



# AAKP RENALIFE

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November 2019

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Jennifer Jones,  
AAKP Ambassador

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*A Publication of the American Association of Kidney Patients*

# AAKP RENALIFE

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Understanding kidney disease is a critical first step to improving your health. The American Association of Kidney Patients is the leader in kidney patient centered education. For 50 years, AAKP has provided patients and families the educational tools they need to understand kidney disease and take a more active and informed role in their health care.

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

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The Independent Voice of Kidney Patients Since 1969™

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*By Deborah Pelaez, AAKP Marketing and Communications Manager*

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### William Fissell, MD, Medical Director, The Kidney Project

AAKP's Innovator Series has featured some remarkable people over the past year! Our latest Innovator Series article features William Fissell, MD, Medical Director, The Kidney Project. The Kidney Project is a national effort with a goal to create a small, surgically implanted, and free-standing bioartificial kidney.

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*By Jeff Harder, MSW, LICSW, University of Washington Medical Center*

As a kidney patient or caregiver have you wondered if a support group would be beneficial? Kidney patients face a lot of medical, surgical, emotional and financial issues. The same stress also applies to caregivers. Support groups are a great way to connect with others. Learn about the benefits of support groups and how to go about finding one by reading this article.

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*By Stephen Z. Fadem, MD, FASN, FACP, AAKP Medical Advisory Board Chairman*

It is that time of year – cold and Flu season! Read this important article by AAKP Medical Advisory Board Chairman, Dr. Fadem about the Flu Shot and why it is important to get. In addition, learn about the high dose Flu Shot that is recommended for dialysis patients.



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# MESSAGE FROM AAKP

Dear Friends,

Welcome to the fall issue of *aakpRENALIFE*. On September 6-8, 2019, AAKP hosted our most successful National Patient Meeting in over ten years, titled *Driving Innovation & Changing the Status Quo*, held in Washington, DC. With over 350 patients, caregivers, and healthcare professionals, along with over 30 exhibitors in attendance and thousands livestreaming the event, AAKP accelerated our drive in the Decade of the Kidney™.

I, along with AAKP's National Board of Directors and professional staff, thank you, our loyal members, for making the National Patient Meeting such a success. AAKP's productive year has seen our organization establish itself as the patient group that continues to focus on the critical role patients play in changing the status quo. What does that statement mean for patients? A quote I made in a recent AAKP Press Release addresses this question and is worth repeating,

*“AAKP’s national strategy to improve patient outcomes, drive innovation and expand patient choice continues to produce solid results due to our non-partisan efforts to engage patients directly with key allies and policymakers at every level.”*

AAKP announced Decade of the Kidney™ at the June 20, 2019, National Policy Summit in Washington, DC. The Decade of the Kidney™, initiated and led by AAKP, is a ten-year national and international initiative designed to intensify the focus of policy-makers, researchers and the private sector

on a broad, patient-focused agenda targeting kidney diseases, new care innovations and an aggressive expansion of patient care choice. On July 10, 2019, President Trump signed an Executive Order on Advancing American Kidney Health (AAKH). The signing of the AAKH Initiative is the most significant event in the kidney arena since President Nixon's signing of Public Law 96-602, which contained a provision that anyone with ESRD will be covered by Medicare.

President Trump's AAKH Initiative is closely aligned with AAKP's Decade of the Kidney™. The blueprint set forth to implement the AAKH Initiative is strongly supported by AAKP leadership. While the sight of a united kidney community on the July 10th announcement of the President's Executive Order was heartening, AAKP leadership focused immediately on the implementation of this industry-changing Executive Order. In the months since the announcement of the AAKH Initiative, the encouraging vision of a united kidney community has been replaced by the reality of those advocating for variations of the status quo or, at best, delaying the implementation of the AAKH initiative.

AAKP leadership is unequivocal in our support of beginning the implementation of the Advancing American Kidney Health Initiative as scheduled in January of 2020. A selected review of the 330 comments on the Centers for Medicare and Medicaid Services (CMS) ESRD Treatment Choice (ETC) Model

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indicates that the industry has concerns about the implementation of the AAKH initiative. Comments to CMS on the ETC Model is the first opportunity for the public to comment on how the President's Executive Order is to be implemented.

Patient engagement has never been more critical than it is now. Industry stakeholders who purport to speak in the best interest of patients have a vested interest in the timeframe of implementation and the extent to which the AAKH initiative is implemented. As engaged and educated patients, we must speak out about moving forward with the AAKH Initiative. Will there be challenges? Yes, but we must focus on how we can implement the Executive Order as contrasted to why we should not pursue the AAKH Initiative. As patients, our primary concerns are centered around positive patient outcomes. Unfortunately, consolidation in the dialysis industry during the past ten years has not led to better patient outcomes.

Additionally, progress towards increasing home dialysis remains slow and remains a small percentage, approximately 12%, of dialysis overall. *Why has this option not been offered to more patients?* Many studies suggest that home dialysis allows for a better quality of life for dialysis patients.

My friends, your patient voice is needed now more than ever. As starters, we must get the Living Donor Protection Act (H.R. 1224/S. 511) passed, the Comprehensive Immunosuppressive Drug Coverage Extension Act when introduced must be passed, and strong support for the goals outlined in the AAKH Initiative is a must. Each of you can play a role in this by joining AAKP as we roll out an array of activities under the umbrella of the Decade of the Kidney™. Remember, in 1969 Shep Glazer, Vice President of the National Association of Patients on Hemodialysis (NAPH), testified to the House Ways and Means Committee while connected to

a functioning artificial kidney machine. At the time, many of the other patient advocacy groups advised him against testifying while connected to a device. Like Shep Glazer, AAKP, the successor to NAPH, will press forward with our support for bettering the opportunities of kidney patients via the AAKH Initiative – even as others say, “let’s delay until we are better prepared to implement AAKH.”

This month's magazine offers you several articles designed to help improve your quality of life. Jeff Harder, MSW, LICSW of the University of Washington Medical Center, discusses the benefits of belonging to a support group. The article is an insightful read and complements the Support Group page on AAKP's website (<https://aakp.org/center-for-patient-engagement-and-advocacy/support-groups/>). As we enter the holiday season, patients need to prepare for this time of the year. AAKP Ambassador Alana Hunnicutt-Carroll shares tips for the holidays in an article entitled: *Balancing Life, Work, and Kidney Disease*.

As an organization, AAKP is fortunate to have members who represent all areas of life. Every month we feature a profile of one of our members to share their personal story with you. This month, in honor of Veterans Day and those who unselfishly serve and served this country, we profile Jennifer Jones, USMC, veteran combat videographer, Global War on Terror (GWOT) Iraq, and AAKP Ambassador. Next, we offer an educational article on probiotics. The use of probiotics for kidney care is an emerging area of medicine. The article provides information on how probiotics can impact your quality of life. *Have you had your flu shot yet?* In our section on Ask the Doc, Dr. Steve Fadem, Chair of the AAKP Medical Advisory Board, discusses the flu vaccine. As patients, the flu is a health risk to be avoided. We recommend you read this article as flu season is upon us. Innovation is one of the critical areas of AAKP's education and research efforts. This

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## Patient & Veteran Profile: Jennifer Jones, AAKP Ambassador

### How My Kidney Disease Journey Began

In July 2011, I was serving in the United States Marine Corps. My military occupation was Combat Camera Videographer. I was deployed to Afghanistan. I began to exhibit symptoms of swelling in my face, arms, legs, and feet. I could not determine why it was happening, so I decided to seek medical assistance from a primary care physician. It was the right decision because my physician suspected that I had Nephrotic Syndrome. It was decided that I needed to be transferred to a more equipped medical facility. That next day, I was medically evacuated to Landstuhl Regional Medical Center (LRMC) Germany. After a couple of weeks of testing, it was confirmed that I did have Nephrotic Syndrome. Because of this, I was unable to return to Afghanistan, but instead was sent back to the states and became a patient at Walter Reed National Military Medical Center in Bethesda, Maryland.

After months of testing to figure out what caused the Nephrotic Syndrome, I was diagnosed with Membranoproliferative glomerulonephritis (MPGN), Type 1 Idiopathic.

### After Diagnosis

Due to my diagnosis, I could no longer serve in the Marines and was medically retired February 2013. Although I was living in Fredericksburg, Virginia at the time, I decided to remain a

patient at Walter Reed because of their excellent nephrology team. That meant 120-mile round trip commute for medical appointments and ultimately three times a week for dialysis.

I didn't handle it well at first. I felt very alone, and I isolated myself. I felt like I not only lost my military career, I lost my identity. I was feeling dumped by friends who I served with as they began to disappear out of my life. It was a very dark time in my life. I wasn't compliant with my treatment and was even considering if living with this illness was worth it. The thoughts I had at that time began to scare me, to the point where that I knew that it would be best if I went to see a psychiatrist. I was told that it was very normal to be depressed and have anxiety after going through what I had endured. Being able to talk about how I was feeling helped so much; it allowed me to redirect my focus on what I could control instead.

I began educating myself as much as possible about my illness, kidney disease, and dialysis. I made sure that I understood everything my nephrologist was telling me and understood my lab work. I became disciplined and followed the renal diet and incorporated low-impact exercise into my daily regimen. I learned how to balance working while going on dialysis. I built a support system of amazing friends who helped take care of me during the rough times and get me out of the house to have fun every now and

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then. My mother was (and still is!) a big help in all of this, she is a retired nurse, so I followed her guidance and wisdom to ensure that I was doing everything I could to take care of myself. Eventually, I was considered a “model” patient. I still wasn’t a fan of going to dialysis, but instead of being upset I reminded myself that this is keeping me alive.

## Transplant Process

I went through the process to become transplant eligible, and while doing so, my transplant coordinator encouraged me to start pursuing a living donor.



I decided to share my story online. I shared the positive and the negative about life with kidney failure while also doing my best to educate those who don’t know anything about kidney disease at all. I was living life

despite the disease, but I wanted to stress how much my quality of life would improve if I had a kidney transplant. On my 31st birthday, I posted this call to action basically writing who I was, what I have been going through for the past few years, and how a living kidney donor would give me a second chance at life. I asked everyone if they could do one thing for me on my birthday, just share this post. It was shared over 500 times from my page.

Because of that, I had 22 individuals contact my transplant coordinator to get tested and I found my perfect match. My donor didn’t know me, but she saw my story, my journey and felt compelled to see if she was a match for me. On April 2, 2015 I received that second chance at life, and I am still so very grateful. My donor

and I keep in touch, I have been adopted into her family and she has into mine. We’re blood sisters as far as I’m concerned.



## After Transplant

I wanted to hit the ground running and do a lot of things once I recovered from my transplant, but I realized quickly that I still had more healing to do. The entire experience affected me not only physically, but mentally as well. This was really a second chance at life for me, so I didn’t want to make the same mistakes I made prior to and after my diagnosis. It took time to build my “new normal.”

It’s been four years and my kidney is still going strong. I’ve continued to share my journey and educate others about kidney disease. I am a public speaker, resiliency trainer, and freelance audiovisual creative.

When I was ready to get out into the real world and help others, I decided to join AAKP because I saw that kidney patients were the voice of the organization. After becoming an AAKP Ambassador, I was fortunate enough to participate in an AAKP and American Society of Nephrology (ASN) Capitol Hill Day in June 2019, watch President Trump sign the Advancing Kidney Health Initiative on July 10th, and participate at the AAKP’s National Patient Meeting 50th Anniversary Celebration this year as a speaker and moderator for other speakers. I was very honored to receive the 2019 AAKP National Social Media Education and Advocacy Award. I always have a tendency to think that I am never doing enough, but that award let me know that I am doing what I promised my donor I would do— and that was make her proud of me.

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# AAKP Innovator Series:

William Fissell, MD,

Medical Director, The Kidney Project



*The Kidney Project is a national effort with a goal to create a small, surgically implanted, and free-standing bioartificial kidney. The device consists of two modules that work together to get rid of wastes. First, a hemofilter module processes incoming blood to create a watery ultrafiltrate that contains dissolved toxins as well as sugars and salts. Second, a bioreactor of kidney cells processes the ultrafiltrate and sends most of the sugars and salts back into the blood. In the process, water is also reabsorbed back into the body, concentrating the ultrafiltrate into “urine,” which will be directed to the bladder for excretion.*

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

In 1987, I was working as an EMT in the impoverished suburbs of Boston's North Shore. Sometimes we answered 911 calls and sometimes we transported patients from place to place. In those days there were not very many patients who depended on dialysis, and it wasn't uncommon for them to require an ambulance to travel from home to the dialysis clinic. Boston traffic being what it was then and now, we had ample opportunity to get to know these patients during the drive. Back then doctors had fewer tools to address renal anemia and osteodystrophy (a type of bone disease that can occur when the kidneys fail and there are improper levels of calcium and phosphorus in the body). These men and women were pale as ghosts and plagued by fractures, often of their spines. They were breathless and in pain and yet each of them soldiered on, because they wanted a little more

life. I remember one patient chatting with me after we hadn't seen each other in a few months, and she asked me how I was doing and about my personal life. I looked at her and said to myself, if this woman nearing the end of her life in pain and fear can be this kind and generous to be interested in a stranger's life, ***I can do anything.*** I've never forgotten the courage and kindness of those men and women who chose to persevere.

**As a researcher and innovator, we know ideas can happen at any time. Can you share with us when and where the concept of the artificial implantable kidney developed?**

When I was in college I flip-flopped between Electrical Engineering and Physics and ended up working in a laboratory developing instrumentation for NASA's Chandra X-ray Observatory, which is in orbit now. Part of that project used a nanometer-scale diffraction grating to act like a prism for X-rays, separating out their wavelengths. This diffraction grating was an array of gold strips about 10 billionths of a meter in size. Years later, when I was studying for my medicine boards, I realized that there was a similarity between those gold strips and the kidneys' filters. They were about the same size and the same shape. This led to the idea that we could change the underlying technology used to make membranes for blood filtration, and that they might be fundamentally enabling for miniaturization and implantation – to create an artificial implantable kidney.

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**The kidney space has largely seen little innovation in over 25 years +, however it seems there's a shift within the community to change the current status quo of kidney care. Can you share with us your thoughts on that? And how you feel the recent Executive Order Advancing American Kidney Health will support that change and spur innovation?**

I think over the last 25 years we have learned two lessons: first, the payoff from investment in discovery science is much more slowly delivered than we'd hoped. The genes responsible for some kidney diseases and some kidney functions were identified decades ago. I think the expectation then was that genes would lead to cures like day leads to night. However, it's been a much more painstaking process than that, and we still are very limited in the remedies we prescribe - repurposed cardiovascular drugs, repurposed cancer drugs, maybe now repurposed diabetes drugs. As a consequence, we still have more than 120,000 new dialysis starts a year.

The other thing we have learned is that under extraordinary circumstances, it is possible for patients with kidney failure to thrive. Intensive dialysis, daily dialysis, nocturnal dialysis, whatever you want to call long slow therapies, they seem to have a real benefit. In-center dialysis is organized around short intense treatments that are stressful to the heart and are a poor match for the way the body circulates molecules in blood. Slow dialysis therapies allow time for fluids and molecules to equilibrate between the body's tissues and seem to be able

to improve much of the morbidity of renal failure. However, the patient has to spend about 1/3 of his or her life connected to the machine. That's not reasonable, so now there's attention to technologies that could lower barriers to prolonged dialysis.

**One of the most common questions we're sure you receive – when do you expect human trials to begin with the artificial implantable kidney? Do you foresee any barriers to progress?**

We are hopeful for the first trial to start in 2020. This timing is dependent on receiving approvals from Institutional Review Boards (IRBs), which oversee human subjects research. Our initial clinical trial is a material safety test of the blood filter. During this trial, we will confirm that all the materials are safe for human blood exposure. After the initial clinical trial is complete and the data analyzed, we will evaluate the filtration capacity in a follow-up study.

We were very fortunate to receive significant funding from the National Institute of Biomedical Imaging and Bioengineering (NIBIB) to address the feasibility of our approach and have now demonstrated all of the key technologies needed for success. Unfortunately, The Kidney Project is now resource-limited. It's always possible that new barriers might present themselves or that some new technology seems even better than what we have planned, but The Kidney Project is currently seeking additional funding to scale up filter manufacturing and cell production in order to build implantable devices with sufficient capacity to treat patients in clinical trials.

**Announced at the AAKP 2019 Policy Summit in June and subsequently again at the AAKP National Patient Meeting hosted Sept. 2019, AAKP initiated Decade of the Kidney™, a ten-year national and international effort starting in 2020 designed to intensify the focus of policy-makers,**

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**researchers  
and the private  
sector on a broad,  
patient-focused agenda  
targeting kidney diseases,  
new care innovations and an  
aggressive expansion of patient  
care choice. The independent  
patient voice has never been stronger  
– what can kidney patients do now to  
support The Kidney Project?**

Interested patients and families can play an important role in supporting The Kidney Project. First, stakeholders can support a new initiative called KidneyX. It would be beneficial for Congress to hear from members of the public supportive of this public-private partnership between the U.S. Department of Health and Human Services (HHS) and the American Society of Nephrology (ASN). KidneyX is focused on patients with kidney failure. The ASN has pledged up to \$125 million dollars, but federal matching funds are needed. Congress has yet to finalize funding for KidneyX and other medical research programs for fiscal year 2020. Patients and families can contact their Senators and Representative to encourage funding for KidneyX.

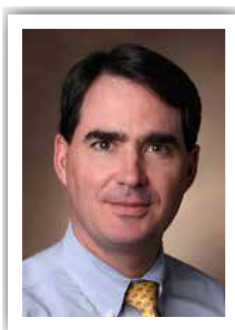
Second, almost all the federal grant funding for the Kidney Project has come from a program at the National Institute for Biomedical Imaging and Bioengineering (NIBIB) called the Quantum Projects program. Now, just as we are getting close, the NIBIB closed the program and we can no longer apply for it. We are hopeful NIBIB, or Congress, may reconsider what a great a difference the Quantum Projects program could make and reopen the program. Patients and families can contact Congress to encourage restarting the Quantum Projects program at NIBIB.

*You can visit the AAKP Action Center (<https://aakp.org/center-for-patient-engagement-and-advocacy/action-center/>) to easily contact your Representatives.*

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

Beyond a doubt my heroes are my patients. All you have to do is look at one of them, talk to one of them, see the scars and hear the tears. Then you will know all you need to know about why I am committed to this project.

*To learn more about The Kidney Project, you can visit: <https://pharm.ucsf.edu/kidney> or <https://www.facebook.com/ArtificialKidney>*




*William H. Fissell, MD graduated from the Massachusetts Institute of Technology with dual degrees in Physics and Electrical Engineering. Dr. Fissell went on to complete his nephrology fellowship at University of Michigan under*

*Dr. H. David Humes, inventor of the Renal Assist Device, the world's first true bioartificial kidney. Before joining Vanderbilt University in 2012, Dr. Fissell directed the Renal Nanotechnology Laboratory at Cleveland Clinic.*

*Dr. Fissell is an Associate Professor of Medicine and Biomedical Engineering at Vanderbilt University, where he directs research in artificial organs, tissue engineering, pharmacokinetics, and dialysis in acute kidney injury. He also teaches nephrology in acute and chronic care settings at Vanderbilt University Medical Center Hospital.*





# Probiotics: Thinking Outside the Box

By Marlena Chesner Kibow® Biotech Marketing Associate

Long before humans unlocked the secrets of microscopic organisms, they were using and benefiting from them. Evidence suggests that prehistoric humans actively used microorganisms to create a “proto-bread” 30,000 years ago from mixing water with crushed grains and cooking it.<sup>1</sup> This early act of fermentation, where the bacteria in the mixture consumes the sugars from the grain to multiply, produced a form of flatbread that humans have only improved upon. Beyond that, mothers have always passed beneficial bacteria to their child during childbirth and breastfeeding to protect the baby from disease and jumpstart their gut microbiome.

## What Are Probiotics?

Probiotics are packaged live, naturally occurring microbes or beneficial bacteria. Because there are so many types and strains of beneficial bacteria, most brands offer their own, unique formulations. Consumers must review and consider the types of bacteria used, probiotic delivery system, and Colony Forming Units (CFU's). These factors determine not only the quality but the individual effectiveness of the product.

- **Types of Bacteria:** The most common groups of beneficial bacteria (i.e. probiotics) found on the retail shelf are Lactobacillus and Bifidobacteria. Lactobacillus controls the population of “bad” (i.e. pathogenic) bacteria<sup>2</sup> while Bifidobacteria “produces thiamine, riboflavin, vitamin B6, and vitamin K”<sup>3</sup>. While they are only abbreviations on the label, the species is written out. Consider each species a unique family within the larger group. For example,

B.longum breaks down carbohydrates while B.lactis helps with immunity and digestion.<sup>4</sup>

- **Delivery System:** Check the package to see if your probiotic comes in an enteric coated gel capsule as it protects the probiotics from gastric acids. If it does not, many of the bacteria may not survive the trip to the gut, severely limiting the effectiveness of the product.
- **CFU's:** Colony Forming Units are the number of viable bacteria in the product that can multiply once ingested. Higher CFU's often yield more benefits.

## Why Do We Need Probiotics?

According to Science Direct “the gut microbiota plays an important role in nutrient, and mineral absorption, synthesis of enzymes, vitamins and amino acids, and production of short-chain fatty acids (SCFAs)”<sup>5</sup>. The human gut microbiome, or gut flora, is the combination of bacteria, fungi, and other microscopic

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organisms that make our body their home. There are as many bacteria in a person's gut as galaxies in the known universe (over 100 Trillion). This system is, unfortunately, easily disrupted by poor eating habits and a sedentary lifestyle but a balanced, healthy gut flora will also aid digestion, support immunity, and can even boost your mood.

## Probiotics Now

Probiotics have since exploded in popularity, with thousands of different products aimed at restoring our gut microbiome and improve overall health. They are widely accepted and used by at least 3.9 million Americans<sup>6</sup>.

## Condition Specific Probiotics

Uses for probiotics doesn't stop there, though. Scientists have also discovered that specific strains of probiotics can also be used to treat condition-specific issues like Irritable Bowel Syndrome, Inflammatory Bowel Disease, and even Kidney Problems.

## Novel Technique

It may not be surprising that probiotics can help condition specific problems related to the gut, but how could they help the kidney?

Compromised kidneys allow uremic toxins to build up in the blood and left unchecked will cause significant damage to the body. Specific strains of beneficial bacteria have the ability and desire to metabolize uremic toxins. Eventually, the metabolized toxins are carried through the body and excreted, relieving the burden placed on compromised kidneys.<sup>7</sup>

Currently, there is only one probiotic explicitly sold to help reduce uremic toxins.

Using probiotics to help maintain kidney function is an unexpected, novel way to use beneficial microbes. Hopefully, as scientists

continue to study probiotics and their effect on the body, it will not be the last unconventional use. There is a wide-open future with probiotics playing a significant role in, not only our general health but for more severe conditions, such as kidney illness, as well.

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*Alana with her little cousins on their traditional Thanksgiving day!*

# Balancing Life, Work and Kidney Disease

**Tips for the Holidays with AAKP Ambassador, Alana Hunnicutt-Carroll**

*By Deborah Pelaez, AAKP Marketing and Communications Manager*

Alana was diagnosed with kidney disease 25 years ago as a teenager growing up in Washington, D.C. Her diagnosis was Focal segmental glomerulosclerosis (FSGS). She had her first kidney transplant, a pre-emptive transplant (which is when a kidney transplant takes place before the individual goes into complete renal failure and before dialysis is needed), in 2005. Her living donor was her older brother, Tory Hunnicutt. However, the FSGS attacked her new kidney about 10 years later, and Alana then went on dialysis. Alana did in-center hemodialysis for one year before her husband, who had kidney stones, was cleared to donate a kidney to her in September of 2016. Alana and her husband, Reginald Carroll, have been married for 18 years and have two children, 17-year-old Kalil and baby Analá, who will turn 1 year old later this year.

Alana has carefully balanced life, work and kidney disease at every stage of her life. Despite her kidney diagnosis, she has been able to live a full life including work and motherhood. With her first transplant,

Alana returned to work for many years at a daycare center and then moved on to work with intellectually challenged adults at a day program. However, when her first transplant failed, she took leave from work while on in-center hemodialysis. She later returned to work during her second transplant as an Administrative Assistant and relaunched her catering business.

Currently, Alana is a busy stay-at-home mom to Analá. In addition, she is pursuing her dream of developing a non-profit with her husband to help feed dialysis patients who live where there is not easy access to quality foods like fresh meat and produce. She also does public speaking and consulting work to help educate fellow kidney patients and teach them how to advocate for themselves.

Alana says that balancing life, work and kidney disease can be tough. And, around the holidays it can be even tougher with added temptations, but Alana gives kidney patients some tips on how she is able to find balance each day.

[Continued on next page](#)



# Tips to balancing life with kidney disease during the holidays:

## It's OK to Say No

Alana says that with her catering and cooking background she is the “chef of the family.” So, when it comes to the holidays her friends and family have come to expect to enjoy her delicious food creations. However, Alana has had seasons where she has not been able to do her usual holiday cooking.

Alana recalls the Thanksgiving after her second transplant, which took place September 26, 2016. As much as she wanted to put on her apron and cook for her family she just was not physically or mentally ready. Alana says, “it’s ok to say no; it’s ok to go to someone else’s house and break tradition.”

Another way that Alana loves to de-stress is by simply taking time to enjoy the season. She says she loves to visit the pumpkin patch, pick apples and play outside in the snow.

## Protect Yourself from Viruses

Alana is also the caregiver to her family. If the children are sick, she knows she can count on her husband to help out so she won’t be directly exposed to the cold or the flu. Alana says that she protects herself from viruses by getting a flu shot, using a face mask in public places like the airport or mall, spraying Lysol on door handles, and using hand sanitizer.

## Stick to Your Kidney Diet

It’s easy to be tempted to overindulge during the holiday season. With all the festivities happening you won’t want to forget to stay on your kidney diet or to stay on top of your medications. Alana says that she tries to stick as close to her regular eating habits as possible during the holiday season. She also says that she tries to plan ahead and make sure she has all her medications refilled because you never know when there could be a winter storm that could make it difficult to get to the store.

## Ways to De-Stress

Alana says that she finds ways to feel whole every day. She enjoys yoga, meditation and reading daily devotionals. One activity that really raises her spirits is giving back to the community she lives in by using her cooking talents to feed the homeless. She says she does this at least every quarter, but around the holidays it is even more meaningful.

Alana says that not every day will be so great, but you can find the good in every day.

*Enjoy this holiday season!*

*Alana and her family serving food to the needy.*





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month our Innovator article highlights Dr. William Fissel, who has spent the past 15 years developing an artificial implantable kidney with colleague Dr. Shuvo Roy. Dr. Fissel will provide us with an update on the progress of this life-changing medical marvel.

My friends, we have developed a fantastic organization. We refer to AAKP as *The oldest and largest fully independent kidney patient organization in the U.S.* As in the past, we stand alone in our unconditional support of change in favor of patients. Other patient organizations may mimic our words, but AAKP alone has such a unique patient-centered legacy. In 1969 it was the change to have Medicare cover ESRD patients. Today it is

the industry change resulting from President Trump's Executive Order on Advancing American Kidney Health. Change does not come easy. But I ask each of you, as a kidney patient, is your life easy? Success happens when opportunity meets preparation. AAKH is



Richard Knight,  
President of AAKP

the opportunity that AAKP has prepared for during the past 50 years. I believe with your unwavering support we can achieve success in ushering in a better life for kidney patients throughout this great country. It truly is the **Decade of the Kidney™**.

#### Feature Story continued from page 6

### Encouragement for other kidney patients

Stay resilient. Have faith that you have the ability to make your life better as long as you spend more time focusing on the things that you can control and less on the things (and people) that you cannot.

You are so vastly more powerful than you think. At times I am my own worst critic and I have my days where depression gets me to believe that I am worthless and damaged. I move in spite of those feelings because wallowing in it for too long will make it worse before it can ever be made better.

Take charge of your situation. Educate yourself about EVERYTHING involving kidney disease, dialysis, and transplantation--not just what your nephrologist tells you.

Make those tough decisions that will get you out of situations where you have become

comfortable with being uncomfortable. You are meant to be happy and at peace. If you can't remember when the last time that was, you know the reasons why and make those changes for the better. Trust me, your Future Self will thank you.



And importantly, find gratitude in every little thing you can. I repeated a mantra daily "that a day without dialysis was a good day." So, I found the most appreciation on Tuesdays, Thursdays, and the weekend.

There is always something to be grateful for, the problem is that we have conditioned ourselves to focus more on what's going wrong than what's going right. Our time is so valuable on this planet, it is our most precious commodity.

Learn more about Jennifer on her website: <http://www.genresilient.com>. You can contact Jennifer by email: [jen@genresilient.com](mailto:jen@genresilient.com)



# 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.



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# SUPPORT GROUPS BENEFITS

By Jeff Harder, MSW, LICSW, University of Washington Medical Center

Kidney patients face so many life changes and challenges when dealing with either dialysis or kidney transplant. Being on dialysis, or having to deal with starting dialysis in the future, is a life-altering change. And, kidney transplantation doesn't always make things easier. If you are a kidney patient you are facing a lot of medical, surgical, emotional and financial issues. The same stress also applies to family members who are supporting you. They can have their own stressful reactions to the kidney disease.



have so many helpful benefits including:

1. It lets you know that you are not alone. Many people are scared and worried when they learn of their kidney disease and the health changes that it can cause. Many times people feel very isolated and alone. That is a very lonely feeling, when you don't know anybody else that has the same health problems. A support group can help you feel less lonely and isolated. It can be very helpful to be with a group of people who may be the only ones that really know what dialysis or transplant is like.
2. You can learn a lot from others that are going through the same struggles. Hearing what other people have gone through can help you feel more in control over your own health care. It can reinforce that what you are going through is normal. The ups and downs of dealing with kidney disease can seem more "normal" and help put things in perspective.
3. When you hear how others have coped with their kidney disease it can help improve your own coping skills. You can learn a lot from others who have walked this same path.

*Where do you go to get the support you need? What can you do when family and friends don't understand what you are going through?*

Support groups are a great way to find other people with problems that are similar to yours. People in support groups share personal stories in an atmosphere of openness and honesty. Some groups are more educational, and some are more supportive, and some combine both an educational presentation with open discussion. Joining a support group can

4. Talking about your feelings can make them less scary and overwhelming. It can make a big difference to be able to talk about your concerns and worries and get feedback from others.
5. Some studies have shown that being in a support group can reduce feelings of depression and anxiety. Both depression and anxiety are common in kidney patients. Counseling and medications are other ways to treat these feelings if they get overwhelming,
6. You can get a lot of good, practical ideas and information from others in a support group. Other people have been through the same thing, and they can have good ideas on treatment options, and how you can advocate for your needs. Collective collaboration can lead to a lot of creative ideas for how to get your needs met.
7. Personal friendships develop from support groups. Bonds develop over time and the support group can feel like a family.
8. You can support others too! Supporting others in the group is also a way to feel more connected with people and to empower both yourself and others.

How do you find a support group that is right for you? If you are on dialysis or need to start sometime soon, ask your nephrologist about the dialysis centers that are closest to you. Every dialysis center has a social worker that can tell you about local support groups or education classes and what you need to do to join. If you are going for a kidney transplant, ask your nephrologist for a list of the nearest transplant centers. Talk to their social worker about any support groups available and how to join. And don't forget to check the AAKP website for a list of support groups across the U.S.!

*Support groups are a great way to connect with others. It may take some work to find a group near you, either in person or online, but the benefits and connections you will make will be worth it!*

What if there are no in-person support groups near you? If you have access to the internet you can likely find online support. If you are on Facebook, search for "kidney patient support group" and you'll find a number of different groups. You can also Google "kidney patient support group" to find a number of options. If you're really feeling motivated, try to work with other kidney patients and start your own support group. You can get practical support, such as meeting space, from a local dialysis center, transplant program, or other social service agency. If you start your own group you can create your own Facebook page for members to communicate.

Support groups are a great way to connect with others. It may take some work to find a group near you, either in person or online, but the benefits and connections you will make will be worth it!



*Jeff Harder received his MSW from the University of Washington in Seattle, Washington in 1986. Since 1992 he has been a kidney/pancreas transplant social worker at the University of Washington Medical Center in Seattle. He, along with his fellow transplant social worker, Bethany Zornes, MSW, runs a monthly support and education group for kidney transplant candidates, recipients and their families.*



# Ask the Doc: The Flu Shot

By Stephen Z. Fadem, MD, FASN, FACP,  
AAKP Medical Advisory Board Chairman

## Flu Season and At-Risk Populations

While in most circumstances, the flu (influenza) is a mild seasonal infection that is characterized by fever, achiness, discomfort with a headache, cough and runny nose, it can be more serious, particularly in people who are at greater risk. This risk population includes dialysis and kidney patients, patients with other health problems like chronic lung, heart, liver or hematologic diseases, as well as those over 50 years of age. At-risk populations also include those who are immunocompromised, children under 5 years of age, and women who are pregnant. Healthcare workers who commonly manage high-risk patients should also receive the vaccine to help further protect those they care for. The disease is of concern because it can spread rapidly through a dialysis unit, hospital, clinic, nursing home or school and is spread by coughing and sneezing. It can also be spread by the hands. During flu season, we should all be extra vigilant in covering our mouths when coughing, and religiously sanitizing our hands. While most persons who have a seasonal flu illness may not require antiviral therapy, the disease should be treated with antiviral drugs in those with a severe clinical picture.

## Targeting the Flu Strains

There are four types of seasonal flu, A, B, C and D but only the A and B viral strains are of public health importance. The flu vaccine is offered annually, around the time that flu season begins – usually around October. The



National Influenza Centers and the World Health Organization monitor the many types of flu strains and then update their recommendations on which strains to target each flu season. They generally target the three most prevalent viral strains (trivalent vaccine – two A strains and one B virus) but may also target four strains (quadrivalent vaccine – two A viral strains and two B viral strains). This year's Centers for Disease Control and Prevention (CDC) recommendations were published August 23, 2019<sup>1</sup>. The flu vaccine is not recommended for those with a prior or known allergy to any component of the vaccine, including those with allergies to eggs, or to those who have had the Guillain-Barre syndrome in the past 6 weeks.

There are three vaccine types – the inactivated vaccine, the recombinant vaccine and the live

attenuated (or live weakened) vaccine. The live attenuated vaccine is recommended for the high-risk or older population, including those undergoing dialysis. It is also recommended in healthcare workers who might come in contact with high-risk patients.

In 2009, a high dose vaccine was released, and there is also an adjuvanted vaccine (which means there is an ingredient added to a vaccine that helps create a stronger immune response to vaccination). The adjuvanted vaccine is designed to enhance immunity, while the high dose vaccine is stronger, and has been clinically studied. The high dose trivalent inactive vaccine was been shown to provide 22% better protection against developing the flu or in requiring a hospitalization in the age group over 65<sup>2</sup>. It has also been studied in dialysis patients. During the 2016 season, those dialysis patients who received the high-dose trivalent inactivated flu vaccine had a significantly lower hospitalization rate<sup>3</sup>.

## Get Your Flu Shot!

In summary, the flu shot is generally recommended for all persons over 6 months of age. In the dialysis population, the high dose trivalent vaccine has been shown so far to have the best results. While getting the flu shot may not guarantee that you will not receive one of the other strains of the virus, it does offer proven protection against significant illness and hospitalization.

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