



RENAL LIFE

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COVER STORY

INNOVATOR SERIES - Dominic Raj, MD, DM, FASN

International Travel While On Dialysis

Nutrition: Color Your Plate This Spring

Fitness: Spring Into Action

Patient Profile: Jason C. Miller



A Publication of the American Association of Kidney Patients

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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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Jason C. Miller is a kidney transplant recipient who wants to dedicate the rest of his life to an unknown hero who gave him the ultimate gift. A proud native of Cleveland, Ohio, Jason refers to himself as a "renal survivor" with 62 months of hemodialysis, two fistulas, one transplant and an infinite number of needle pricks under his belt. Jason is ready to seize this second chance at life.

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MESSAGE FROM AAKP



AAKP awards U.S. Labor Department for FMLA for organ donors! (Left to Right) AAKP's Chair of Policy and Global Affairs, Paul Conway; Secretary Acosta; FMLA Chief Helen Applewhaite; White House Admin. Sonderling; and AAKP's President, Richard Knight.

I hope all is well with each of you. Spring is here in full bloom in Washington, DC, as is the level of action with AAKP's friends and allies!

I've been elated with the level of activities and efforts AAKP has been able to accomplish this year – during our 50th Anniversary Celebration. I am particularly excited about the engagement we have from many of you, from your participation in advocacy efforts at Hill Days and AAKP's Action Center to your involvement in the online surveys AAKP has been involved in with our esteemed research and industry partners – we thank you!

As you know, April was National Donate Life month. AAKP honored organ donors by holding a social media campaign on National Blue/Green Day to celebrate patients who received transplants, those who are waiting for transplants, as well as the donors who selflessly provided a fellow human with a second chance at life. Thanks to all of you who participated in the social media effort to increase awareness of the importance of organ donation.

In this issue of *aakpRENALIFE* there are several informative articles that we feel will be of great interest to you. There is an article on international travel while on dialysis to help you plan your summer getaway featuring

a Top 10 Checklist to make your trip a success. We often speak of diet and exercise, but aren't sure how to incorporate it into our daily lives in a way that will keep us committed and motivated. This article, authored by Carolyn Feibig, MS, RD, LD, Transplant Dietitian at The George Washington Hospital shares easy strategies for getting more involved with exercising. Also featured in this issue is an important food and nutrition article that aims to provide insights on the importance of fresh fruits and vegetables in a Chronic Kidney Disease (CKD) diet. Potassium, phosphorus, or fluid content - all issues for CKD patients can be improved by proper use of fruits and vegetables. Also, check out the patient profile on Jason Miller. Jason's story is very motivating and personifies the mindset of a kidney warrior. When I read his profile, I was reminded of how awesome my fellow kidney patient friends are in pursuing life's goals and ambitions in spite of CKD.

I'm also extremely pleased that AAKP and The George Washington University School of Medicine and Health Sciences (SMHS) is hosting a collaborative, inaugural Global Summit on Innovations in Patient-Centered Kidney Care this month in Washington, DC at the GWU campus in the Jack Morton Auditorium. To highlight the

outstanding work and services GWU provides to kidney patients, AAKP is honored to feature Dominic Raj, MD, DM, FASN in this month's Innovators Series. Dr. Raj is a dedicated Nephrologist, teacher, researcher, and visionary. The relationship between AAKP and GWU has evolved over the past three years. Read how Dr. Raj has built upon this relationship and continued to develop the unique legacy of GWU SMHS by building a world-class team of health care professionals. He also discusses his role in pioneering and launching the AAKP and GWU SMHS Inaugural Global Summit on Innovations in Patient-Centered Kidney Care.

On the national scene, AAKP continues to forge ahead in representing the voice of the patient in a variety of venues. We live in a world of metrics, and by any measure, AAKP is on pace in 2019 to increase our metrics well beyond what was a successful year in 2018. AAKP's Staff, led by Diana Clynes, Executive Director, is doing a great job of implementing AAKP's National Strategy. Thanks to many of you - patients, allies, and friends alike - we are conveying our message to all areas impacting CKD patients. Your participation in the two most recent Hill Days are examples of YOUR power. The Kidney Patient Summit hosted by the National Kidney Foundation (NKF) was attended by over 30

AAKP Ambassadors supporting the effort. The American Society of Nephrology (ASN) held their Kidney Health Advocacy Day (KHAD) on March 20, 2019. AAKP Ambassadors and AAKP Board members joined Advocates from ASN for the sixth consecutive year to visit members of Congress. We focused on innovation in the kidney space and specifically asked for \$25 million in matching Funds in the (FY 19) 2019 Appropriations bill. Again, thanks to you and the AAKP professional staff, the day was a success. We visited over 100 Congressional and Senate offices to discuss funding for KidneyX.

AAKP continues our efforts to work with the Executive Branch. I joined Paul T. Conway, Chair of Public Policy and Global Affairs (Immediate Past President) in meeting with U.S. Department of Labor Secretary Acosta where we discussed several kidney and workforce issues. AAKP presented Secretary Acosta with a plaque thanking him for his efforts on clarifying that the Family Medical Leave Act (FMLA) covers organ donors (Watch OnDemand at bit.ly/AAKPFMLA). During this visit, we also presented FMLA Chief Helen Applewhaite with an award for authoring the letter from Secretary Acosta which confirmed that FMLA covers organ donors. The support from Secretary Acosta is a building block for the ultimate passage of the Living Donor Protection Act (LDPA). AAKP is one of the few organizations deploying this strategy to achieve the objective of increasing the donor pool for kidneys.

For the past three years AAKP has vigorously opposed the Dialysis PATIENTS Demonstration Act (DPDA). We believe that this

legislation is not in the best interest of our patients for several reasons, but primarily because the DPDA limits the patient's choice. AAKP and one of our allies visited several sponsors of this legislation to encourage them to reconsider their support of this legislation should it be introduced during this Congress. Our goal in these pre-emptive talks is to educate the members and their staff about how independent patients view the bill. Additionally, AAKP Ambassadors and Board members will be participating in upcoming Hill Days with American Society of Transplant Surgeons (ASTS) and the American Society of Transplantation (AST). The primary topic of each Hill Day will be DPDA. Thanks to each of you for your tireless efforts in making phone calls, writing letters, and posting on social media. Continue to visit the AAKP Action Center for the latest policy and legislative updates: www.aakp.org/action-center.

If we are not aware of our history, we are subject to repeat mistakes of the past. AAKP existed before Kidney Care became a thriving business. Large corporate dialysis lobbyists write legislation for kidney patients without sufficient input from you. AAKP and our allies will always stand for what is in the best interest of our patients' and our families. Our strength is our ability to stand on the shoulders of those patients who have come before us. Each of us must continue to stay tied into AAKP's many educational vehicles from webinars to meetings and summits.

Our Ambassador Initiative is a major success. I believe that imitation is a sincere form of flattery. Our members – Ambassadors, caregivers,

and friends – because of your experience, commitment, and engagement tend to attract other organizations to each of you. A helpful aspect of our National Strategy is that it does not only provide us with guidance about what to do, but it also informs us as to what we should not do. AAKP has a unique agenda that is borne out of our independence in fact, and appearance. We anticipate growing our Ambassador Initiative to 400 in the next few years. Stay tuned for the rollout of our plan to implement this effort. You are the cornerstone of the Ambassador Initiative, and we need your involvement for its continued growth and success.

Finally, as our 50th Anniversary Celebration is taking place throughout this year; the theme of our events remains consistent with AAKP's charge to educate patients, caregivers, policymakers, and other stakeholders. We are making history as we show the nation that engaged patients play a critical role in increasing patient outcomes and improving our quality of life. Please be sure to visit www.aakp.org/50thanniversary for information on our major events and activities throughout the year, including links to event web pages to register and join us!



Richard Knight,
President of AAKP

Enjoy this issue of *aakpRENALIFE*. We ask that you follow us on social media and let us hear from you (Facebook @kidneypatient and Twitter @kidneypatients).

AAKP Innovator Series:

Dominic Raj, MD, DM, FASN,

School of Medicine & Health Sciences

THE GEORGE WASHINGTON UNIVERSITY

*George Washington
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was founded in 1824, the
GW School of Medicine and
Health Sciences (SMHS) is the 11th*

*oldest medical school in the country
and the first in the nation's capital. Since
its establishment, the school has been at the
forefront of medical education and has grown
to include highly-ranked programs in the health
and biomedical sciences. With dozens of top-
tier residency programs, SMHS is a competitive
and esteemed destination for medical school
graduates across the country. Today, students
and residents are exposed to some of the most
innovative educational techniques, taught by
world-renowned faculty members, in state-of-
the-art facilities. In this Innovator series article,
AAKP is pleased to feature Dr. Dominic Raj,
Director of the Division of Renal Diseases and
Hypertension at GW School of Medicine and
Health Sciences and Co-chair of the Inaugural
Global Summit: Innovations in Patient-Centered
Kidney Care – an educational collaboration
between AAKP and the GW SMHS.*

Who are your personal heroes?

My heroes include the late Professor JCM Shastri, MD, who was the Chief of Nephrology at Christian Medical College in Vellore, India. He was an inspiring teacher, role model, and a remarkable physician. He taught me that there is no substitute for hard work. Another hero is Dr. William E. Mitch, Professor of Medicine at Baylor College of Medicine, former president of the American Society of Nephrology (ASN) and a passionate researcher and who was an inspiration to me. He always found time to help junior faculty from any institution and expected nothing in return.

Why did you choose the field of Nephrology?

Nephrology chose me. During my residency (MD) at the Stanley Medical College, I was debating between neurology and cardiology when I was called to cover the nephrology inpatient service for a week. Soon I realized that the kidney is the smartest organ in the body. Never before had I seen such astute application of physiology and immunology in clinical medicine. I was captivated by the nephrologist's ability to control the interior milieu of the body by dialysis and to modulate the immune system to accept a transplanted kidney. However, the most important deciding factor was the impact on patient outcomes. Without renal replacement therapy, the patient's mortality is 100%. I realized that besides out-thinking

other specialties, nephrologists save lives every day. It is a great feeling and I am a very proud nephrologist.

How did your first experiences with kidney patients impact your approach to patient engagement?

I observed how dialysis remarkably improves physical symptoms in patients with end-stage kidney disease, but soon realized the anxiety, stress, and financial impact of the disease. Treating kidney disease should be a collaboration between the physician and patient, to ensure that we are taking care of the patient's physical and emotional well-being. I am a lifelong learner and throughout my career, patients have and continue to teach me a great deal, both professionally and personally. The insights they share from their experiences and ability to persevere are truly amazing.

At George Washington University School of Medicine and Health Sciences, you built and manage a highly talented medical team – tell us how you attract and retain talent.

George Washington University School of Medicine and Health Sciences has a unique legacy of providing innovative patient care for the population of Washington, D.C. In 1956, George Washington University purchased its first artificial kidney - a "Kolff Kidney" - and in 1964 Professor Alvin Parrish opened Washington D.C.'s first dialysis unit to serve the public. This began a tradition of progressive renal medicine that continued at George Washington University under the leadership of Professor Anne Thompson M.D., Professor Juan Bosch MD, Professor Paul Kimmel MD, and Professor Susie Lew MD. I was fortunate to inherit a strong clinical division, with the faculty members committed to advancing nephrology through education, research, and compassionate patient care. We attract talented physicians who are passionate about innovating

patient care and serving the community. Under my tenure, the George Washington University kidney transplant program was re-established, a state-of-the-art acute hemodialysis unit was built to provide a myriad of extra-corporeal therapies, and we established satellite clinical services in Maryland and Virginia to provide care for our patients closer to home. We are now a quaternary care center for Onco-nephrology, Glomerulonephritis, complicated hypertension, and Kidney Wellness Clinic that promotes life style modification for slowing progression of kidney disease. We were honored to be ranked as a high performing division in the U.S. News & World Report. George Washington University is at the forefront of nephrology research, inventing gene-based therapies for hypertension, exploring novel therapies to improve outcome in hemodialysis patients, piloting new therapies for chronic kidney disease and participating in research aimed at improving kidney transplant outcomes. The George Washington University Division of Nephrology is also pioneering microbiome-based therapies for kidney disease. We are fortunate to have outstanding faculty and the very supportive leadership at George Washington University, who help us to advance our mission of providing the best care for our patients. I draw my inspiration from our patients and my faculty and fellows have been the pillars of support on whom I lean.

As a practicing nephrologist, teacher, mentor, researcher and visionary – what innovations do you foresee for patients in the next 3-5 years?

After decades of neglect, the government is focusing on the epidemic of kidney disease, thanks to the efforts of organizations such as the American Association of Kidney Patients (AAKP) and the American Society of Nephrology (ASN). A number of innovative initiatives have been launched such as the National Institutes of Health/National Institute of Diabetes, Digestive and

Kidney Diseases (NIH/NIDDK) sponsored “Kidney Precision Medicine Project,” the APOL-1 long-term kidney transplant outcome (APOLLO) study focused on African-American patient disease impacts, which is also lead by NIH/NIDDK, and the new U.S. Department of Health and Human Services collaboration with ASN known as the KidneyX Innovation Accelerator Project. Each of these initiatives are positioned to develop prevention strategies and deliver personalized treatment based on variation in the genes, environment, and lifestyle for each patient. Advances in manipulation of matter on an atomic and molecular scale (nanotechnology) and 3D printing, a process of making three-dimensional solid objects from a digital file are poised to transform the way we are currently managing kidney problems and kidney transplantation. I am also very optimistic about the new alignment of the U.S. Food and Drug Administration (FDA) and the Centers for Medicare and Medicaid Services (CMS) in kidney care which will make it easier to regulate and pay for new devices that are on the horizon such as potential implantable and wearable kidney replacement therapies.

You helped pioneer and launch the AAKP and George Washington University Inaugural Global Summit on Innovations in Patient-Centered Kidney Care. What you do you hope attendees walk away with after participating this event?

George Washington University and I are honored to be partnering with AAKP in this Inaugural Global Summit, which I am optimistic will be an annual event, given the enthusiasm among

patients, providers, and policy-makers. Paul Conway, AAKP Chair of Policy and Global Affairs and I had been contemplating such a conference for a long time individually, waiting for the right partner. When we met, the concept rapidly took shape fueled by the unabated enthusiasm of AAKP and George Washington University’s desire to host the event. It has been conclusively shown that when patients partner with physicians, it leads to improved health outcomes, enhanced quality of life, and delivery of more appropriate and cost-effective treatment. I hope our attendees walk away with a better understanding of the latest research underway worldwide, as well as the unique perspective of patients and providers. This is a first small step towards a larger dialogue on transformative kidney care because the epidemic of kidney disease is a worldwide issue and it will take a global commitment of both patients and experts to collaborate and to drive innovative solutions.

George Washington University treats a wide variety of patients – ranging from Presidents to Congressional leaders to high-powered executives and, of course, a wide-range of international and local D.C. residents. What is your common approach to all patients and what key factors does every kidney patient have in common?

We provide the exact same compassionate and personalized care to the rich and powerful as we do for “John or Jane Doe” – to George Washington University and to our medical professionals, this is both a matter of ethics and principle and we know kidney disease can strike anyone. No matter who we treat, their questions are the same, namely 1.) why was I not warned before about my kidney problem so that it could be prevented?; and 2.) given the magnitude of the problem, why aren’t more resources prioritized toward this disease? Each patient motivates us to strive harder for a cure. The long hours and the heavy workload of the

nephrologist is more than compensated by the appreciation and gratitude from each one of our amazing patients, regardless of their position professionally or in life. 🌸



Dominic Raj, MD, DM, FASN

Born:

Nagercoil, Tamil Nadu, India

Education:

Madurai Medical College, India

Family:

My intelligent and fantastically supportive wife, Sheeba S Dominic, MBBS; my lovely and gifted daughter, Elizabeth A Barrows, MD, MS; and my outstanding son-in-law, Ian R Barrows, MD.

Interests outside Nephrology:

Poetry, World History and Travel




Dominic Raj, MD, DM, FASN is board-certified in Internal Medicine and Nephrology. He is a Professor of Medicine, Biochemistry & Genetics and Biostatistics and Epidemiology at the George Washington University (GW)

School of Medicine and Health Sciences. He is also the Director of the Division of Renal Diseases and Hypertension at GW.

Dr. Raj is a Fellow of the American College of Physicians and a Fellow of the American Society of Nephrology. He has received a number of awards and recognition from various national and international institutions including the Distinguished Researcher Award from GW in 2014.

During his tenure at GW, Dr. Raj expanded the research portfolio, added new clinical services and revamped the educational program. He established a number of sub-specialty clinics such as the glomerular diseases clinic, kidney stone clinic, Polycystic Kidney Disease clinic, Kidney Wellness Clinic and ultrasound clinic. He is pivotal to establishing the kidney transplant program at GW. In order to serve the community needs, he established satellite practices in Maryland and Virginia. He has been named Washington Top Doctor multiple times. During his tenure, the Division of renal Diseases and Hypertension has been named “high performing” specialty by the US and World Report.

Dr. Raj has been invited as a visiting professor to a number of prestigious institutions including Harvard Medical School, Cornell University and New York University. He has chaired and spoken in multiple symposia organized by the American Society of Nephrology, International Society of Nephrology, German Society of Nephrology and European Association for the Study of Diabetes.



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International Travel While on Dialysis

*By Barbara Wallace, Renal Dialysis Nurse,
and Deborah Pelaez, AAKP Marketing and Communications Manager*

At AAKP, we know how important quality of life is for kidney patients, including those on dialysis. Planning a vacation away from home can seem like a daunting task. This article was written to help those who are considering not just a vacation, but an International vacation while on dialysis. AAKP interviewed international dialysis nurse, Barbara Wallace, co-owner of Irish Holiday Dialysis, to learn about important things to consider when planning a trip abroad including a Top 10 List, which you will find highlighted below.

Choosing a Vacation Destination

So, you have decided to plan an International vacation while on dialysis. How will you decide where to go? Maybe you've always dreamed about traveling somewhere like Paris or Ireland, but before you book that trip there are many things to consider.

First, Barbara suggests choosing a vacation destination in a country with a reputation for high quality healthcare and with clinics that have similar high standards to your own center. This will ease your mind and make many of the other travel decisions easier.

Additionally, she encourages patients to talk to their clinic's social worker or patient concierge to ask for help when planning as well. You don't

have to plan alone, there are many people and resources to help you. Your social worker may have additional resources and services for you, but Barbara recommends these websites when investigating International travel destinations with dialysis clinics:

Travel Resources

<https://www.booknowmed.com/> - An online booking engine for international travel dialysis, allowing users to check availability, cost and book dialysis in real time. It is non-promotional and free of charge for the patient.

<https://traveldialysisreview.com/> - This website is run by a group of dialysis patients who like to travel internationally. It is a very honest website that shares good and bad reviews. This website also offers a travel blog.

<http://www.globaldialysis.com/> - A long established website for dialysis and travel with a database of thousands of international clinics and lots of practical travel advice.

If this is your first international vacation while on dialysis, you may also want to choose a country where there is no language barrier. Furthermore, Barbara suggests choosing a country with established tourism links with the U.S. She says that this makes planning much

easier, such as finding direct flights, travel reviews and more.

Planning for your Trip – Important Information

Allow time for the clinic you choose internationally to receive all your medical information. This could take about one month. Your physician will need to deem you fit to travel. Most international clinics will require a letter of consent, as well as all medical records in advance. All records should be sent electronically and securely between your home clinic and holiday clinic well in advance. You will not usually need to bring any medical records with you when travelling – care should be taken with your personal data. Diabetics should bring blood sugar records.

Dialysis Treatment Internationally – What to Expect

Dialysis patients get to see a side of a country that few people get to see – the medical side. The aim at any clinic is to give you the exact same treatment as you would at home. The dialysis machine may be a different model, but it can be programmed to your specific prescription. Any slight difference there may be will be identified in the planning stage. You should travel in confidence, with no worries about safety, and trusting you will get the same type of treatment.



Barbara's Top 10 Checklist to Planning International Vacation for a dialysis patient:

1. Start planning early! Decide on specific date for your trip but be prepared to be flexible within those dates.
2. Do not book any other parts of your trip until you have secured your dialysis appointment(s) schedule.
3. Make sure you understand the acceptance criteria for the clinic you are going to. Be aware that if your medical situation changes in any way, you will need to notify the clinic and make sure you can still be accepted.
4. If on the Kidney Transplant Waitlist – consider that you will be suspended from the list temporarily while out of the country.
5. Make sure you bring enough medication (prescriptions) to cover your entire trip. Medication should always be carried with you in your hand baggage.
6. Look into your insurance – health and travel. Does your health insurance cover you internationally? You may need to apply for international health insurance, so if you become unwell and you need further medical attention, you would be covered. Likewise, you may want to purchase travel insurance for your trip in the event of a cancellation due to health or other factors.
7. Think about your food and drink challenges. When you go abroad you will experience different food and drink. It is a good idea to speak to your renal dietitian before traveling to get advice on how to eat kidney-friendly while still enjoying the international fare!
8. Plan your trip around your clinic. Get specific locations of destinations you wish to visit – use Google maps to see exactly how far the travel is from your accommodations.
9. Consider your travel companions - how will your dialysis days impact others? Can you travel independently for your treatment or do you need a companion to accompany you?
10. Be in the best physical health possible before travel – long distance travel can be very demanding on your energy levels!

After planning your trip in confidence using these tips and pointers, we wish you safe travels and remember to enjoy what a holiday is all about – enjoy the culture, the people, the country you are going to and enjoy the ones you are with. 🌿



Barbara Wallace is currently a Nurse manager and co-founder of Irish Holiday Dialysis (www.irishholidaydialysis.ie / info@irishholidaydialysis.ie). Barbara qualified as a renal dialysis nurse in London in 1998 and has

worked hands-on at the frontline of patient care. She has a wide range of experience in public, private and commercial healthcare settings and has worked in many different countries. A position as Clinical Nurse Specialist with a

major dialysis equipment manufacturer saw her train both home patients and nurses to use dialysis equipment. She has a wealth of experience and knowledge in all aspects of this specialized field of nursing. In 2017 she co-founded the first-ever dedicated holiday dialysis clinic in her home country of Ireland after having identified the lack of this essential service for international holidaymakers and seeing the many positive benefits that travel and holidays can have on them.



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Jason C. Miller

Jason C. Miller is a kidney transplant recipient who wants to dedicate the rest of his life to an unknown hero who gave him the ultimate gift. A proud native of Cleveland, Ohio, Jason refers to himself as a “renal survivor” with 62 months of hemodialysis, two fistulas, one transplant and an infinite number of needle pricks under his belt. Jason is ready to seize this second chance at life. “I seek to exceed the expectations of my unknown hero and the family, friends surviving his untimely end. My second chance at life will celebrate his gift to the magnitude of the gift.”

Growing Up

No stranger to enormous endeavors, Jason became a champion horse rider by age two. He earned the honor of Cub Scout Arrow of Light by elementary school and became a Patrol Leader at the National Jamboree by middle school. Jason went on to raise in-excess of \$25,000 dollars in high school to first honor his late mother with completing his Eagle Scout project and re-building an outdoor chapel from his mother's childhood. Next, he represented the United States of America at World Jamboree in Soul Korea, sparking his interest in travel and seeing the world.

During his senior year of high school, Jason established a government contracting company in his hometown municipality and secured a \$40,000 street services contract. He dropped out of college after three semesters to pursue hospitality and ultimately became a proprietor of a restaurant in Dayton, Ohio. The next two decades Jason continued several notable achievements before walking away from a hugely successful career, returning to complete



Taken in September 2018 on the Eastern coast of the Yucatan peninsula of Mexico in the Sian Ka'an Biosphere, in the state of Quintana Roo, and municipality of Tulum Mexico and was listed as a UNESCO World Heritage Site in 1987.

his higher education. Seeking a more fulfilling life, Jason returned to college at the age of 35 to pursue a career path that would allow significantly more quality time in his life for things he loved like travel.

Diagnosis & Dialysis

That's when life came to a screeching halt with a diagnosis of onset end-stage renal failure. It was at this time, with no medical insurance, that he discovered his kidneys had stopped processing and accumulated 16 kilos of fluid and toxins sitting on his chest. The diagnosis resulted in an unexpected month-long visit to the local hospital where he began hemodialysis.

Jason had to drop out of college temporarily due to his new diagnosis but persisted the very next semester with fifteen credit hours of course work and fifteen hours of chair time each week. His dialysis center accommodated his determination to maintain employment and a healthy lifestyle with a 5 p.m. chair time on Monday, Wednesday and Fridays and provided in-chair exercise



equipment and a laptop table for studying, allowing Jason to attend school by day and dialysis by night.

Even with a full life of accomplishments, Jason grew depressed as dialysis took over his life. He had very little time to hang out with friends or pursue his purpose or passions. Between classes, medical appointments and dialysis, his daily routine became discouraging and caused him to wonder if it was worth the fight. Depression and suicidal thoughts became the norm, and after an attempt on his own life, Jason received help and entered therapy. His second therapist proved to be a perfect match and the needed support his family and friends couldn't or wouldn't provide.

Both clinical depression and gross obesity prevented Jason from getting on the transplant waitlist for two years. With his depression now under control, Jason made steps to improve his health and lose weight. He ate healthier, enjoyed outdoor workouts and underwent weight loss surgery reducing his stomach two-thirds and losing 185 pounds!

Transplantation

Jason graduated from The University of Akron with a BA in Public Relations with Honors and started a rewarding career in the non-profit sector. To get more control of his life and after 62 months of hemodialysis, Jason pursued, and received approval for Peritoneal Dialysis at home instead of In-Center Hemodialysis. It

was only two weeks into his Peritoneal Dialysis experience when he got the unforgettable series of two calls first instructing to standby and then to rush to The University Hospital in the prestigious Cleveland University Hospital Circle. His third and final call from the transplant coordinator was just six hours prior when Jason began surgery. Just 12 hours later, waking to his older brother by his side, was the start of his recovery and just another 18 hours was his first steps on a walker in that direction to see the world.

After learning of a one-year travel ban after a transplant, Jason dreamed of the places he could go with his new kidney and how to honor this gift of life and a lifetime. With a vague understanding of the World Heritage List, he began a year-long research endeavor into the United Nations Educational, Scientific, and Cultural Organization (UNESCO).

International Travel

Once cleared for international travel, his first journey was across the pond for a Belgian waffle, and he felt the breeze from the windmills of Holland followed by a nightly hunt for the elusive northern lights of Iceland. Jason experienced two UNESCO World Heritage Sites during his first of 18 trips in 2018.

Jason coupled his passion for seizing his second chance with his determination for seeing the world by creating a YouTube Channel to honor

his unknown hero's life and gift. The debut episode titled "The Ultimate Thank You" (<https://youtu.be/juJxGON9Um4>) was dedicated to his donor and his donor's family. Jason hopes that the many friends and family of his hero will find pleasure in seeing their loved one live on through his adventures and travels to each UNESCO site. (A UNESCO World Heritage site is a legally protected site or area with historical significance or prominence. In fact, 1,092 sites have been inscribed and protected by the 167 nations that ratified and committed to preserving our natural and cultural sites for all of humanity.)

Jason hopes you will join him on his quest to visit each UNESCO site, where he hopes to inspire and motivate all to "Seize the Day." These three words are how he lives each day of his second chance at life and hopes to encourage the newly diagnosed, the veterans and the lifers of dialysis to remember time is the great equalizer and time is the most precious asset, so get out there and SEIZE THE DAY! 🌸



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- Represent AAKP at conferences, events & exhibitions
- Author articles on various topics (*aakpRENALIFE*, AAKP Blog)
- Network with fellow kidney patients & caregivers

AAKP's Ambassador Initiative is part of our Center for Patient Engagement & Advocacy that works to ensure that the voices of kidney patients and their families are heard. AAKP Ambassadors are our most engaged volunteers.

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Color Your Plate This Spring

By Jennifer Moore, Registered Dietitian



Spring Color with Fruits and Veggies

Spring and summer bring an abundance of fruits and vegetables to local grocery stores and farmers markets. The vast array of color that accompanies this produce speaks of more than merely juicy deliciousness; it signifies nutrients and health.

Unfortunately, people with chronic kidney disease (CKD), both early stages of CKD and individuals on dialysis, often believe that they must avoid these foods due to potassium, phosphorus, or fluid content. However, plant-based phosphate is poorly absorbed, so it will not significantly raise phosphorus levels for early CKD or dialysis. Fluid excess in dialysis typically is from drinking too much, not from food. Potassium should be approached with caution but not over-restricted. Nonetheless, many have been wrongfully counseled to avoid most fruits and vegetables altogether.

Notably, fresh fruits and vegetables are vital to a CKD patient's health for many reasons including thwarting inflammation, creating a more alkaline environment and boosting fiber intake.

Inflammation

Persistent, low-grade inflammation characterizes the health status of CKD and dialysis patients. This inflammatory state is partly responsible for the increased risk of cardiovascular disease and low albumin levels, and it contributes to many causes of mortality among the CKD population. Inflammation also encourages oxidative stress in the patient's body.

Picture an apple. When cut, the apple, being exposed to oxygen, begins to turn brown. This illustrates what happens in the CKD patient's body with inflammation. Over time, oxidation leads to internal "browning," i.e., tissue damage and health problems. Now, picture squeezing lemon juice on the apple, a common practice. Why does the lemon juice stop the browning process? Lemon juice contains vitamin C, a potent antioxidant.

Thus, what do we need to counteract this process of inflammation and oxidation in the CKD patient's body? The answer is ANTI-oxidants. What foods represent the best source of antioxidants? Fruits and vegetables. Therefore, people with kidney damage and corresponding high inflammation levels should include antioxidant-rich fruits and vegetables in their diet daily to reduce risks associated with inflammation. Additionally, as inflammatory markers decline, albumin tends to increase. Some examples of fruits and vegetables rich in antioxidants and lower in potassium that are appropriate for CKD and dialysis patients include:

Fruits	Vegetables
Berries	Dark Green Leafy (Kale, Raw Spinach)
Plums	Brussels Sprouts
Cherries	Broccoli
Red Grapes	Red Bell Pepper

Nutrition Article continued on next page

Alkaline Environment

Metabolic acidosis, common in CKD patients, has long been a concern of nephrologists, as this complication gives rise to substantial loss of muscle mass in all kidney patients. In those who are not on dialysis yet, it contributes to accelerated decline in kidney function.^{2,3} Fruits and vegetables are naturally alkalizing. In fact, a study was done in 2012 where researchers treated stage 2 CKD patients with either a sodium bicarbonate supplement or simply increased the number of fruits and vegetables in the diet. Both treatments were intended to lower acid levels in the patient's body. Results showed that not only were the patient's bodies more alkaline, but indicators of kidney injury were actually lower in the fruit and vegetable group!¹²

Because many CKD patients avoid fruits and vegetables due to potassium fears, they compensate by eating a large amount of animal protein. High consumption of animal protein leads to an excessive acid load; animal protein is NOT alkalizing.

Furthermore, muscle-based animal products are naturally high in potassium but often excluded from high potassium food lists. Additionally, meat is often enhanced with potassium additives and preservatives. In fact, one analysis found potassium enhanced boneless loin strip steak contained 930mg/100g potassium.⁴ There are, however, many alkalizing fruits and vegetables

low in potassium. Check out the recipes using lower potassium, super alkalizing fruits and veggies provided at the end of this article.

Fiber

Finally, CKD patients need fiber in their diet. Fiber, a carbohydrate the body can't digest, comes in two forms, soluble and insoluble. Soluble fiber benefits include lower glucose and cholesterol levels. Insoluble fiber favors bowel regularity. Adults need at least 20-30 grams of fiber daily, but most are lucky to get 15 grams per day.⁵

A common issue encountered by dialysis patients is constipation. Fluid restrictions and lack of fiber contribute to the problem. Once again, these patients are not consuming fruits and vegetables that boost the fiber content of the diet.

High fiber foods are easy to include in the diet. Start the day off right with a high fiber breakfast.

One idea is **Apple Oatmeal**:

- 1 cup cooked oatmeal
- 1 apple chopped
- 1 tablespoon flaxseed
- 1 teaspoon cinnamon
- 1 teaspoon honey

Summary

After a long winter, refreshing, crisp fruits and vegetables can be a joy, even for those with kidney disease. By reducing inflammation,

Cucumber Watermelon Salad



6 ingredients · 20 minutes · 2 servings

Directions

Chop and add watermelon and cucumber to a large salad bowl. Mix olive oil, lemon juice, and agave up in a small cup or bowl to make a dressing. Season the dressing with cracked black pepper. Pour the dressing over the melon and cucumber in the bowl and stir so everything is coated. Sprinkle over the fresh mint and stir gently again. Cover bowl and place in the fridge for 20 - 30 minutes to let the flavors infuse.

Ingredients

- 3/4 cup Seedless Watermelon
- 1 Cucumber
- 1/2 cup Mint Leaves
- 1 tbsp Extra Virgin Olive Oil
- 2 tbsps Agave
- 2 tbsps Lemon Juice

Nutrition - Amount Per Serving

Calories	167	Protein	2g	Calcium	45mg
Fat	7g	Cholesterol	0mg	Iron	1mg
Saturated	1g	Sodium	6mg	Vitamin D	0IU
Carbs	28g	Potassium	337mg	Vitamin B12	0ug
Fiber	2g	Vitamin A	759IU	Phosphorous	48mg
Sugar	22g	Vitamin C	17mg		

Modified from A Virtual Vegan, <https://avirtualvegan.com/>

Broccoli Pepper Stir Fry



8 ingredients • 15 minutes • 3 servings

Directions

Saute garlic and ginger in vegetable broth until fragrant. Add broccoli, bell pepper, and green onion. Saute until crisp/tender (3-5 minutes) Add low sodium soy sauce and sesame oil. Toss to mix in completely. Remove from heat. Can be served over rice.

Ingredients

- 1 cup Broccoli (cut into florets)
- 1 Chopped Red Bell Pepper
- 1 tbsp Fresh Grated Ginger
- 2 stalks Green Onion (chopped)
- 1 tbsp Garlic (minced)
- 2 tbsps Organic Vegetable Broth
- 2 tsps Sesame Oil
- 1 tbsp Soy Sauce

Nutrition - Amount Per Serving

Calories	56	Carbs	6g	Protein	2g
Potassium	357mg	Calcium	22mg	Vitamin B12	0ug
Fat	3g	Fiber	2g	Cholesterol	0mg
Vitamin A	1773IU	Iron	0mg	Phosphorous	38mg
Saturated	1g	Sugar	3g	Sodium	185mg
Vitamin C	79mg	Vitamin D	0IU		

acidosis, and boosting fiber, these nutritious gems will have CKD patients hopping right into spring with energy and vitality. Try some of the ideas provided here and keep your eyes peeled for additional spring and summer produce available near you. For tips to include more nutrient-rich fruits and vegetables in the diet, consult your local dietitian who will be able to provide guidance. Most of all, remember you are more than someone with kidney disease. You are a person who brings color to this world so add some color to your plate and gain vigor to enjoy the sunshine and warm weather this spring. 🌸

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Jennifer Moore, Registered Dietitian, is passionate about helping all people realize optimal health. This includes the renal population for whom she has served for over 15 years. Throughout her years of practice and research, Jennifer has

discovered that a diet centered on whole, plant-based foods promotes the most nutritious option. As a result, she has numerous articles published on this topic as well as a history of speaking and educating on both renal and plant-based nutrition. (Watch a recent AAKP webinar that Jennifer Moore spoke on called "For the Love of Plants" on our Past Webinar tab at: <https://aakp.org/aakp-healthline/>)

She has worked with individuals with end-stage renal disease on all forms of dialysis. Additionally, she works with chronic kidney disease patients to help them slow or prevent progression.

Jennifer achieved a nutrition degree from Mississippi State University and interned at Vanderbilt University Medical Center. She holds a Master's Degree from Central Michigan University in nutrition. She is a Certified Specialist in Renal Nutrition through the Academy of Nutrition and Dietetics and a Certified Plant-Based dietitian through Cornell University. You can reach Jennifer at: plantfedkidneys@gmail.com



Spring Into Action

By Carolyn Feibig, MS, RD, LD

Spring is the perfect time to shake off those winter blues and start something new. The world is coming alive again after the cold and dark winter. Everywhere you look new life is popping up, the trees are budding, flowers are peeking through the once frosted ground, birds are chirping, even the sky seems new and bright.

Spring is the ideal time to set physical activity goals. A lot of us make New Year's resolutions promising to get into better shape but, by the time Spring rolls around many of us have given up on those goals. Maybe the resolution is on target, but the timing does not work. January might be a great time to start cooking more or to read that book you have been carrying around but may not be the best time to rev up your physical activity. Starting a physical activity routine in January is tough. It is too dark in the morning, too dark in the late afternoon, too cold in many places but, now when everything is springing anew, we can spring into action too.

Beginning your activity in the springtime is the way to go especially if you don't like exercise. Spring activity doesn't feel like exercise, it feels like busting out from your winter hibernation. This is why Spring is the perfect time to start a physically active routine. We want to spend time enjoying the longer days and warmer weather. Increasing your physical activity doesn't have to be intimidating.

Do not think of exercise as going to the gym for hours, running a marathon, or going to an early morning boot camp. Do not think that you must devote your life to exercise. The best type of exercise is the exercise you do. Let me say that again: **the best type of exercise is the exercise**

you do. It doesn't have to be extreme; maybe it is taking a walk after dinner.

When we start something new and, possibly something we find intimidating, we make excuses:

- I'm too busy
- It's too expensive
- People will judge me
- I don't like gyms
- I'm not coordinated
- I'm too tired
- I don't have the time

Choosing an activity you enjoy makes it easier to break the excuse cycle, stick with it, and change it into something you look forward to.

Many of us find it hard to start or commit to daily activity even though we know the benefits:

- Better blood pressure
- Better blood sugar
- Improved cardiac function
- Possible weight loss/maintenance
- More energy

Finding 30 minutes every day for the recommended exercise stint is hard. Don't worry about that. Use the time you can find. Five or 10 minutes increments actually work! Once you are in the habit of daily activity you might want to increase the time you spend doing it or even find that you miss it if you skip a day! The more consistent you are, the easier your routine becomes making it more likely you will continue.

Remember it is about increasing your everyday movement. It could be parking in the furthest spot, taking a walk after dinner, listening to music and dancing while cleaning or cooking, or even

doing some form of exercise while watching TV.

Great TV watching activities:**

Leg Lifts – sit on the edge of your chair* and lift your left leg (off the ground but no higher than hip height) and hold for a count of 10, do the same with your right leg. Do a set of 20 alternating legs for a total of 10 lifts for each leg.

Opposite Elbow Twist – sit on the edge of your chair* and bend your right elbow down while raising your left knee, like you are trying to touch the pair, and do the same with your left elbow and right knee. Do a set of 20 for a total of 10 near touches with each elbow.

Chair Crunches – (do not attempt with a PD catheter) sit on the edge of your chair*, hands on the side of the chair, knee together, and lift both knees to your chest then lower tap the floor with your toes (but careful to just touch your toes and not the whole foot) and repeat. Do a set of 20.

Chair Squats – sit in the middle of your chair*, feet flat on the floor hip width apart: stand up and sit down. Do this 30 times. For an extra challenge do not sit back down but instead, hover above your chair for a count of 10 and then stand up and repeat.

March in Place – sit on the edge of your chair*, feet flat on the floor hip width apart and lift each knee in an alternating fashion like you are marching in place. Try to lift your knees as high as you can. For an extra challenge try this activity while standing.

* Choose a chair without wheels

** To make even more effective, engage your core by pulling in your stomach muscles and sitting up straight

Other ways to add activity:

- Take a walk around your favorite neighborhood or park
- Go on a picnic
- Plant flowers
- Walk 4 times around the perimeter of the grocery store before getting the cart
- Go to a museum

- Walk around a shopping mall before it opens
- Form a walking club at your dialysis center and walk before your shift starts
- Go online to see if there are any free activity clubs to join

Just because it doesn't feel like exercise doesn't mean it isn't beneficial. The more you move the better off you are. The trick is finding what works for you! Let this Spring be the one that gets you in action! Remember Newton's First Law: A body at rest will remain at rest and a body in motion will remain in motion. Be your own force and get in motion!



Carolyn originally from Saint Louis, MO, has been a Dietitian in the Washington DC area since 2011, and is currently the Kidney Transplant Dietitian at The George Washington University Hospital. She has also worked as the Dietitian

in a dialysis facility. Carolyn found her passion for renal nutrition when her nephew was born with only one working kidney. Throughout her career, Carolyn has sought opportunities to educate the general public about the importance of early detection of kidney disease and the benefits of a healthy diet and kidney health. She volunteers with The National Kidney Foundation; is on the NKF's Capital Area Medical Advisory Board, Patient Education Committee, and the NKF's 2018 Regional Recognized Renal Dietitian Award winner for the DC Metro Area; is a speaker for The American Kidney Fund; wrote the nutrition content for AKF's website; has presented at the 2018 American Association of Kidney Patients' National Conference; teaches renal nutrition to Virginia Tech (DC campus) and Mid-Atlantic Sodexo dietetic interns. In her spare time you can find Carolyn exploring Washington DC with her camera at the ready and in search of new and delicious restaurants or farmers' markets.

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Registration Information:

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or go online to
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:

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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.
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