



# AAKP *RENALIFE*

Volume 52 • Number 4 *The Independent Voice of Kidney Patients Since 1969™*

July 2019

COVER STORY

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## **A Preemptive Kidney Transplant**

**Professional Feature:**

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CKD/Transplant Specialist

**Innovator Series:**

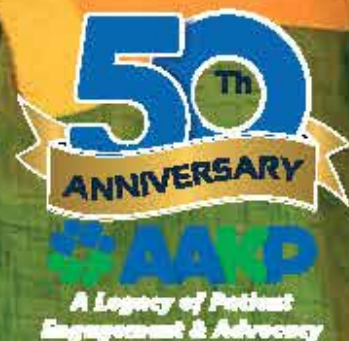
AstraZeneca, Kerry Cooper

**Special Article:**

A Connection You Should Know  
About - Heart and Kidney Disease

**Nutrition:**

Quenching your thirst for the  
"good life"



*A Publication of the American Association of Kidney Patients*



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*aakpRENALIFE* is published six times a year by the American Association of Kidney Patients (AAKP). It provides articles, news items and information of interest to kidney disease patients and their families, as well as individuals and organizations in the renal health care field.

*aakpRENALIFE* is distributed in January, March, May, July, September and November and is a membership benefit.

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Non-profit postage paid at Tampa, Fla., and additional mailing offices.

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# MESSAGE FROM AAKP

Dear Friends,

I hope all is well with you. We are midway through the calendar year of AAKP's 50th Anniversary. Summer is upon us, and Team AAKP continues to honor our 50th year. In addition to AAKP's traditional annual events – Medal of Excellence, National Patient Meeting, and Policy Summit – we introduced the Inaugural Global Summit on Kidney Disease in collaboration with the George Washington University (GW) School of Medicine & Health Sciences (SMHS). The focus of this inaugural event was Global Innovations in Patient-Centered Kidney Care. The AAKP/GW Summit was a success. During the Inaugural Global Summit, 35 presentations on topics ranging from emerging transformative initiatives to diagnosing disease progression to evolutions in transplantation were discussed. Patients, caregivers, medical professionals, industry representatives and representatives from Government agencies made up the audience of this two-day event – and thousands more from 37 countries viewed the online live-streaming video of the event.

I was honored to serve as a Co-Moderator for several sessions at the Global Summit. However, it was a greater pleasure to have my fellow AAKP Board of Director (BOD) members serve as Co-Moderators for all of the panels. The BOD members included Suzanne Ruff; Kent Bressler; Edward Hickey, III; Dan Abel; Brian Hess and Paul T. Conway.

The AAKP leadership team continues to pick up the pace. AAKP followed the Inaugural Global Summit with the second annual Policy Summit – *A Legislative Look at the State of Kidney Care*. The topics covered included sessions on Immunosuppressant Drug Coverage, The Living Donor Protection Act, and Emerging Issues: Research, Regulation, Payment & Reauthorization. On the second day of the Policy Summit, we hosted a Stakeholder Roundtable focused on issues

of shared concern with the Executive Branch and coordination of letters, petitions, social media campaigns, and coalitions. The Policy Summit, as did the Global Summit, featured fellow patients engaged as panelists and moderators.

When it comes to policy-related issues, AAKP has the following key distinctives that separate us from other patient groups:

- We are a 50-year national patient education & advocacy organization with **credibility based on independence & fairness** – we are not “reactionary,” and we do not “burn allies.”
- AAKP is grassroots with a **patient-led** and patient majority BOD.
- We are known for **credible & knowledgeable leadership** - AAKP leaders have served “**at the national policy table**” as both **professionals and patient advocates**.
- Based on **our bipartisan** networks, we can insert the true, independent patient voice at every official & unofficial juncture in the policy process.

AAKP is a member of the Center for Disease Controls' (CDC) Healthcare Infection Control Practices Advisory Committee (HICPAC), where Paul T. Conway, Chair, AAKP Policy and Global Affairs, serves as the liaison for AAKP. On June 25, 2019, AAKP attended the annual Making Dialysis Safer for Patients Coalition Meeting. I provided a presentation on AAKP and our history with the CDC. The presentation included the announcement of a video produced by CDC, which highlights patients as part of the care team and provides information on preventing infections, especially infections related to dialysis vascular access. The CDC Making Dialysis Safer Coalition was awarded the AAKP Jenny Kitsen Patient Safety Award grant. These grant funds are being used to produce the infection prevention video that features AAKP Ambassador Melissa Bensouda!



One area of keen interest to all patients and caregivers is innovation in the kidney space. Innovation is front and center in the kidney arena, and AAKP plays an important role in representing the patient voice in innovation. In past *aakpRENALIFE* issues, we have discussed our meetings with the Secretary of the U.S. Department of Health and Human Services (HHS), Secretary Alex Azar, II. Continuing from those meetings AAKP's Paul T. Conway led a panel titled "Patient Experience and Why Innovation is Needed" during the KidneyX Innovation Accelerator, while AAKP BOD members David White, Patrick Gee, and Ambassador Glenda Roberts served on the panels reviewing the Redesign Dialysis Phase I submissions for the initial prize competition.

Continuing with innovation, Paul T. Conway also served as Co-Chair of the Kidney Health Initiative's *Seventh Annual KHI Stakeholders Meeting* titled, "Collaborating for Innovation to Improve Patient Care & Outcomes." Paul interviewed Adam Boehler, Senior Advisor to the HHS Secretary and Deputy Administrator of the Innovation Center for the Centers of Medicare and Medicaid Services. On day two of the KHI Stakeholders Meeting, I presented on "Collaborating for Innovation with KidneyX." AAKP's participation in meetings such as this provides AAKP members with the credibility to be an effective voice for patients at policy tables.

In our Innovator's Series this month, you will read about the role AstraZeneca plays in addressing critical issues afflicting chronic kidney disease (CKD) patients through an interview with Kerry Cooper, VP, U.S. Medical Affairs, Renal Cardio. AstraZeneca provides products that lessen the impact of anemia on CKD patients and help manage hyperkalemia (high potassium). It should not surprise you that coexisting cardiovascular disease (CVD), diabetes, and related conditions cause many CKD patients to die before they even reach kidney failure. AstraZeneca is a global company that provides treatments that help patients cope with comorbidities and improve a patient's quality of life. In this issue you will also see an article focused on summer nutrition

and hydration written by Michelle McInay, Lead Renal Dietitian for Fresenius Kidney Care (FKC).

Another article of great interest to patients and caregivers takes a look at preemptive transplants. AAKP Board Member and Author of *The Reluctant Donor*, Suzanne Ruff, writes about this option in our Patient Profile. She shares with us a great story of a woman who received a kidney from a living donor this past May. Patients and caregivers should take note of this story. Preemptive transplants are a viable option for those headed towards kidney failure.

As you plan for the remainder of this year, please mark your calendar for our 44th Annual AAKP National Patient Meeting: Driving Innovation & Changing the Status Quo (September 6 -8) in Washington, D.C. Please plan to join us as we celebrate our 50th Anniversary with the largest annual meeting in our rich history. Be sure to follow AAKP on social media (Facebook: @kidneypatient and Twitter: @kidneypatients). You can also visit us at [www.AAKP.org](http://www.AAKP.org) or call us at 800-749-2257 for detailed information on upcoming events.

During our 50th Anniversary Celebration, AAKP continues to embrace our legacy of educating and advocating for patients, caregivers, policymakers, and friends on issues affecting the lives, hopes, and dreams of fellow patients.



Richard Knight,  
President of AAKP

Please know that this issue of *aakpRENALIFE* provides you with the opportunity to read about your fellow patients. AAKP has a diverse group of patient members with fascinating stories to share. I continue to enjoy learning about each of your individual stories. We encourage you and your family members to read the articles, share the magazine with others, and follow us

on social media so that you can keep abreast of the latest information, research and policy issues affecting those with kidney diseases.



## PATIENT PROFILE: A Preemptive Kidney Transplant

By Suzanne Ruff, Living Donor, AAKP Board of Directors, Author

What is a preemptive kidney transplant? Let's examine the word: preempt and its adjective: preemptive. The Oxford dictionary defines preempt as a noun, with the definition:

1. a. forestall b. acquire or appropriate in advance.
2. to prevent (an attack) by disabling the enemy. The adjective, preemptive, defines it perfectly: taking action against the enemy. In the case of a preemptive kidney transplant, the enemy is kidney disease.

A perfect example of someone who embraced the concept of a preemptive kidney transplant is 63-year-old Karyn Waxman of the Memphis, TN area. She was diagnosed nearly twenty years ago with polycystic kidney disease (PKD), a disease without a cure. PKD is a hereditary disease, but in Waxman's case, there was no family history of the disease.

Waxman explains, "When I was initially diagnosed with PKD, I felt frightened, alone and confused." Doctors determined her disease was caused by a mutated gene. "Dealing with the unknown was like entering an unwelcome dark part of my life that I wasn't wanting to explore. But there it was... no choice... just me and PKD. Arming myself with knowledge and finding others with experience with this disease helped shed light on the unknown and strengthened my resolve to keep plugging along to live my best 'healthy life'." Waxman, once she recovered from the initial shock of her diagnosis, jumped in fully to 'attack the enemy'.

*Two days after the successful transplant on May 21, 2019. Both ladies are doing fine.*



Her kidney disease progressed, "Very slow for me and very gradual, thank goodness. I felt okay."

Over five years ago, Waxman asked the owner of a gym about hiring a personal trainer for herself, telling him about her polycystic kidney disease. Waxman says she was at about Stage 4 CKD with 30% kidney function then.

The owner of the gym decided another trainer, Sara Kelly, would be a good fit for Waxman and told Kelly that Waxman had polycystic kidney disease.

Waxman laughs now. "I thought he was going to train me himself, but he turned me over to Sara Kelly! The owner passed me over to a perfect trainer. Here I was recruiting this guy..."

Kelly said, "I Googled PKD and tried to find out a little bit about it. I learned a little, but not much before the training began. Karyn, though, was mainly the source of the information about what Karyn could or couldn't do and what she would feel comfortable with as far as exercising. My main concern with her workout was safety and avoiding things like sit-ups or crunches that may bother her kidneys."



"Karyn seemed like a healthy person, but maybe about once a year we were dealing with something that put her over the edge..."

Waxman added, "Yeah, you know when you get a cyst rupture - it's just not working for you". (Some patients suffering from PKD, a disease that forms cysts on the kidney, can sometimes suffer from painful cyst ruptures).

Kelly says about Waxman, "The thing that impressed me was how involved she was, what a champion for the PKD Foundation she is, trying to raise money and trying to raise awareness, they have their license plates on their car and they have their golf tournament every year, doing PKD fundraising, just helping people."

Understanding the disease can cause total kidney failure, Waxman said, "The thought of living my life tethered to a machine was beyond disturbing." She talked with her nephrologist often and in her own words told him "dialysis was NOT in my plan if I could help it." Waxman repeatedly asked that he let her know when a good time to search for a living donor would be. Waxman continued, "At one visit he actually smiled and told me that I should not worry and when the time was right, I would have no trouble finding a donor. My smug reply was that they don't grow on trees and I need him to give me ample time to put the wheels in motion."

In 2018, her nephrologist told her it was time to be referred to the transplant center for evaluation. Her eGFR was 21%. No one in her immediate family shared her blood type. Waxman said, "I studied the campaigns of others through Facebook and some other media outlets. I decided that asking for a kidney was not what I wanted to do, but moreover ask for the sharing of my need. I began with the creation of golf balls for our PKD Tournament that said #KidneyforKaryn, Donate Life, Share your spare. As soon as my transplant coordinator gave me the green light, I created 250 business cards to help accomplish this. I posted to Facebook. People



*Celebrating that Sara was approved to be the donor for Karyn.*

have been so kind and supportive. It's truly the beautiful part of this difficult journey."

Sara Kelly, her trainer, age 52, said her first thought when she saw Waxman's business cards was "Oh my gosh, she's going to need to get this from a stranger. I knew that I had O+ the universal blood type so I knew the blood type would not be an issue. How could I watch her go through the process of looking for a donor; what would be my reason for not offering to donate?"

Kelly told Waxman that she was going to call the transplant center to be evaluated adding, "I bet I'm the first person they'll call."

The transplant center did call Kelly back. Kelly told Waxman who said, "You shouldn't tell me about these things." Waxman didn't want to get her hopes up.

Kelly laughed and said, "I have to talk to someone about it!"

Waxman said, "It was remarkable."

Kelly stated, "She never put pressure on me at all."

Waxman laughed and said she cautioned Kelly about being a donor because it is major surgery, "I was telling her the ugly. I wanted her to know it was a big deal."



As a fit and healthy personal trainer, Sara Kelly had concern about not being able to exercise.

“I’m one of those people who exercises every day as part of my mental well-being. So this was going to be one of my challenges.”




As she recovers and gets back to her routine as a personal trainer, Sara said she will not be as pampering to her clients at first by not picking up their weights but instead telling them, “See that 5 lb. weight, you go get it.”

Kelly also expressed her belief that Waxman would take good care of the gift of her kidney and respect the sacrifice of it, saying, “I just know Karyn is going to treat it like something special. She has so much knowledge about the disease and being so proactive and going ahead and getting it before dialysis.”

Waxman said, “I am in awe of someone who is alive and healthy and willing to take time out of their lives and give a piece of themselves to a person so you can have your best life. I don’t see how anyone would be able to live with themselves and not treasure, value and take care of that precious gift.”

When Kelly was approved to be Waxman’s donor, they celebrated the date set for surgery: May 21, 2019. The transplant was a success and both are doing well.

Sara Kelly, newly living kidney donor, stated, “I hope somebody else donates, just from hearing our story. I hope one person, no matter how far removed, can say, ‘I think I can do that.’”



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In July 2020 Both women hope to compete at the Transplant Games of America at The Meadowlands, New Jersey. I’d bet on them! 🌸

## SUZANNE RUFF

*Suzanne Ruff is a freelance writer for the Charlotte Observer and author of the non-fiction book The Reluctant Donor. The Reluctant Donor was a Finalist in the MIPA book award and also received the 2015 Illumination book award. She has been published in Chicken Soup for the Soul books. She is a living kidney donor and serves on the executive Board of Directors at AAKP, the Living Donor Council of the National Kidney Foundation and volunteers for the PKD Foundation. Passionate about kidneys, Suzanne speaks, writes and volunteers about all aspects of kidney disease, organ donation and the gift of another day.*





## PROFESSIONAL PROFILE:

Doris Harrison, RN  
CKD/Transplant Specialist



*Doris at the 2018 National Patient Meeting with AAKP Board Members and Attendees.*



*Doris Harrison, Bob Abbott (AAKP Life Member), and Dr. Stephen Fadem (AAKP Medical Advisory Board Chair)*



*Lobby Day at Doris' clinic. 74-year-old transplant recipient who found a living donor comes back to visit.*

Approximately 14 years ago, I began my career in the medical field working within a kidney transplant clinic as a medical assistant. At first, I was not sure if this was where I would stay, I was hoping to work in the hospital with newborn babies, but God had another plan for me. I love working in the medical field and helping patients is very rewarding. At the kidney transplant center, I was able to see firsthand how organ donation changed their lives and how grateful and loving these patients are for another chance at life. It was a very fulfilling career, and I loved it.

Unfortunately, in 2011, the transplant center where I worked was forced to close, and I transitioned over to the Nephrology department within the same facility. In 2012, I accepted a job with a non-profit dialysis organization, Dialysis Clinic, Inc. in Jacksonville, FL. Here, I continued to work with kidney disease patients and even started providing education to patients on understanding kidney disease. In 2013, I planned a community health fair event to raise awareness on kidney disease and its risk factors; we had a good turnout.

At this point, I knew I wanted to continue caring for kidney disease patients, and I also wanted to do something more to help them. I decided to return to school and pursue a nursing degree. I was a single mom raising two boys and worked full-time, so, needless to say, it took a little longer than anticipated but in 2016, I finally became a nurse.

I continue to work with Dialysis Clinic, Inc., as a CKD/Transplant Specialist and continue efforts to promote awareness with community outreach projects, provide education, advocate, care, and offer hope to patients with kidney disease.

This year, I helped to form a kidney disease support group. Many patients who come to the clinic feel all alone. I wanted patients to sit down and really talk to each other and share their stories and experiences so they could see that they are not alone. At the support group, we have patients who are newly diagnosed, as well as those on dialysis and those who have had a transplant. It is nice for them to all come together and see the full circle of a kidney patient. When



I decided to start a support group, I reached out to AAKP for help. AAKP has resources available to get support groups up and running such as a listing on their website, a guide to help you start a group and free educational materials.

Some other unique things we do at our clinic to help patients are educational boards and lobby days. The educational boards are done monthly. At first patients just thought they were pretty – a nice decoration on the wall at the clinic. But now, patients look for the educational tips and advice we provide. The boards might discuss how to watch your fluid or give tips on potassium intake.

Our lobby days take place a few times a year. Our last lobby day was all about transplantation. One of our “alumni” came back to the clinic for the event, a 74-year-old transplant patient who self-advocated and found a living donor. This was helpful for patients to see someone at his age be successful at finding a donor on his own and getting a transplant. Patients said, “well, if he can do it, then maybe I can too.” It’s always a stronger message when they hear it from an actual

patient than when they hear it from a doctor or someone on the staff.

Last summer, I was able to attend AAKP’s National Patient Meeting. The meeting was held in St. Petersburg, FL, which was driving distance from Jacksonville. I had no idea what to expect at the meeting– but it was amazing! I was able to get a ton of information, as well as make new connections and get continuing education credits. When I got back to the clinic, I used some of the videos I had taken of the sessions at the AAKP meeting to inspire patients about new innovations and technology that is being developed for kidney patients. Additionally, I have kept in touch with one of the attendees I met at the AAKP meeting – this person continues to inspire me because he is always attending community events and always advocating for patients. His name is Bob Abbott and he is a Life member of AAKP. I recently told him, “I want to be like you!”

I hope to continue to do whatever I can to help kidney patients as long as God allows. 🌱



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# AAKP Innovator Series:

AstraZeneca,  
Kerry Cooper,

Vice President, U.S. Medical Affairs, Renal Cardio



*AstraZeneca is a global, science-led biopharmaceutical company that focuses on the discovery, development and commercialization of prescription medicines, primarily for the treatment of diseases in three therapy areas - Oncology; Cardiovascular, Renal & Metabolism; and Respiratory. AstraZeneca operates in over 100 countries and its innovative medicines are used by millions of patients worldwide.*

*Cardiovascular, renal and metabolism together form one of AstraZeneca's main therapy areas. By following the science to understand more clearly the underlying links between the heart, kidneys and pancreas, AstraZeneca is investing in a portfolio of medicines to protect organs and improve outcomes by slowing disease progression, reducing risks and tackling comorbidities. Our ambition is to modify or halt the natural course of diseases that impact the heart, kidneys and pancreas, and potentially regenerate organs and restore function, by continuing to deliver transformative science that improves treatment practices and organ health for millions of patients worldwide.*

**Tell us about your first experience with kidney patients and what impressions that left on you as a person and as a professional.**

I was fascinated by the complexity of the kidney as a medical student and quickly decided that I wanted to devote my career to helping to improve the lives of patients with chronic kidney disease (CKD). I have been able to passionately

pursue this goal through direct patient care as a nephrologist, educating as a professor and now helping to provide new innovative therapies as a leader in the pharmaceutical industry. We know all too well that even today with the many advances that have come in CKD, patients still need and deserve more help in navigating the complexities of treatment management and the health care system. My journey is truly about their journey and helping them live their highest quality life. It's the main reason I joined AstraZeneca, a company which is markedly increasing its focus on kidney diseases. I believe there is so much we can still do to innovate in this space and bring new hope to patients living with CKD and their associated comorbidities. AstraZeneca was the place to be, to be at the forefront of this science and to reach patients in new ways that can help deliver a greater future for this critical patient population.

**Explain the need for innovation in the treatment/management of anemia and hyperkalemia to help improve patient outcomes. What encouraged AstraZeneca to focus on these conditions?**

AstraZeneca saw a need in general in the renal disease area. Building on their legacy of understanding cardiovascular and metabolic disease, it was clear that there was a critical space to follow the science and understand more clearly the underlying links between the heart,



kidneys and pancreas. In particular, advancing and increasing evidence specific to the kidney was critical as we saw a tremendous unmet need in this population given the slow pace of innovation. We are investing across the spectrum of CKD in hopes to slow disease progression, reduce risks and tackle co-morbidities.

In particular, two areas we saw immediate needs for the patient were in hyperkalemia and anemia. We believe in general there is a tremendous lack of awareness of both of these complications and the potential impact they can have on a patient's overall health. Although hyperkalemia and anemia should be treated with the same medical urgency as hypertension and diabetes, the risks associated with hyperkalemia and anemia of CKD are often underappreciated and these conditions are often under treated. If hyperkalemia is left untreated it can lead to higher risk of morbidity and mortality including hospitalization, serious cardiac arrhythmias and sudden death. Similarly, inadequate treatment of anemia of CKD can have important consequences to the cardiovascular system as well as to quality of life and an individual's ability to stay employed and contribute to society.

As an organization, we feel responsible to address this high unmet medical need and bring urgency to treat these comorbidities. Through continuous research and development of innovative medicines, we've been able to bring disease awareness, diagnosis and treatment for patients with hyperkalemia and anemia of CKD.

**Please share how AstraZeneca's research and development in the areas of anemia and hyperkalemia could have a significant impact on all kidney patients.**

As we continue to research the use of LOKELMA™ (sodium zirconium cyclosilicate <https://www.azpicentral.com/lokelpma/lokelpma.pdf#page=1>) and roxadustat on broader patient populations with hyperkalemia and anemia of

CKD, we'll be able to understand and tackle multiple unmet needs for patients and treat them along the spectrum of their disease overall. Specifically, with LOKELMA, we have been able to treat patients with hyperkalemia by increasing potassium removal from the body quickly and with sustained effects over time. For patients managing anemia of CKD, roxadustat has been shown to promote the generation of red blood cells across the spectrum of CKD by stimulating the body to produce more erythropoietin, low levels of which are the main reason for anemia in this population. In addition to research and development specifically in the areas of anemia and hyperkalemia, we are investing in research that can intervene earlier and potentially slow progression of the disease which could impact all kidney patients in improving their long-term quality of life.

**Please share how Roxadustat is different from other forms of anemia treatment?**

Typically, patients with anemia of CKD are treated with erythropoietin (EPO)-stimulating agents (ESAs). EPO is a hormone produced by the kidneys that stimulates erythropoiesis by bone marrow. The loss of EPO production as kidney function declines is the principal cause of anemia of CKD. Roxadustat, is a potential first-in-class hypoxia-inducible factor prolyl hydroxylase inhibitor (HIF-PHI). It works differently than ESAs by mimicking the body's natural response to low levels of oxygen and promotes red blood cell generation by increasing endogenous production of EPO. Roxadustat can be beneficial in the presence of inflammation and without a need for supplemental intravenous iron.

Although roxadustat is still under clinical investigation in the U.S., we are very excited about the potential this drug could have on improving the lives of patients with anemia of CKD.

*Information Article continued on next page*



**There has been little advancement in the treatment of hyperkalemia for many years, more recently we are seeing this serious condition garner more attention, especially for individuals who have kidney disease – how can Lokelma help patients lower potassium levels?**

We recognized that there wasn't much urgency around hyperkalemia, which can be a life-threatening complication in CKD patients. LOKELMA is an innovative treatment option for patients with hyperkalemia because it lowers potassium levels in the blood by selectively capturing potassium in exchange for hydrogen and sodium. LOKELMA works differently than other potassium binders as it has a unique structure and works in the GI tract, resulting in early capture of potassium. The design of LOKELMA can reduce serum potassium levels as early as one hour after initiation of treatment with the recommended approved dose, which brings patients with hyperkalemia quick relief.

**Can you share other novel approaches AstraZeneca is taking to help advance care for those with chronic kidney disease?**

Even after approval, we continue to test the optimal use of the treatments to help us reach a broader CKD patient population. For example, we recently completed a study that looked at the use of LOKELMA in patients undergoing hemodialysis, for which we saw positive results for and we are also looking at the use of LOKELMA in other patient populations and settings. Additionally, we are committed to continually bringing new science to this disease area with a goal to provide evidence on ways to ultimately slow and potential stop disease

progressions, address residual risks and prevent organ damage while prioritizing and bringing new medicines to patients in the renal space quickly. We achieve this by investing in a robust clinical program that researches how our current medicines in the renal space effects a diverse range of patients living with CKD.

**As a Global leader in health care, you know well that it is not easy to develop a novel approach to treatment or enhanced care. What do you draw upon internally to keep your drive, optimism and focus on patients going at full-speed during the tough days?**

As an organization, we consistently keep the patient in mind through the research and development that we do. We have a highly dedicated and committed team at AstraZeneca that really drives the optimistic atmosphere even on days when we may not see progress as quickly as we'd like to. For me personally, I've seen some major medical breakthroughs within my career, and I know it's possible for treatments to keep improving. As a nephrologist who has committed my career to advancing treatment for CKD, I continue to let my passion and ambition drive me to improve the lives of patients who are dealing with such a debilitating disease. AstraZeneca is a patient-centric organization with an eye on ways we can innovate differently in the future to tackle new ways of reaching patients. This, combined with our commitment to drive science in this space, is what drives us as an organization.

**By the year 2020 – what do you expect to see in terms of how care is provided to kidney patients, what immediate changes do you think can occur?**

With the level of commitment AstraZeneca has devoted to increase awareness on treating the kidney and the expected advancements coming from our pipeline, I believe by 2020 we'll live in a world where patients are diagnosed earlier – feeling empowered to understand and manage




their complications more effectively and, hopefully, lowering the need for patients to be on dialysis or receiving kidney transplants.

In terms of immediate changes, we can hopefully, improve the clinical outcomes of CKD patients by providing innovative treatments like LOKELMA and continuing to advance the science for products like roxadustat. We can also continue to drive awareness on treating hyperkalemia and anemia of CKD, disease areas in which innovation in treatment has been dormant for decades. I believe all nephrologists have an imminent responsibility to have conversations with their patients regarding hyperkalemia and anemia of CKD. We must educate our patients about the severity of these comorbidities and help them understand their treatment options. By working with our partners and allies across the space, together we can advocate for the importance of continued science and awareness in the renal disease space.

It's essential that we continue to hold ourselves accountable to make this a reality and be a catalyst of change in the industry.

**Final question – AAKP believes this can reveal a lot about a person – who is one of your heroes and why?**

It is very hard for me to pick a single hero. So many of the patients I have cared for with advanced chronic kidney disease and their families are heroes to me. I am always amazed at the courage, optimism and grace that so many have demonstrated to me especially during times when I am not sure I would be able to do so. They have helped provide me with the energy and passion to continue to pursue my goal of improving the lives of those that



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still suffer from the consequences of kidney failure and constantly remind me that every day of good health is so precious. 🌱



*Kerry Cooper MD is the US Vice President, medical affairs at AstraZeneca. A former practicing nephrologist, Dr. Cooper most recently led medical affairs in nephrology at Amgen for nearly a decade prior to joining AstraZeneca in 2018. Prior to this, he led direct patient nephrology care, with substantial experience in chronic kidney disease. He has served patients in many capacities, including his experience as a dialysis unit medical director. Dr. Cooper was trained at Yale University where he advanced to the position of associate professor of medicine.*





# A Connection You Should Know About - Heart and Kidney Disease

*By Tricia Haydon*

It is challenging enough having chronic kidney disease (CKD), however include the all-too-common co-morbidities that coincide with kidney disease and there is a lot to manage!

One of the common health problems that go along with kidney disease is heart disease. This can come in various forms, however sometimes the heart disease needs specific treatments either through different types of imaging or potentially more invasive procedures.

It is important for people with kidney and heart disease to be mindful of how any treatment may affect their kidney function. The following highlights some important information that can be helpful to discuss with your physician.

## The Heart-Kidney Connection

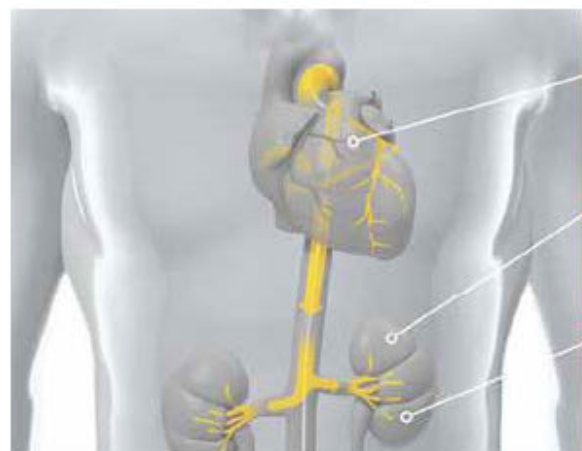
(Read more about the heart-kidney connection <https://www.niddk.nih.gov/health-information/kidney-disease/heart-disease>)

The heart and kidneys work closely together and affect each other more than you might realize. The heart pumps blood filled with oxygen through all parts of your body. The kidneys clean the blood, removing waste products. It is important to know that having kidney disease can directly affect your chances of developing heart disease. Having heart disease can directly affect your chances of developing kidney disease.<sup>1</sup>

## Know your Kidney Numbers

Kidney numbers include Serum Creatinine (SCr) and estimated Glomerular Filtration Rate (eGFR). Both of these numbers measure kidney function and how well your kidneys are doing their job.

Serum Creatinine is a waste product in your blood that comes from muscle activity. SCr is normally removed from your blood by your kidneys, but when kidney function slows down, the creatinine level rises.<sup>1</sup> A blood test is done to measure your SCr levels.



The heart is a hard-working pump that pushes blood throughout your body.

Hydration and reduction of contrast dye should be initiated to protect kidneys during heart procedures.

Kidneys filter fluid and toxins from your body and eliminate them as waste through urine.



eGFR tells how much kidney function you have remaining. eGFR is calculated by your doctor based on your SCr levels, age, race, and gender.

It is important to talk to your healthcare provider about your kidney numbers and what they mean to you.

## Who is at Risk?

Along with CKD, you are at increased risk for Acute Kidney Injury (AKI) if you have:

- Diabetes
- Hypertension
- Heart disease
- Older age

## What is Acute Kidney Injury?

Acute Kidney Injury is defined as an abrupt (within hours) decrease in kidney function, which encompasses both injury (structural damage) and impairment (loss of function).<sup>2</sup>

Acute Kidney Injury can lead to health problems like:

- Irreversible damage to kidneys
- Longer hospitalizations
- Long-term dialysis
- Higher risk of death


## Kidney Kindness in the Cath Lab

Some patients with heart disease will need to be treated with imaging or interventional procedures in a cardiac cath lab. For patients with kidney disease, the contrast dye used for visualization during interventional cardiology procedures can be hard on the kidneys—even causing Acute Kidney Injury (AKI). To protect CKD patients' kidneys, and minimize the risk of further kidney damage, professional medical societies recommend a 3-step approach<sup>3</sup>:

1. **Screen for CKD.** You may have reduced kidney function and not know it.
2. **Hydrate.** This may help protect your kidneys during your cath lab procedure.

3. **Reduce contrast dye.** Lowering the amount of dye delivered to the patient may reduce the risk of AKI.

If you have or are at risk for kidney disease, your doctor should take special steps to protect your kidneys when you are having cardiac procedures. If you know you have chronic kidney disease, be your own best advocate and talk to your doctor before any cardiac procedure is done to ensure your healthcare team is doing everything they can to protect your current kidney function and not cause further damage or AKI.

You and your doctor can be thinking about the health of both organs: your heart AND your kidneys. To learn more about how to protect your kidneys during cardiac procedures, visit [Ospreymed.com/patient](https://www.ospreymed.com/patient). 



**be kind to  
KIDNEYS**



*Tricia Haydon works with Osprey Medical to develop educational and awareness initiatives as part of Osprey's Be Kind to Kidneys Program. Osprey Medical's vision is to make angiography safer for patients with Chronic Kidney Disease.*

### References:

*Information provided should not be used as a substitute for talking with your doctor. Always talk with your doctor about diagnosis and treatment considerations.*

1 National Kidney Foundation. [www.kidney.org](http://www.kidney.org)

2 Clin Biochem Rev. 2016 May; 37(2): 85–98.

3 Levine GN, et al. Circulation. 2011; 124:e574-e651



# CAN A HEART PROCEDURE HURT YOUR KIDNEYS?

## Learn what your doctor can do.

If you're having a heart procedure, it's important for your doctor to take care of your kidneys too. That's because the contrast dye used in many procedures can be hard on the kidneys when you have renal disease. Fortunately, there are effective measures your doctor can take to protect you.



To learn more, download  
our patient education guide at  
[ospreymed.com/dtpatient](https://ospreymed.com/dtpatient)

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# Quenching your thirst for the “good life”

By Michelle McIlhenny, MS, RDN, LD

Summer is here; the birds are chirping, the flowers are blooming, and the temperature is rising. My family and I love living the “good life” in the Texas Hill Country. We stay busy in the summer with hiking, grilling out with friends and tubing down the river. As the thermometer climbs, we often find ourselves reaching for a cold drink to cool off our bodies, when in fact there are better ways to cool off. Staying cool while limiting your fluids is especially difficult when you are living with Chronic Kidney Disease (CKD). To the right are some tips to help you manage your thirst and fluid intake while enjoying an active summer with your family and friends.

My family loves to go hiking during the summer. On one of our first trips I made the mistake of bringing beef jerky for a snack and a lunch of ham and cheese sandwiches, chips and apples. We each brought one bottle of water to drink thinking we would be fine since we were hiking in the shade. As the day wore on, we found our water gone and we were struggling with dry mouth and incredible thirst. I became unusually tired and started to develop a headache.

What happened? We had nearly 2000 mg of sodium in that one meal and snack. The recommended sodium intake is 2300 mg daily for the average adult and less than 2000 mg daily for a person with CKD. Salt binds water, so when you eat salty foods, your body will crave more fluid. If you are living with CKD

your kidneys may not be able to remove the extra salt and fluid you consume, so as it begins to accumulate in your body you may develop shortness of breath, swelling and a lack of

## Outsmart Your Thirst!

Additional Tips to outsmart your thirst and keep you feeling better:

- Good oral hygiene helps reduce the “dry mouth” feeling. Brush your teeth and tongue twice daily and use a refreshing mouthwash.
- Put half a lemon in your mouth – it will create a thirst-quenching sensation!
- Freeze your water bottle, it will help you drink more slowly as you wait for the ice to melt.
- Prepare ice cubes with droplets of lemon or other sour fruit and suck on them slowly for a refreshing way to relieve your dry mouth. Remember to count them as part of your fluid restriction. Or even better... try sucking on a reusable ice cube. It feels cold, yet it doesn't add any fluid to your body.
- Freeze grapes or blueberries and eat slowly to relieve your thirst.
- Take your medications with your meals or take them with applesauce.

*Nutrition Article continued on next page*





energy. Over time, this fluid accumulation left untreated will lead to other health concerns like high blood pressure and heart disease.

What can you do to ease your thirst and avoid the fluid accumulation? One of the most important changes you can make is to follow a low sodium diet. As we learned on our next hiking trip when I packed a low sodium snack and lunch of unsalted nuts, peanut butter and jelly sandwiches, granola bars and apples; we were able to reduce our sodium intake down to 550 mg. Now the one bottle of water was perfect, we felt better and had more energy. We also brought along sugar free gum that helped keep our mouths moist and fresh.

Our society's love of salt is a learned behavior, in other cultures salt is rarely used, instead they use herbs and spices to flavor their foods. You too can learn to make delicious low sodium meals to eat at home or on the go that are easy on your thirst. Some great options to increase your taste sensation without adding salt are garlic, onion, celery, vinegar, lemon or lime juice, and many more. Herbs and spices are also essential to making your low sodium foods taste great. Some of my favorites are chives, parsley, oregano, thyme, cilantro, paprika, and Italian seasoning.

Grilling out is another low-sodium, healthy way to add flavor to your foods. We love to invite our friends over for dinner in the summer and have a DIY (do-it-yourself) kabob bar. We start with fresh meats and/or vegetables and select

## *How much fluid is too much?*

Drinking less fluid can be a difficult change in your diet. Your doctor or dietitian can help you understand how much fluid you can have each day to feel your best. Usually this means 4 cups (32 ounces) plus your total urine output over 24 hours. Remember anything you drink should be counted toward your daily fluid limit. You will also want to count foods that are liquid at room temperature, such as ice, ice cream and soups.

low sodium marinades and spices for added flavor. Each guest gets to design their own skewer by selecting their favorite meats and vegetables for grilling. A bonus of grilling is it helps keep your home cooler since you are cooking outside.

Social events can be a challenge when it comes to limiting your fluid intake as it is easy to drink more than you planned to. One successful strategy is to plan ahead by decreasing your fluid intake earlier in the day. Once you are at your event, use a small glass and take sips not gulps. You will find when you savor your drink it becomes an enjoyable experience, not just a thirst quencher.

Even when following a low sodium diet, keeping cool in the summer can be a struggle. My family has learned the best way to cool off is a dip in the pool or even better a restful float down one of our many rivers. The cool water quickly reduces our body temperature which in turn

*Nutrition Article continued on next page*



decreases our thirst. Research has shown that your body cools down more quickly if moisture is applied to the outside versus the inside. A dip in the pool or river is much more refreshing than a big glass of tea and it lasts longer. If taking a dip in the pool or river isn't in the cards for you, try wrapping a cool moist towel around your neck or using a spray bottle filled with water to mist your face and body, allowing the moisture to cool you as it dries.

Staying cool and enjoying your summer may be easier than you thought. So, remember these tips to help quench your thirst and enjoy the "good life" wherever the summer heat may find you. 🌿



Michelle with her family outside on the river by their home.



*Michelle McIlhenny, RDN, LD is a Lead Dietitian with Fresenius Kidney Care (FKC). She received her B.S. in Human Nutrition and Food Service Management and M.S. in Metabolic Nutrition from University of Nebraska. She has enjoyed*

*working with FKC for the past 25 years helping people living with kidney disease understand their diet and thrive in their new lifestyle. Michelle currently works with FKC renal dietitians to provide professional education and support and serves as a co-chair of the Patient Education Committee on the Nutrition Services Advisory Board. She is an active member of the National Kidney Foundation's Council on Renal Nutrition. Michelle is married with 3 children who enjoy spending time together traveling and being active in the great outdoors.*

A large advertisement for Avantus Renal Therapy. The background is a photograph of a smiling couple walking on a sandy beach. The woman is wearing a white dress and a wide-brimmed hat, and the man is wearing a white polo shirt and shorts. Overlaid on the right side of the image is a large, stylized graphic of the word "GO" in a light blue, semi-transparent font. Text is overlaid on the image, including a headline, a sub-headline, a paragraph of text, contact information, and the Avantus logo with the tagline "tomorrow's therapy today".

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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.

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