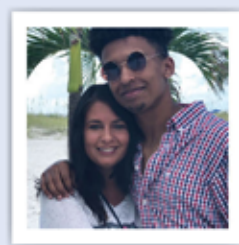


**Rebecca Schmidt, DO, FACP, FASN**  
*Physician*

Dr. Rebecca Schmidt takes care of kidney patients throughout the care continuum from those with early chronic kidney disease to

those with kidney failure, such as patients on dialysis and in need of a kidney transplant. She works in multiple clinics across North-Central West Virginia, including hemodialysis clinics, and she also does telemedicine. She has worked with kidney patients for over 25 years. She chose Nephrology as a career because it was an area where she thought she could make an impact. She wanted a career that would allow her to care for patients with chronic illness, with whom she could build a relationship. She loves that her job allows her to be sensitive and show kindness to patients – she says that “sometimes kindness is all one can give to be helpful to patients.”

For Dr. Schmidt, National Kidney Month provides a special opportunity to highlight the growing prevalence of kidney disease. She says that kidney disease can often get overlooked because it does not have the “glamor” of cancer or heart diseases – people don't really understand kidney disease. This is the month to really highlight how much this disease impacts the daily lives and aspirations of patients and their families. She hopes that increased awareness will in turn lead to better opportunities for patients as well as funding for research and innovation.



**Tessa Byars**

*CKD patient, non-dialysis with primary idiopathic FSGS*

Tessa found out she had a high amount of protein in her urine during a routine exam when she

was 18 years old and pregnant with her son. What should have been a joyous time turned into a worry-filled, rough nine months with weekly doctor visits, monthly ultrasounds, two hospitalizations and new medications to help control protein, blood pressure, contractions and more. Her world was shaken and she had to quickly learn how to become her own advocate, researching her disease and learning how to live as healthy as possible.

Tessa gave birth to a healthy baby boy! Soon after recovering from pregnancy, she had a kidney biopsy and started aggressive treatment including high dose steroids and more potent medication for blood pressure and cholesterol.

She feels lucky that her kidney disease was caught before she reached kidney failure. Over the years, her



disease has stabilized. Tessa wants to share this to others in honor of National Kidney Month:

- You have to have faith that it will work out.
- Count your blessings- you are still here and so am I.
- Know your body and what's going on with it and your treatment. People make mistakes...and you know your body better than anyone. If you feel something is off, it probably is. Get second opinions if needed...educate yourself.
- Do your part in maintaining a healthy life.
- Connect with doctors that are knowledgeable in the treatment of your disease.
- Connect with other people going through (or who have gone through) similar situations. Share your story as you may be the person to provide hope for others.

Most importantly: Don't Give Up! This may be a bad chapter, but it's not the entire book.



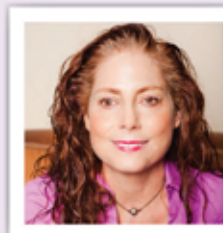
### Scott Burton

*Peritoneal Dialysis (1996-1999), Deceased Donor Transplant (1999-2003), In-Center Hemodialysis (2003-2018), Currently on Home Hemodialysis*

"Having battled kidney disease since birth, I think the biggest thing that I would like people to know, is everything. For something that affects such a broad and diverse demographic, with so many comorbidities that go along with kidney disease, I feel that the general public is at a disservice, not having more light shed on kidney disease, especially with high blood pressure and diabetes both becoming growing epidemics in America, and the two leading causes of kidney disease. We as a society are in a perfect place to slow the progression by raising awareness and educating the masses.

Kidney disease hasn't so much changed my life, as it just "is" my life, being born with posterior urethral valve blockage and not expected to make it two days, it has just been a part of life. I always knew I would end up on dialysis and needing a transplant, it was never if, just when, and even with my kidneys lasting 10 years longer than expected, it was looming over me

for as long as I can recall. So, I would say it's changed my life, but it has added to how I see the world around me and I have developed an appreciation for every single moment. I learned so early the reality of mortality, and with that understanding. I realized the importance of the impact you leave behind on the world and I strive to live each day better than the previous. It developed me into an open book, wearing my heart on my sleeve and letting it bleed out daily in my poetry and art. I became fascinated with the world and the people around me, and their stories and became a quiet observer, as I took everything in. This also made me realize my own dreams and passions, and the value of finding that which truly makes you feel alive, and chasing it, even when the cards are stacked against you and you're constantly told what you "can't do" or is "impossible." With this, I have set out on paths that do, in some way, seem impossible and are discouraging at times but, I am unable to give up, or back down. And thus, the journey continues, as I remain with a million dreams in my head, some, seemingly impossible... but are they really, though?"



### Maile Robb

*Currently In-center Hemodialysis Patient, 24 years (3 years, transplant patient)*

Diagnosed in 1994 with end-stage renal disease, Maile's family came together to support her immediately. Both her father, and her sister, donated a kidney to her. Unfortunately, at the time, no one knew that the Atypical Hemolytic Uremic Syndrome would come back and destroy the transplants. Luckily today, there is a new medication being used to keep patients with this rare disease in remission. In fact, Maile's sister, with the same disease, will celebrate her 5 year transplant anniversary next month.

For Maile, kidney disease is about being grateful. She is grateful for all the people in her life. She is grateful for the last 24 years and all the love, generosity and hope that she has received.

She feels it is both her honor, and obligation to give back to the kidney community, especially during National Kidney Month. 🌸



# AAKP Innovator Series:

## Dr. Robert Star

Robert A. Star, M.D., is the director of the Division of Kidney, Urologic, and Hematologic Diseases at the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), part of the National Institutes of Health (NIH). *aakpRENALIFE* interviewed Dr. Star to learn more about his career and NIDDK's current kidney-related research projects:

**As the leader of a major Federal government program at the National Institutes of Health, you serve America and our fellow citizens as a U.S. civil servant. Can you describe why you chose to serve our country as a public servant?**

I am proud to work at the NIDDK, where I am part of a team that values both innovation and altruism. These priorities allow us to – on a large scale – contribute to treating and curing diseases that have a profound impact on so many people's lives. I enjoy taking what I learned in academia, including struggles with drug development and clinical trials, to make it easier for others to move their research projects forward. Unlike academia, we can create programs that affect everyone in the United States. We also devise programs to train and mentor younger scientists, who are the future of nephrology.

**AAKP patients and leadership are honored to play a role in several NIH/NIDDK strategic research initiatives, including the Kidney Precision Medicine Project (KPMP). For our readers who are not familiar with KPMP, can you describe the vision and purpose?**

The KPMP, focused on finding new ways to treat acute and chronic kidney diseases, was established in 2017 to build the science to enable clinicians to deliver the right treatment to the right patient at the right time. We aim to answer key precision medicine questions for patients: What is my diagnosis? What is my prognosis, and which treatments can help me?

Recent advances in multi-scale interrogation of human tissue and single cells have now allowed precision medicine to be used in kidney disease. KPMP will obtain kidney tissue (biopsies) from people volunteering to participate in KPMP. The tissue will be analyzed to redefine kidney disease into new molecular subgroups. We will also identify critical cells, pathways, and targets for novel therapies. Specifically, the KPMP aims to develop or facilitate:

- A set of cellular and molecular markers that classify cells as healthy, injured, activated, or undergoing repair.
- A kidney tissue atlas, which is a set of maps used to classify and locate different kidney cells and areas between the cells. The atlas will help researchers and clinicians define disease subgroups and identify cells, pathways, and targets for novel therapies.
- Molecular pathways developed using data to identify and understand healthy and disease pathways that are activated in a particular cell type in a particular subgroup of participants.



- Disease subgroups to define participant subgroups and allow for clinical stratification into distinct subgroups that might respond differently to individualized therapy.

The final result we envision is personalized medicine for kidney disease, where each patient is treated with drug(s) chosen based on the results of their kidney biopsy.

### **Can you discuss the importance that you and your team place on patient perspective and input within the KPMP process?**

Incorporating the patient perspective and patient input has been absolutely critical. Because KPMP involves research biopsies that are not clinically needed, we wanted to put ethics and patient safety first – while maintaining our focus on improving care for future generations.

For example, the Community Engagement Working Group (CEWG) wrote the first draft of the informed consent document. They also pushed for insurance, so that the enrolled subjects will not need to pay for any medical complications that might arise from the biopsies. And we appreciate that the CEWG has kept the research grants of the consortium on track, helping to ensure that we aim for our 10-year goal.

From the first KPMP Steering Committee meeting, patient participants have had a substantial presence. They contributed their insights regarding study protocol design, activities, ethical questions, and data analyses. The CEWG has also partnered with researchers to determine how best to return results of biological profiling in an ethical, culturally-sensitive manner, and to develop materials to explain the study to fellow patients.

Notably, the CEWG has increased investigator appreciation of patients' contributions. One researcher noted he would never again allow "leftover" kidney biopsy tissue to go to waste.

**In addition to the KPMP, NIH/NIDDK has been doing tremendous work on the APOL1 gene research and the impact of kidney disease among the African American population. Can you share the vision and purpose of this initiative?**

NIH-supported studies identified genetic variants associated with susceptibility to the development of kidney disease and with faster progression of established chronic kidney disease. These variants were found almost exclusively in people of recent African descent.

The variants are thought to be an adaptation to the prevalence of trypanosomiasis (known as "sleeping sickness," this disease is found only in rural Africa and is transmitted by the tsetse fly), similar to the way sickle cell variants may protect against malaria. These genetic findings explain the overrepresentation of African Americans with chronic kidney disease and with end-stage renal disease.

Shortly after the identification of the genetic risk, observational studies suggested that the presence of two risk variants was strongly associated with poor kidney transplant outcomes. Because of this, in 2017, the NIDDK launched the APOL1 Long-term Kidney Transplantation Outcomes Network (APOLLO). This 13-center, national study is designed to prospectively evaluate the effect of APOL1 gene variants on kidney transplant outcomes and is expected to start recruitment in spring 2019.

The APOLLO study has established collaborations with the United Network for Organ Sharing and national organ procurement organizations. We hope that APOLLO's results will have an impact on national kidney transplantation policies. The results of APOLLO will be clinically meaningful as they will inform clinical practice by letting patients and transplant physicians know whether donors with one or two APOL1 gene variants should be excluded from serving as kidney donors.

*Information Article continued on next page*



**Obviously, during the course of your research and medical career, you have interacted with many patients. Is there one key observation you have gleaned from those patient experiences that fuels your passion to make an impact for kidney patients?**

As I clinician, I learned that every patient is different; every patient is unique. Each person wants to make choices about his or her treatments and to decide what is best for his or her care.

When I was in resident training, ACE inhibitors were just beginning to come into common use. Everyone got the same medications. Fast-forward 35 years, everyone with chronic kidney disease is still put on an ACE inhibitor or ARB. Unfortunately, we still have limited therapeutic options. We hope to help forge the path toward more individualized treatments for those with kidney disease, and the work we are doing with KPMP and APOLLO is helping to set that foundation.

**Your participation in AAKP events, like our National Patient Meeting and our Inaugural Policy Summit are always rated high by our patients because of your optimism. For our readers, can you share a few thoughts on why they should be optimistic about the future of kidney medicine and treatments?**

The pace of scientific advances is breathtaking. We can now see details in how single cells respond to injury, which was impossible 20, 10, or even five years ago. We have been waiting to start the KPMP project for a long time. The clinical need has long been there, but now we feel

the research tools are in place to do the study well and make an impact for our patient participants and future generations. We will take our time to do this project ethically, with a focus on safety and quality control.

**As a veteran of government service, can you give us a final thought on the importance of an independent patient voice in the national policy process – and your advice for patients who wish to become more involved in education and advocacy activities?**

My advice: Just do it. Of course, public speaking and advocacy for a cause can be scary and may feel outside your comfort zone. But remember that you are doing this work for your family, your friends, yourself – and for all of us. With your voice helping to pave the way to better treatment and potential cures, the future will be brighter for everyone. 🌸



*Robert A. Star, M.D., oversees the Division of Kidney, Urologic, and Hematologic Diseases at NIDDK. The division supports research on important health problems, including all kidney diseases (acute, chronic, diabetic, hypertensive, glomerular diseases, transplantation,*

*dialysis), and benign disorders of the urinary tract and blood forming organs. The division supports the training and career development of people committed to scientific research.*

*Star is also a senior investigator and chief of NIDDK's Renal Diagnostics and Therapeutics Unit, where he leads a team that studies sepsis and acute kidney injury (AKI). The team focuses on identifying markers to detect and therapies to treat or prevent sepsis and AKI.*



A man and a young girl are sitting on a couch, playing acoustic guitars. The man, wearing a blue long-sleeved shirt, is leaning over the girl, who is wearing a green and blue striped shirt. They are both looking down at their guitars, and the man is pointing at the fretboard of the girl's guitar. The background is a soft, out-of-focus indoor setting with warm lighting.

worry for **confidence.**

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clinic visits for **jam sessions.**

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## Why choose Peritoneal Dialysis?

### It's dialysis therapy **on your own terms**

A diagnosis of kidney disease can feel overwhelming. You may also feel anxious about the lifestyle changes it involves. However you do have treatment choices and your healthcare team to help guide you.

### Consider the flexibility of peritoneal dialysis with Baxter.

Peritoneal Dialysis (PD) uses one of your body's own membranes, the peritoneal membrane, as a filter to clean your blood when your kidneys no longer can. PD helps to rid your body of wastes and fluids, which may help control your blood pressure.<sup>1,2</sup>

### How will PD affect your lifestyle?

Most people enjoy the flexibility and independence that they have with PD.

- PD therapy can be done at home eliminating trips to and from a clinic multiple times a week
- You may also do therapy while sleeping allowing time for daily activities<sup>3,4</sup>
- Many PD patients are able to continue working<sup>3</sup>
- The convenience of PD may also let you pursue your hobbies or travel
- PD therapy slowly removes fluid and toxins which is similar to your normal kidneys<sup>5,6</sup>
- PD doesn't use needles or direct contact with the blood
- PD studies have shown that patients have an equal or better chance of living longer after transplant versus other treatments.<sup>7</sup> More studies are needed to support this association

To learn more about peritoneal dialysis, visit [www.pdempowers.com](http://www.pdempowers.com)



**91%**  
of US kidney  
doctors

If given the choice for their treatment, 91% of US kidney doctors surveyed would select home therapy compared to in-center dialysis.<sup>8</sup>



**78%**  
of potential  
dialysis patients

At least 78% of potential dialysis patients are suitable candidates for PD.<sup>9,10</sup>







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## Can I switch to PD from other dialysis treatments?

Yes. Switching from another form of dialysis to PD may be an option for you. Your doctor will be able to tell you if PD can work for your situation. Studies show more and more people are choosing PD every year. In 2014, PD use grew at a faster rate than in-center hemodialysis.<sup>11</sup>

People on PD can adjust their treatment schedule according to work, school, or travel plans. So, you are in charge of your own treatment. Your doctor can tell you whether PD is appropriate for you.

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With the **Sharesource** Platform, you may be able to make fewer visits to your clinic.<sup>12</sup>

To learn more about the **Amia** System with **Sharesource** Platform, visit [www.amia.com](http://www.amia.com)





## Why PD with Baxter?

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Baxter's Global Technical Services are available 24 hours a day, seven days a week to answer any questions you may have about your PD device.



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### Are you interested in PD?

Visit [options.pdempowers.com](http://options.pdempowers.com) to take the PD Assessment and see if peritoneal dialysis may be right for you.

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Patient names have been changed to respect their privacy.

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# The Mediterranean Diet: A Must-Have for 2019

*By Jennifer Rose Parker, RDN, CSR, LDN*

Now you can eat like an Italian or Grecian local—even while state-side.

Perhaps you have heard that the Mediterranean diet is one of the healthiest diets of all times, boasting weight loss, improved diabetes management and better health for all. But did you know that even with Chronic Kidney Disease (CKD), you too can enjoy this diet and reap the benefits?

If living with CKD is new to you, take heart—the Mediterranean diet will give you flexibility and help protect your kidneys. Recent evidence shows that a diet rich in plants slows the progression of Chronic Kidney Disease<sup>1-3</sup>.

What makes this diet so good? PLANTS. Whole, unprocessed, fruits, vegetables, beans, grains, nuts, seeds and oils. And “unprocessed” is key. One of the reasons why the Mediterranean diet

is so healthy is because of fiber-rich plants. Research shows that higher intakes of dietary fiber reduces the risk of developing several chronic diseases, including cardiovascular disease, type 2 diabetes, some cancers, and has been associated with lower body weights.<sup>4</sup>

Can I still eat meat and dairy? Yes, but not much. This is quite a contrast to the fad diets of late—think Paleo or Keto (which, by the way, can cause kidney damage because your kidneys have to work harder to excrete nitrogen and balance electrolytes). And if you’re reading this and are on dialysis, don’t worry—you can still meet your protein, potassium and phosphorus needs. Do consult with your Registered Dietitian Nutritionist (RDN) for specific guidance.

So in a nut-shell (pun intended), let’s review this Mediterranean diet...

*Nutrition Article continued on next page*





Less Is  
More

Eat Like  
A Local

Mastering the  
Mediterranean Diet

Be  
“Whole”

Fat Is  
Good

### Less is More

**Meatless More-days.** Choosing beans, lentils, and veggie-based meals more days is better for your health. Think of meats (including chicken) as a side-dish or even optional to your meal. For those that enjoy seafood, choose heart-healthy tuna, herring, salmon and sardines, but only twice a week. Are you a dairy-lover? You can enjoy some but go easy on portion sizes.

**Avoid added sugars.** Coming soon, all nutrition facts labels will show how much added sugar a food or beverage has. Until then, read the ingredients and choose foods without sugar listed and above all, avoid high-fructose corn syrup.

### Eat Like A Local

Yup, turns out even the those living right on the Mediterranean love their plants. Snack on fresh veggies like baby carrots, grape tomatoes, or bell peppers throughout the day and choose fruit as your dessert.

### Be “Whole”

Choose 3 servings or more of whole grains like barley, brown rice, whole-wheat cereals or 100% whole wheat bread. Start your morning right with whole-oats, almonds, strawberries and Soy milk.

### Fat is Good Afterall

**Fat is good.** Believe it or not, plant-based fats like walnuts, pecans, almonds, sunflower seeds, olives and avocados are great choices for helping you feel full and cooking a delicious and satisfying meal.



## Daily Tips and Tricks

for Mastering the Mediterranean Diet

### Snacking

- Try air-popped popcorn for a satisfying snack full of fiber and add unsalted garlic or chili powder for a flavor boost!
- Edamame is an excellent source of protein, folate and Vitamin K

### Cooking

- Save time and money and use an electric pressure cooker to make wild rice, lentils or other affordable dried beans and grains.
- Choose whole wheat pasta, instead of a processed boxed pasta meal like Hamburger Helper. This will add fiber and nutrients while reducing sodium, phosphates, and added sugars.

### Shopping

- Choose products with less than 10% Sodium per serving.<sup>4</sup>
- Frozen fruits and vegetables still have the same amount of nutrients and are often less expensive than their fresh counterparts.
- Buy no-salt added canned beans for an affordable and filling protein that's also high in fiber. (Tip: rinse canned beans to remove excess fluid and potassium)

So, if you're interested in boosting your health, slowing kidney disease, and enjoying the fruits of mother nature, make the Mediterranean diet your new diet for life! 🌱

---

**Always consult with a Registered Dietitian Nutritionist (RDN) before beginning any new diet. You can search for a Renal RDN by going to: [www.kidney.org/ckdrd](http://www.kidney.org/ckdrd) or for all RDN specialties, go to: [www.eatright.org](http://www.eatright.org) and click on "Find an Expert."**

---

### PEAR PERFECTION



Did you know that 1 medium pear has a whopping 6 whole grams of fiber? That's impressive when you consider that the daily fiber goal is 20-30 grams each day for those living with Chronic Kidney Disease (20-25 if you're on dialysis). 1 medium sized pear will count as two carb choices and has 206 mg of Potassium.



*Jennifer Rose Parker, RDN, CSR, LDN is a Lead Dietitian with Fresenius Kidney Care (FKC) and enjoys helping patients, supporting dietitians and participating in company-wide campaigns focusing on eating well with Chronic Kidney Disease and Dialysis since 2010.*

*She completed her B.S. at Florida State University and Dietetic Internship at Barnes-Jewish College at Washington University and has been working in nephrology and diabetes management since 2005. She has presented at NKF's Renal Professional Forums, ANNA and AAKP conferences, and other FKC corporate wellness programs on both the bioavailability of phosphorus and the positive effects of plant-based eating for CKD and Dialysis. She is an active member of the Academy's Renal Practice Group and the NKF's Council on Renal Nutrition. In her free time, she and her husband love traveling and investing in their community through their local church.*

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Becky, DaVita patient,  
Theresa, DaVita teammate



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American Association  
of Kidney PatientsMEDAL OF  
EXCELLENCE  
A W A R D

# Medal of Excellence: Get to Know the 2019 Honorees

The American Association of Kidney Patients' (AAKP) Medal of Excellence is the Association's highest honor for kidney healthcare professionals and is designed to elevate national and international figures who have been in the forefront of advancements in kidney care and patient empowerment. The award recognizes professionals who are committed to improving and extending the lives of all kidney patients through advocacy, research, technology and quality-driven treatments that protect patient dignity and fully align with patient aspirations. This prestigious award program recognizes a variety of professionals within the health care team including: nephrologists, transplant surgeons, transplant professionals, nurses, social workers, dietitians and dialysis technicians.

## Physician Category:

Stephen Z. Fadem, MD, FACP, FASN;  
Kidney Associates, LLC (Houston, TX)

*What have patients taught you and/or how have patients impacted your career?*



*"There is no life experience that can prepare one for the words from a physician like 'your kidneys have failed and you will soon need dialysis,' or 'you have cancer and it is metastatic.' For years, as I gave patients bad news, I silently admired them because I did not think that I could ever endure hearing such fateful words. But in 1998 osteosarcoma, a rare bone tumor I previously had, metastasized to my lungs. How I chose to fight it was drawn from the insights of dealing with my brave and tenacious patients. I surrounded myself with a sense of positiveness that required a great deal of trust in my doctors and their staff. As I recovered and transitioned back to caring for patients, I realized the greatest lesson my patients taught me was simple - that they require my trust to do well. The burden is on me as their physician not to let them down."*

Dr. Fadem is a champion for Chronic Kidney Disease education. He is a Clinical Professor of Medicine, Baylor College of Medicine, Section of Nephrology. He attended Tulane University and graduated the University Of Oklahoma College Of Medicine. He completed his Internship and Residency at the University of Texas Health Science Center – MD Anderson and Hermann Hospitals, and his Renal Fellowship at the University of Texas Health Science Center, San Antonio. He was one of the first doctors to discover the value of the Internet for patient education, and is the founder of several websites dedicated to public service and the dissemination of clinical information including The Nephron Information Center, Wikikidney and dialysisunits.com. He has participated heavily in the development and the revision of the AAKP Patient Plan. Dr. Fadem is the recipient of the National Kidney Foundation's Distinguished Service Award, the AAKP Visionary Award and the AAKP Peter Lundin Award. He serves as Chair of the AAKP Medical Advisory Board and was named AAKP Historian in 2016.



## Transplant Surgeon Category:

Sherilyn Gordon, MD, FACS,

Methodist Hospital (Houston, TX) (presented posthumously)



*"Dr. Sherilyn Gordon was an exceptionally strong advocate for her own patients and for all patients suffering from ESRD, particularly minority and vulnerable populations. She was also a mentor for the next generation of surgeons and a highly dedicated advocate for surgery trainees and medical students."*

Sherilyn A. Gordon Burroughs, MD, FACS was a transplant surgeon at the Houston Methodist J.C. Walter Jr. Transplant Center and Associate Professor of Surgery at The Methodist Hospital in Houston, where she served as the first physician Designated Institutional Official and the Residency Director for the Department of Surgery. She was also the Assistant Dean, Graduate Medical Education, at Texas A&M Health Science Center.

Before her untimely passing, she was a member of the ASTS Diversity Issues Committee, chair of the ASTS Legislative Committee and, in that capacity, also served on the MACRA Task Force.

## Transplant Professional Category:

Ronald Gill, PhD,

Colorado Center for Transplantation Care (Aurora, CO)

*What have patients taught you and/or how have patients impacted your career?*



*"While I was drawn to biomedical science due to its compelling nature of curiosity and discovery, engaging patients themselves added a completely new dimension to research. Witnessing the plight of patients and families afflicted with conditions requiring organ transplantation has created a sense of mission and compassion in me that extends far beyond mere academic interest."*

Dr. Gill is Professor of Surgery and Immunology at the University of Colorado Denver and the Scientific Director of the Colorado Center for Transplantation Care, Research and Education (CCTCARE). He is also currently the Past President of the American Society of Transplantation. Dr. Gill's research program is focused on both the immunobiology of tissue/organ transplantation and autoimmune diabetes. His primary research focus has been in pancreatic islet transplantation as a treatment for insulin-dependent diabetes. As such, projects related to islet

*Special Feature continued on next page*

American Association  
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transplantation cover a range of topics including mechanisms of immune-mediated graft rejection, autoimmune pathogenesis of islet injury, mechanisms of transplant tolerance induction, and the role of metabolic distress on islet transplant outcome. Related diabetes studies address the ability to utilize bone marrow transplantation as a means of correcting the immune dysregulation associated with autoimmune diabetes.

### Nursing Category:

Barbara Casazza, FNP,  
The Rogosin Institute (Woodside, NY)

*What have patients taught you and/or how have patients impacted your career?*



*"I have always been amazed at how resilient patients are, despite having multiple medical issues; and how well they rise above bad situations. Patients have taught me patience; and to listen to the whole story, and never to jump to conclusions or presume."*

Barbara Casazza started working in 1976 as a lab tech in allergy and immunology, working with rats and mice; she soon discovered that she preferred working with people. She had considered pursuing a nursing degree and after a three-year stint of being a lab tech, entered a generic masters NP program at Pace University in New York. It was a very challenging, stimulating program.

Her first real NP job was several years later, working in an inner-city hospital, primary care adult medical clinic. Fortunately, part of her responsibility in that position was to serve as the NP for the transplant clinic, the CAPD clinic and the renal consult clinic. This was her first exposure to renal disease and an incredible learning experience for her. She was fortunate to work with an excellent clinical staff who served as great teachers and mentors. This position later expanded to purely renal where her responsibilities increased, and she took on hemodialysis and quality assurance as well as policy and procedure development for the Nephrology Division.

In 1999, a position opened up at the Rogosin Institute; they were considering employing NP's in one of their dialysis units, and she was the first NP that Rogosin ever had on staff (since then, the number of NP's employed by Rogosin has expanded to 8). In her current position, she is responsible for anemia management, lab review, daily treatment monitoring of patient, quality assurance and infection control issues, evaluation of new patients for dialysis treatment and the acute and chronic issues that occur on a daily basis in both our hemodialysis and peritoneal dialysis population.

Barbara enjoys travelling, exploring new areas of New York City, and trying new cuisines.



## Social Work Category:

Renée Bova-Collis, MSW, LCSW,

Quality Insights Mid-Atlantic Renal Coalition (Richmond, VA)

*What have patients taught you and/or how have patients impacted your career?*



*“Patients have taught me to partner. Biggest ah-ha moment: After spending a ton of time developing a project plan, only to be told by patients, “That’s not important to us.” Of course! I made assumptions and got it all wrong. Together, we developed the successful What If...? emergency preparedness campaign.”*

Renée Bova-Collis, MSW, LCSW is the Patient Services Director for Quality Insights Renal Network 5 and is responsible for coordinating patient engagement activities, managing quality improvement projects, and investigating patient grievances and access to care issues. Ms. Bova-Collis has 13 years’ experience in the clinical nephrology field as a social worker and has been a licensed clinical social worker in the state of Virginia since 1997. She is a seasoned presenter and is well published. In her personal life, Renée is a rabid quilter and scrapbook-a-holic, and cohabitates with two delightful fuzzy kitties and a fairly tolerant spouse.

## Dietetic Category:

Stacey Phillips, RD, LD,

Mercy Health (Grand Rapids, MI)

*What have patients taught you and/or how have patients impacted your career?*



*“Working in a clinical setting has taught me that there is no medical nutrition therapy plan that meets the needs of all patients. Patients are very passionate about food—especially as this is one thing with chronic disease that they can control. In order to create an impact, individualizing nutrition recommendations is necessary and the positive outcomes from this approach has been rewarding!”*

Stacey has been a registered dietitian nutritionist for over 13 years working for Mercy Health Saint Mary’s in Grand Rapids, Michigan. She received her undergraduate degree from the University of Illinois in Champaign-Urbana, completed her dietetic internship at the Mayo Clinic School of Health Sciences, and earned her master’s degree through Central Michigan University. In her work as a clinical dietitian, Stacey has worked with patients in all phases of CKD and serves as the primary inpatient dietitian with renal transplant recipients and living kidney donors. In addition, working in a teaching hospital has enabled Stacey to mentor over 70 dietetic interns as they rotate through their clinical renal nutrition rotation.

Outside of her clinical work, Stacey has been involved with the Renal Practice Group through the Academy of Nutrition and Dietetics in various roles including the Renal Nutrition Forum Editorial Board, Treasurer, Awards

*Special Feature continued on next page*



## Medal of Excellence 2019 Honorees

Chair and currently the Marketing Chair. She has served as co-editor of AAKP's Delicious! recipe series and also acts as the Patient Education Editor for the Journal of Renal Nutrition. With each of these roles, Stacey hopes to continue to improve the resources available to individuals with CKD.

### Dialysis Technician Category:

Dwelyn Williams, CCHT,

Traveling Hemo Tech, Innovent Global, Inc. (West Palm Beach, FL)

*What have patients taught you and/or how have patients impacted your career?*



*"Patients have taught me to be more humble and not to take life for granted. Every day we live is worth cherishing. Patients have impacted my career by allowing me the privilege to help them and become more than just an inspiration in their lives. Overall, our patients inspire us."*

Dwelyn Williams is a Certified Clinical Hemodialysis Technician. He currently serves as the National Association of Nephrology Technicians/Technologists (NANT) President. His interest in becoming a hemodialysis technician is due to the fact his late mother was an ESRD patient in the early 90's and later received a transplant. She passed away in 2003, but her spirit continues to drive Dwelyn's career. He began his career in 2000 in his home state of North Carolina at the Metrolina Kidney Center. Since then, he became a traveling Hemodialysis Technician and an Assistant Facility Administrator within DaVita Dialysis. 🌱

## Medal of Excellence Awards Ceremonies:

AAKP is pleased to honor the 2019 recipients at events hosted throughout the year in front of a community of their peers.

- **American Society of Transplant Surgeons Winter Symposium** January 10-12 in Miami, FL – recognition of Dr. Sherilyn Gordon, transplant surgeon category (posthumously)
- **National Association of Nephrology Technicians Dialysis Tech ConneXion Annual Conference** March 19-22 in Las Vegas, NV at the Tropicana – recognition of Dwelyn Williams, dialysis technician category
- **Renal Physicians Association's Annual Meeting, Medal of Excellence Award Dinner** March 28-30 in Chicago, IL at the Chicago Marriott Downtown Magnificent Mile. The Award Dinner is hosted on Friday, March 29 from 6:30 p.m. – 8:30 p.m. Tickets are available for \$125/person. Visit [www.aakp.org/medal-of-excellence](http://www.aakp.org/medal-of-excellence) to purchase ticket(s) online or contact AAKP at (800) 749-2257 to purchase by phone. The Award Dinner will recognize awardees in the physician, nurse, social worker and dietitian categories.
- **American Society of Transplantation Town Hall** June 3, Boston, MA. Honoring Ronald Gill, PhD.



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This year's meeting agenda will focus on relevant information critical to those impacted by kidney diseases and highlight the latest in research and innovations in the renal space. AAKP will host a diverse line-up of speakers crossing all sectors of the kidney community including the Federal government; the U.S. Congress, academia; industry; allied kidney organizations and associations; patients and other various stakeholders.

**2019 National Patient Meeting  
will be a milestone event as the  
Association is celebrating its  
50th Anniversary!**

*Details on how to join us are below.*



**Registration Information:**

To register, call AAKP at 1-800-749-2257  
or go online to  
[www.AAKP.org/national-patient-meeting](http://www.AAKP.org/national-patient-meeting)

The Meeting Package includes entrance into the exhibit hall, educational sessions, an attendee tote bag, souvenir items, and meals including: three breakfasts, two lunches, afternoon breaks and dinner during the Saturday evening Awards Banquet (Early-Bird Rate is \$99).

Continuing education credits available for nurses, social workers, dietitians, and dialysis technicians with purchase of healthcare professional registration only (Early-Bird Rate is \$199).

**Hotel Information:**

**The AAKP National Patient Meeting  
will be held at the  
[Hyatt Regency Washington.](http://www.Hyatt.com)**

The group rate is **\$159/night** and applicable for rooms booked between **Sept. 4 - 9**. Reservations can be made by calling **(877) 803-7534**, please reference the **AAKP 2019 Meeting** to receive the discount. Reservations can also be made online. Go to [www.AAKP.org/national-patient-meeting](http://www.AAKP.org/national-patient-meeting) and look under hotel reservations.

The deadline for reservations is August 16th or until the room block is full, so please make your reservation early!

**For more information including scholarship information, dialysis information, etc.  
please call AAKP or go online to [www.AAKP.org/national-patient-meeting](http://www.AAKP.org/national-patient-meeting)**





American Association of Kidney Patients  
14440 Bruce B. Downs Blvd.  
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## About AAKP

The American Association of Kidney Patients (AAKP) is a national non-profit organization founded by kidney patients for kidney patients. We are dedicated to improving the quality of life of kidney patients through education, advocacy, patient engagement, and through fostering patient communities.

## STAY *Connected*

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We can be found under American Association of Kidney Patients on YouTube.