



RENALIFE

Volume 55 • Issue 3

The Independent Voice of Kidney Patients Since 1969™

May/June 2022

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PATIENT PROFILE

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Home Dialysis Patient,
Kidney Advocate**

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ROZELLE CALLANGAN, AAKP GLOBAL AMBASSADOR

A Publication of the American Association of Kidney Patients™

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Design and Production - Bellanti Creative

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

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

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

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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, healthcare professionals, and other support groups is an important goal of AAKP's.

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*By Deborah Pelaez, aakpRENALIFE
Independent Writer*

David Rush's kidney journey began as a teenager and has taken him from deep depression to passionate kidney advocate. He is a home dialysis patient who believes in a "wins only" motto and encourages other patients to do the same. Read David's story and be inspired to make a difference and live your best life with kidney disease.

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AAKP INNOVATOR SERIES WHAT IS THE BEST BLOOD LEVEL OF PHOSPHATE FOR PEOPLE WITH KIDNEY FAILURE ON DIALYSIS? AN UPDATE ON THE HILO TRIAL

*By Myles Wolf, MD, MMSc for the
HiLo Steering Committee*

In this Innovator Series article, learn about a new type of randomized clinical trial called a "pragmatic clinical trial," which is conducted by patients and their health care teams within day-to-day clinical practice. Find out how the HiLo study is using pragmatic randomized clinical trials to address an important, unanswered question about the management of hyperphosphatemia (too much phosphate in the blood) in patients receiving dialysis.

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HEALTH AND WELLNESS ARTICLE HOW TO REDUCE THE RISK OF FALLING

*By Stephen Z. Fadem, MD, FASN,
AAKP Medical Advisory Board Chair,
and Michelle L. (Misha) Nguyen,
Senior Fitness Specialist*

Falls are common in those who are elderly and individuals with chronic disorders, including chronic kidney disease. In this health and wellness article, read tips on how to fall proof your home and learn balance and strength training exercises that may help you to prevent falls and minimize potential injury.

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NATIONAL HIGH POTASSIUM AWARENESS DAY PATIENT PROFILE ARTICLE ROZELLE CALLANGAN, AAKP GLOBAL AMBASSADOR

*By Deborah Pelaez, aakpRENALIFE
Independent Writer*

Rozelle has battled chronic illness since birth. In this article, Rozelle shares her journey of being born with small kidneys and a twisted urethra, developing diabetes and chronic kidney disease, and receiving a kidney transplant. Today, Rozelle is a young adult who is passionate about kidney advocacy and mentorship. Her specialty is supporting teens and young adults in their transitions from pediatric care to adult care.

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Helping patients

MESSAGE FROM AAKP

Hello Friends,

I sincerely hope that you are doing well and enjoying the changing season. Spring is upon us, and we are recovering from a long winter season filled with hope for many. Yes, COVID-19, in its many versions, still haunts us, but improved therapeutics give those of us who are immunosuppressed and immunocompromised reasons to hope for protection from the virus and its variants.

The AAKP team has been busy hosting webinars that provide the latest information about these new therapeutics as well as how to continue to minimize your risk of contracting the virus. I suggest you view the *AAKP HealthLine* webinar titled “Emerging Therapies, COVID Prevention, and the Immunosuppressed”: <https://youtu.be/CSc2vRQnSv4>. I recently received an injection of Evusheld, one of the therapeutics discussed during the webinar. I am anxiously waiting for the results, which I will share with you.

Meanwhile, May 1 (5.1) was National High Potassium Awareness Day, a day marked by the AAKP in 2020 aimed at putting a national spotlight on the devastating impacts of high potassium (hyperkalemia) on individuals with advanced chronic kidney disease (CKD). Through the AAKP-led “Are You O-K+” campaign, AAKP has educated millions on the risks of hyperkalemia and the availability of innovative treatments to prevent the most

devastating impact of this condition. If you missed the free virtual educational event that marked this national awareness day in 2022, you can view it OnDemand <https://youtu.be/fAnLz2t4MS8> or www.areyouok.org.

In this issue of *aakpRENALIFE*, we share several articles that focus on related health conditions that many individuals with kidney disease face, such as phosphorus management and current research being done by our researcher partners at Duke University through the HiLo study as well as a discussion on fall prevention from frequent contributor and Chair of the AAKP Medical Advisory Board, Dr. Stephen Z. Fadem.

We are also honored to feature David Rush, a home dialysis patient and fellow kidney advocate in this issue’s patient profile. Read about David’s journey with kidney disease as it began in high school. David’s ordeal included crashing into dialysis at 24 years old. When he discovered home dialysis, his outlook on his disease and life changed, and he began to thrive. Read David’s story and learn how he persevered through more adversity. Next, read about Rozelle Callangan, an AAKP Global Ambassador in Canada, born with small kidneys. AAKP members inspire us, and these two are examples of how to thrive when faced with challenges.

Continued on next page

As we enter conference season, the AAKP team continues to work on our 2022 signature events. All AAKP events will be hosted virtually this year and they are NOT TO MISS! Please note the revised event dates below and register today for free!

4th Annual Global Summit: Global Kidney Patients Voice™ – The Key to Accelerating Innovation – June 29 – 30, 2022

47th Annual National Patient Meeting – September 21 – 23, 2022

5th Annual Policy Summit – November 16, 2022

On the legislative front, AAKP continues to play an essential role in representing the independent voice of the kidney patient. Please be sure to visit the AAKP Action Center at <https://bit.ly/AAKPActionCenter> for the latest updates on policy issues AAKP is engaged in, and sign up to receive alerts when your voice is needed to impact positive

change for patients. We invite and encourage you to engage in all AAKP activities and current social media campaigns across all our communication platforms!

Join at www.aakp.org/join and continue to follow us on social media (Facebook: @kidneypatient and Twitter: @kidneypatients).

Please enjoy this issue of *aakpRENALIFE* and share it with your family and friends. We appreciate your continued support and ask that you encourage family and friends to join via social media to make our voice heard even louder throughout the healthcare community.



Richard Knight,
President of AAKP



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American Association of
Kidney Patients

REGISTER TODAY for AAKP's 2022 Events!

All of AAKP's 2022 events will be held virtually to ensure the safety of patients and all involved. Registration for ALL AAKP events is now open, and it's **FREE** to register!

We can't wait to see you there!

4th Annual Global Summit

June 29-30

Register:

<https://bit.ly/3lpEOBd>

47th Annual National Patient Meeting

September 21-23

Register:

<https://bit.ly/2Vno5E6>

5th Annual Policy Summit

November 16

Register:

<https://bit.ly/36onisU>



AAKP CYSTINOSIS PATIENT EDUCATION AND ACTIVITY SCHOLARSHIP PROGRAM



Cystinosis is a rare genetic, metabolic, lysosomal storage disease caused by gene mutations which result in an abnormal accumulation of the amino acid cystine in various organs and tissues of the body such as the kidneys, eyes, muscles, pancreas, and brain. The cystine accumulation causes tissue and organ damage. Cystine accumulation can lead to kidney failure, muscle wasting, swallowing difficulty, diabetes, hypothyroidism, cerebral atrophy, photophobia, blindness, corneal ulceration, ventilatory impairment, and more. Without treatment, children with cystinosis will usually develop end-stage kidney disease (ESKD) or die prematurely. If cystinosis patients receive a kidney transplant, their new kidney will not be affected by the disease. However, without specific treatment, cystine accumulation can cause complications in other organs of the body.

Cystinosis Scholarship Program

The objective of the scholarship program is to give an exclusive opportunity for people living with cystinosis to provide inspiration, further their education, and pursue opportunities toward long-term career goals and life aspirations.

This scholarship program is open to individuals diagnosed with cystinosis. Scholarship funds are available to age groups 5-17 years of age and 18+. Scholarship submissions are accepted year-round, however scholarships are awarded in November and June.

Learn more and apply today by downloading the scholarship application:

<https://bit.ly/AAKPCystinosisScholarship>

Read about Cystinosis Scholarship Recipient Ayla Maher in this article from *aakpRENALIFE*:

<https://bit.ly/AAKParticle-AylaM>



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PATIENT PROFILE:

David Rush, Home Dialysis Patient, Kidney Advocate

By Deborah Pelaez,
aakpRENALIFE Independent Writer



David's battle with kidney disease began in high school in Highland Park, New Jersey. He dreamed about following in his older brother's footsteps of playing football in high school and college. During his routine sports physical, his doctor said there was protein in his urine. David remembers thinking that too much protein in his urine must mean that he was eating too much meat and protein-filled foods. He was a linesman and the team was fed well. David did not really understand at the time what it all meant.

David and his mom went to a nephrologist (kidney doctor) in New York City for a follow-up appointment, where his nephrologist took another urine sample, bloodwork, and a kidney biopsy. His nephrologist ended up doing another urine sample, bloodwork, and kidney biopsy. The doctor saw scar tissue on his kidney and thought an acute kidney failure or CKD chronic kidney disease was a possibility, but David was not formally diagnosed. The doctor prescribed medication and asked David to sit out that football season to work on his health. In addition to his kidney problems, David had high blood pressure and was overweight. Understanding the need to monitor his health, he agreed with his doctor



and sat out that year, only to return to play football in 11th grade and part of his 12th grade year before suffering an injury that ended his football season. His dreams of playing football in college now shifted and became dreams of playing music and attending art school. He went on to attend the Art Institute of Atlanta after high school.

The college life coupled with moving out of state and away from his parents and doctors led David to develop poor health habits, including stopping the medication his kidney doctor had prescribed as he began to not feel well when taking it. Instead, he did what felt good and freeing. He enjoyed his years as a college student and made music. David graduated from the Art Institute of Atlanta with 'Best of Show' honors. After college, he landed a good internship in his field. He worked there for a while, but eventually left when he saw other interns being promoted and he was left behind.

David eventually moved back home to New Jersey and reconnected with his longtime girlfriend, Mimi. Mimi was interning with a medical practice and convinced David to be her guinea pig for the day. She brought him into the office and did a full medical workup on him. Mimi noted that David's blood pressure was very elevated. When the bloodwork results came in, Mimi called David to tell him the doctor she worked with said that he needed to go to the emergency room immediately. His creatinine levels were very high, which meant there was a problem with his kidneys. David was not expecting this news. He thought his kidney problems went away and did not realize that his possible CKD (chronic kidney disease) could progress into a bigger,

Continued on next page

more permanent issue. He agreed to go to the emergency room, where he was admitted and found out that his kidney issues had worsened. He had CKD and was finally diagnosed by his nephrologist with Focal Segmental Glomerulosclerosis (FSGS).

Focal segmental glomerulosclerosis (FSGS) is a type of glomerular disease and results in scarring (sclerosis) in your kidney.

Normally happy and cheerful, depression set in as David feared his life and independence were over. He did not understand how this happened while he was still young and just starting out in life. He looked back and was disappointed in how little he felt he was able to accomplish before his chronic disease diagnosis.

David was working for Staples at the time delivering paper products, and his job was physically demanding. By the end of each day, he was exhausted, yet had no appetite, and food began to taste like metal. He would fall asleep mid-conversation, and one day, his sister found him passed out and was unable to wake him up. She brought him to the hospital and he was admitted. On March 16, 2007, at just 24 years old, David woke up in the hospital to see a catheter in his chest and a dialysis machine by his bedside. He was scared, terrified, and angry.

He remained in the hospital for six weeks because his creatinine levels were so high. He started hemodialysis three days a week for five hours each treatment. His mindset shifted to an unhealthy place, and he shares that he started to “write himself off.” When he got out of the hospital, he continued his hemodialysis in-center. Each day he went to dialysis, he would get a hospital bracelet with his name, the date, and other details. When David got home each day, he’d immediately take it off and throw it away. After weeks of dialysis sessions, David’s mom asked him what his plan was, but he did not have one. In response, she revealed that she had been saving every one of those hospital bracelets and made a chain with a poem for him. She read it to him. It was a poem that would lift David out of depression and inspire him to find out how to live again. The poem read:

The Bands Around My Neck



The bands around my neck, they are the ones my son wore around his wrist.

They represent days, they represent hours, they represent weeks.

The pain I see when we meet.

The bands around my neck, I feel strength, I feel life, I feel courage.

Know why, with this treatment, you can't be in a hurry.

The bands around my neck will continue to get longer until the Lord says no more.

And here comes Jesus to open the new door.

Don't feel sorry. Don't feel bad, Young Boss.*

Determination he has. He's got favor. He's got grace.

And, I know with God's mercy you will win this race.

Love you forever and a day.

Mother

**Young Boss was David's nickname when he was younger.*

David's mom, Cindia “Mama Rush,” passed away in 2012 at 55 years old from hepatitis of the liver. She was also on dialysis when her organs were shutting down.

After that day, something in David changed. He wanted to live. He got back into his music and cut his hair into a mohawk. David says he started his “rebellion stage.” He describes going hard into his music. He performed at hip-hop clubs, drank, and partied late into the night.

One day, the woman David routinely sat by at dialysis did not show up. David asked about her, and although the staff could not tell him what happened, they said enough that he knew she had died. This realization that the same could happen to him, coupled with his strong desire to rebel, changed his mentality.

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He decided that ‘living’ didn’t mean he had to rebel. He chose to be a more positive patient and became compliant with his healthcare routine. From that moment on, David never missed a dialysis session and dove into learning

more about dialysis and the machine that was keeping him alive. He asked questions and worked with his doctors. He also continued with his passion of making music.

David’s music career now started to take off. His mixtape fell into the hands of Miami rapper Pitbull. He started flying to Miami on the weekends between dialysis sessions to work with him. David was signed to Pitbull’s label, and the two collaborated on songs including “Go Girl” from his Boatlift album and his biggest hit to date, “Shooting Star.”

Pitbull asked David to go on a 45-city tour with him, where David would open the shows and perform some songs with Pitbull. David knew he wanted to do it, but was on dialysis and did not want his health to suffer, so he spoke to his manager and healthcare team.

David explains that when he went on dialysis, he was never told there were options. He calls it the “death, dumb, blind phase.” He said he just did what he was told and did not ask many questions. But now, he needed to be mobile. He soon learned about home dialysis options and knew that was the right dialysis option to transition to. David trained for six weeks on a home dialysis machine that would allow him to perform dialysis while traveling on tour. He worked with his manager to ship his dialysis boxes to each location where he would perform. First up was California—a long way from his home in New Jersey.

The tour had 45 stops in 52 nights. David never missed a show nor a dialysis session. He describes his schedule as:

- ✓ Arrive at the city
- ✓ Dialysis
- ✓ See the venue, set up, and rehearse
- ✓ Perform as opening act
- ✓ Perform with Pitbull
- ✓ Briefly attend the offstage party
- ✓ Leave the party early with his crew and travel
- ✓ Arrive in the next city a day early
- ✓ Dialysis

As the tour ended, David’s health was better than ever. Doing consistent home dialysis helped him get his blood pressure under control, and he had been able to lose the weight he needed to in order to get on the kidney transplant waitlist.

Before leaving on tour, David proposed to his longtime girlfriend, Mimi, and the two planned to marry on July 10, 2010. On July 9, 2010, David received a call that a kidney match may be available from a deceased donor. David, Mimi, and David’s mother, Cindia, discussed it. Mimi was not upset about delaying the wedding for the surgery, but David ultimately decided that it did not feel right. He turned it down, and the two got married as planned. Later, he learned that the kidney was probably not the best match for him, but he was grateful he could make that decision.

Shortly after the wedding, David’s older brother Dwaine decided to get tested to be a kidney donor for David. He was a perfect match. The surgery took place on November 9, 2010. David said there were over 80 people in the waiting room. They were filming a documentary at the time, and the room was filled with film crew, friends, and fans. Watch the documentary episode RUSH[ED] EPISODE 4 “THE O.R.” at: <https://www.youtube.com/watch?v=w8l9jwehKJs>.

After marriage and a successful kidney transplant, David was on top of the world. When life felt like it could not get any better, Mimi surprised David with the news of a baby on the way. David was shocked, as he thought kids were no longer a possibility after what he had been through. On September 22, 2011, baby boy Maddex was born. Then, just 11 months later, Mimi and David had a baby girl named Jayla.

Continued on next page

David became a stay-at-home dad and worked on his music on the side. He was busy with diapers, school drop-offs and pick-ups, homework, and other family duties and enjoyed being there for his kids and wife. But, with the busyness of life, he admits he was not always on top of taking his transplant medications on time. He felt good and did not realize the impact of taking medicine late or missing a pill.

In late 2017, David started to feel ill. He felt fatigued, his face swelled, and his socks left prints on his legs. He got a hold of his nephrologist and said he felt like he was losing his kidney. Six months later, David's transplanted kidney rejected. He returned to home dialysis.

Two years later, in 2019, while still on home dialysis, David started to feel sick again. He was throwing up and had pain in his back. His gallbladder was removed, but his health did not improve. Bloodwork and an MRI discovered that he had a tumor the size of a melon in his native kidney. He was put on medicine to shrink the tumor, but the medicine caused insomnia and made him irritable. He says the lack of sleep and his high emotions helped him make a lot of good music, but it was not good for his overall health, family, or life. The tumor did shrink, and he had surgery to remove his two native kidneys. After being removed, doctors found out that the mass on his kidney was cancer. Luckily, the cancer had not spread outside the kidney because of David's fast action in seeking medical help when he started to not feel well.

After surgery, David decided to go back to in-center hemodialysis. His home started to feel like a medical center and the boxes were taking up room that his two growing kids needed. But, when COVID-19 hit in 2020, his medical team spoke with him about returning to home dialysis. David was hesitant, but the medical team said the new home dialysis machine was easy to use. In October 2020, he decided to see a demo of the Outset's Tablo home dialysis machine. He ended up switching to that machine and a dialysis schedule of four days a week for four hours a day. He also decided to work on his kidney-friendly

diet and stopped eating meat. David says a plant-based diet is better for him because of dialysis and because he no longer has a gallbladder, but there's no "one-size fits all" kidney-friendly diet, so be sure to consult with your healthcare team and a dietitian that specializes in kidney disease before making any changes.

Need to find a nutrition expert? Visit <https://www.eatright.org/find-a-nutrition-expert> to find a qualified food nutritionist and nutrition practitioner that is right for you.

Currently, David continues to make music, be the best dad and husband he can be, and continues with home dialysis. He is also a patient advocate and wants to be a voice for fellow patients and the kidney community. David emphasizes that you can still live on dialysis, and developed a new brand based on his mantra, "Wins Only," which he says means that life is all "Wins," even kidney disease. "You just have to look at it that way and adopt that thought," David explains. He is looking to make his mark on the world in a positive way to support those with kidney diseases. Additionally, he is working on getting back on the kidney transplant list and remains optimistic until the timing is right for him to receive a new kidney.

Follow David on social media at: Twitter/Instagram - @davidrushonline.

Additional Resources:

Coping, Living, and Thriving with Kidney Disease brochure:

<https://bit.ly/AAKPCopingLivingThriving>

Understanding your Home Hemodialysis Options brochure:

<https://bit.ly/AAKPHomeHemoDialysis>

Understanding Your Peritoneal Dialysis Options brochure: <https://bit.ly/AAKPPDOptions>

Read more about Focal segmental glomerulosclerosis (FSGS):

https://bit.ly/AAKP_FSGS

How to Reduce the Risk of Falling

*By Stephen Z. Fadem, MD, FASN,
AAKP Medical Advisory Board Chair,
and Michelle (Misha) L. Nguyen,
Senior Fitness Specialist*

February was rodeo season in my hometown of Houston, Texas. Here is where young cowboys compete to stay on a 2,000-pound snorting, ornery, bucking, kicking, and twisting bull for at least eight seconds. The only thing for certain is that the cowboy will inevitably fall off. Bull riders prepare extensively for their eight seconds of exhilaration and treacherous dismount. They wear protective vests, mouthguards, and helmets. They exercise, stay fit, study how to land on their hands and feet, then run for their lives to the nearest gate. With a 100% certainty that one will fall, preparation becomes essential. But what if the certainty of falling is 33 to 35%, such as in the elderly ^[1]? In 90-year-olds, the risk rises even higher; 58% are reported to fall once a year ^[2]. While bull riders have a 3.2% injury rate ^[3], hemodialysis patients who fall have over twice the incidence of sustaining a head injury at 7%. Fractures are a consequence of falls and, according to the World Health Organization (WHO), the cause of over 50% of accidental injury, and 39% of fatal injury in the elderly population ^[4]. This well encompasses those with kidney disease. Falls are the fifth leading cause of death in the general population. Once a person has fallen, the risk for subsequent recurrent falls increases even further. Given the odds of falling and the unfortunate potential for an adverse consequence, it is imperative that individuals with chronic kidney disease (CKD), especially the elderly with this condition, are aware of fall risks, prepare accordingly, and remain vigilant to the negative consequences in order to avoid falls.



Fall Categories

Falls can be divided into two categories—mechanical and non-mechanical. Mechanical falls, i.e., slips and trips, are caused by environmental factors such as poor lighting, clutter, slippery floors, or obstacles on the floor. Falls can also be the result of underlying diseases and conditions. Age and living alone are both risk factors of falls, as well as vision impairment, improper footwear, or underlying gait (walking) disorders. Seemingly minor foot problems such as bunions or ulcers can also lead to unsteadiness and falls. As we age, we tend to lose our sense of balance, which may also result in falls. Arthritis, especially in the knees, may be associated with muscle and bone weakness, pain, and unsteadiness. This is compounded with other disorders such as high blood pressure, heart disease, diabetes, or CKD. Medications most commonly linked to falls include the excessive use of sedatives or drugs used to treat blood pressure or diabetes. Cardiovascular disease can result in a fall as a consequence of a sudden arrhythmia (heart rhythm disturbance). Dehydration, the result of poor fluid intake, vomiting, or diarrhea, can also lead to a fall. Medical conditions such as stroke or dementia can also increase the risk of falls. Diabetes is not only associated with the potential

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for hypoglycemia, but a neurological condition known as autonomic insufficiency. This causes postural hypotension. Kidney disease has its own set of risks—metabolic acidosis and disorders of mineral metabolism—which result in the loss of bone mass. Abnormal vitamin D metabolism can impair the formation of new bone, while an inherent excessive production of parathyroid hormone by tiny glands located in the neck increases bone disintegration and breakdown. This makes bones more fragile, increasing the risk for a fracture. Kidney disease directly leads to muscle loss, also called sarcopenia^[5]. In advanced CKD, as well as metabolic acidosis and sedentary behavior, muscle cells are targeted and tagged for breakdown and recycling. Sedentary behavior may occur with advancing age, underlying conditions such as CKD, or even a fear of falling. Not just decreased activity, but a lack of exercise also promotes muscle loss. In the average person, muscle breakdown can occur at 1% per year, but this is exaggerated in CKD. Sarcopenia has been associated with mortality, functional decline, and a high risk of falls^[6].

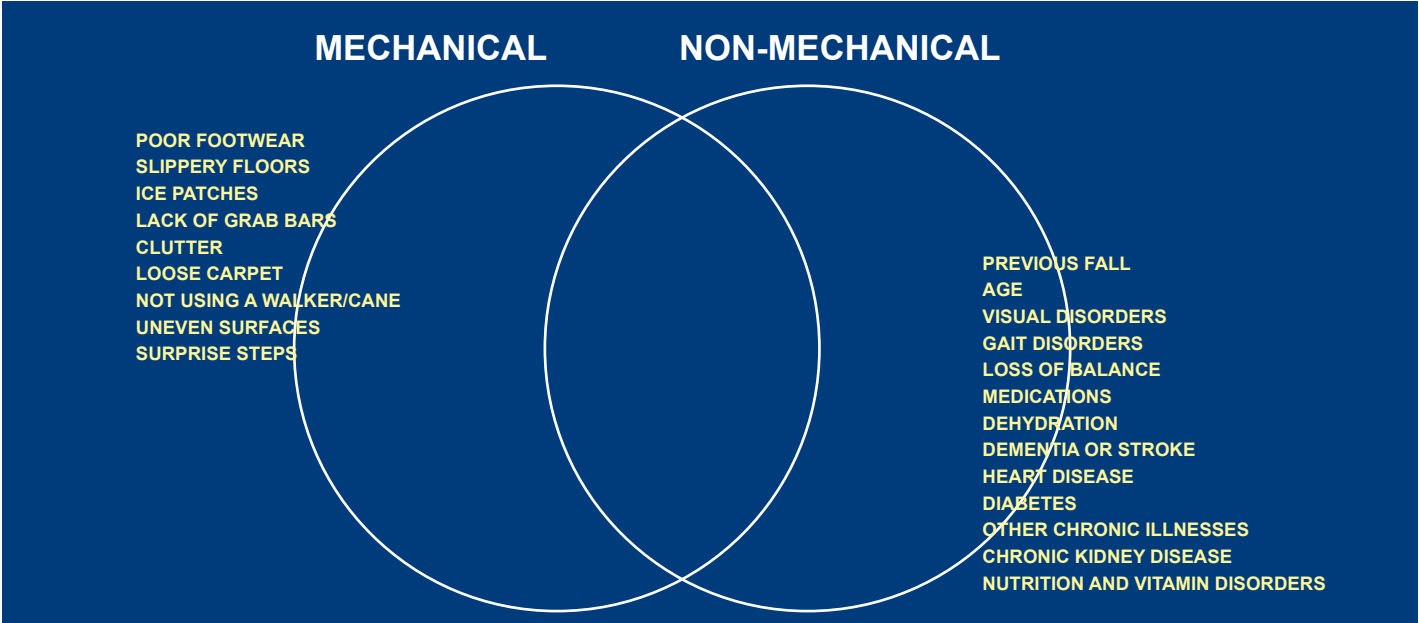
Preventing Non-Mechanical Falls

Efforts should be made to prevent falls whenever possible. There is considerable overlap between mechanical and non-mechanical falls. In other words, patients who are at higher risk for falls because of an underlying condition are also more likely to sustain a mechanical fall.

Both mechanical and non-mechanical risk factors should be evaluated for each individual to make management and prevention decisions that can help avoid falls. The most important risk factor is a previous fall. Risks can be further evaluated by assessing one’s gait, muscle strength, and ability to hold one’s balance. It is further assessed by identifying visual acuity disorders such as cataracts, macular degeneration, glaucoma, or the need to adjust the corrective lens. Assessing footwear and inspecting the feet for non-healing diabetic ulcers, the loss of pain sensation, or bunions is likewise important.

It is essential to optimize care for most underlying conditions by consulting with your doctor and reviewing medications at each visit. Excessively controlled diabetes is associated with hypoglycemia. When overmedicated with antihypertensives, one can become dizzy upon standing and easily fall. Sedatives and pain medications may lead to drowsiness and result in a fall. Vitamin D deficiency is associated with falls and can be remedied with the use of supplements.

Hemodialysis puts patients at high risk for a fall, particularly at the end of their treatment, when dialysis fluid removal has resulted in a large volume shift. Many patients with ESKD (end-stage kidney disease) also have underlying hypertension and heart disease. Therefore, they are on blood pressure-lowering medications and,



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if diabetic, may also have neuropathy. The blood pressure tone that normally compensates for a shift in volume is absent, particularly in patients with advanced diabetes. The excess removal of fluids may cause the blood pressure to be low as the treatment ends because there is no mechanism to enable compensation. Combining these factors increases the chance of losing one's balance and falling. Dialysis personnel are well aware of this phenomenon and often accompany high-risk dialysis patients to the waiting room after their treatment.

Preventing Mechanical Falls

If at risk for a fall, one should seek medical care to stabilize underlying clinical conditions such as heart failure, diabetes, or kidney disease. This may include working with a physical therapist to treat gait disturbances, getting one's vision evaluated, and visiting an ophthalmologist. Medications causing low blood pressure, low blood sugar, or leading to oversedation should be minimized. One should review his or her medications routinely with a provider and see an orthopedist or foot specialist to determine if footwear is proper and if there are any disorders that could result in a fall.

One should also fall-proof his or her living quarters. This includes inserting grab bars in the bathroom and shower areas to prevent slipping. Carpeting should be secure, slip-resistant, and padded. Those with gait disturbances, dementia, or balance disorders should have assistance when walking on uneven surfaces or approaching small "surprise" steps. Nightlights are inexpensive yet essential, as well as the practice of making sure anything that could clutter a pathway has been safely removed prior to going to bed. Stairs should always have handrails, and those at risk should never climb up or down the staircase without using them.

Many people who are at risk of falling are fearful of increasing activity. This can lead to further danger because inactivity weakens both bones and muscles. However, activity should be planned with caution and, if necessary, assistance should be provided. Physical therapy might be useful for those with a physical impairment. For

many individuals, a personal trainer, particularly a certified senior fitness specialist, can offer invaluable tips for seniors on how to increase or maintain activity safely.

Individuals with kidney disease are often on multiple medications and at risk for fractures, loss of balance, and cardiac disturbances. The patient with advanced kidney disease, like the elderly patient, should be treated with vigilance.



Demonstration of a biceps curl
(Photo by MishaFit)

Elastic bands are inexpensive and can be used for various resistance training exercises. The photo shown to the left is a demonstration of the biceps curl. Stand with feet at shoulder length apart and straddle the band. Perform a full curl by flexing the biceps (upper arm motion) and then releasing back to starting position 10 to 15 times. Repeat for a total of three sets.

Even if one is not a direct risk for falling, many of the steps above help to improve one's well-being. There are several exercises one can do to increase strength and improve balance. Resistance training helps offset the muscle loss associated with kidney disease and aging. Balance exercises can build back muscle memory and improve one's equilibrium. Many practical exercises are discussed in "Staying Healthy with Kidney Disease." These exercises are highlighted by Senior Fitness Specialist Michelle (Misha) L. Nguyen to help improve balance and preserve muscle^[7, 8]. Exercise has been demonstrated in a large systemic review to reduce falls in community environments^[9]. Tai chi classes can improve balance. Walking up the stairs can build up the muscles in the back of the leg and the gluteus area, while walking down the stairs can help rebuild and strengthen bone. Always use the handrail. In addition, all patients should try to learn how to land safely to prevent serious injury when falling. Keep your arms and legs slightly bent as you fall.

Most importantly, protect your head. If falling forward, turn your face to the side. If falling backward, be sure to tuck your chin to your chest so your head does not hit the ground. Like the bull-riding cowboys who train to land on their hands and feet after being bucked off the bull, CKD patients or the elderly should learn how to step into balance when off balance to prevent falling. While these maneuvers may not always prevent a fall, they may be helpful for many to decrease the chances of falling.

This exercise will help you practice regaining your balance to prevent a fall. First, stand with both feet together. Beginners may hold onto a handrail to first practice the motions.



- 1 Lean slightly forward until you feel off-balance.
- 2 Step forward with one foot in front of you until you have reestablished balance. Repeat this ten times. Perform the same exercise with the other foot. Next, try stepping backward ten times, first with the left and then the right foot.
- 3 Next, when feeling off balance, step across with one foot until you have reestablished balance.
- 4 Finally, stand with your feet together, then lean to the side until you feel off-balance. Step to the side with one foot until you regain balance. When you feel comfortable, you can practice “falling” and regaining balance without holding onto anything.

Although we cannot rewind our chronological clocks, we can impact the effects of aging by reducing inflammation, eating healthier, and exercising^[10]. For further information on falls, visit the CDC’s STEADI website, <https://www.cdc.gov/steady/>. Falls in CKD patients are also discussed in “Staying Healthy with Kidney Disease.”^[8]

Conclusion

Falls are a leading cause of death and common in the elderly and patients with chronic disorders, especially CKD. They can be mechanical or non-mechanical. Kidney patients should be assessed and if determined to be at risk for a non-mechanical fall, strategies should be developed to prevent falls.

Regardless of one’s fall risk, fall-proofing the home, wearing proper footwear, assuring vision is optimal, and getting into an exercise program to work on balance, muscle strength, and fall prevention, will not just improve one’s well-being but also help reduce the risk of injury in the event of a mechanical fall.

Tips to fall proof your home:

- Install and use grab bars in the bathroom and shower
- Be sure carpets and rugs are secure, slip-resistant, and padded
- Install nightlights
- Declutter pathways, especially before going to bed
- Use stairway handrails
- Get assistance if you need help, especially if you have gait disturbances, dementia, or balance disorders

Additional tips to prevent falls:

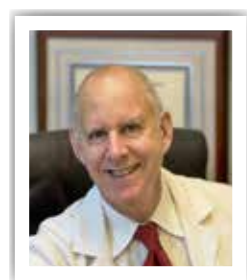
- Wear proper footwear
- Get your vision checked regularly
- Practice balance exercises and muscle strengthening exercises

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Photos by MishaFit

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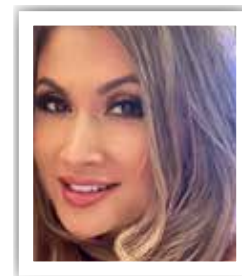


Dr. Fadem is a champion for chronic kidney disease education. He is a Clinical Professor of Medicine, Baylor College of Medicine, Section of Nephrology. Dr. Fadem attended Tulane University and graduated

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Dr. Fadem is the recipient of the National Kidney Foundation’s Distinguished Service Award, the AAKP Visionary Award, the AAKP Peter Lundin, MD Award, the AAKP Medal of Excellence, and the President’s Volunteer Service Award. Dr. Fadem is listed in America’s Top Doctors. He serves as editor of *aakpRENALIFE* magazine, and as historian for AAKP.



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as a Senior Fitness Specialist and Weight Loss Specialist. Misha uses her positive energy to motivate and inspire her clients. In her spare time, she enjoys spending time with her family.

Myles Wolf, MD, MMSc
for the HiLo
Steering Committee

What is the best blood level of phosphate for people with kidney failure on dialysis? An Update on the HiLo Trial

Hyperphosphatemia, defined as having too much phosphate in the blood, is a common problem in kidney patients receiving dialysis. Treating hyperphosphatemia can be time consuming and often frustrating for patients, families, dietitians, and nephrologists alike because of the burden of managing this condition. Common management of hyperphosphatemia requires patients to remember to take many phosphate binders pills multiple times per day before each meal, day after day, and to significantly restrict dietary choices. It is tough!

Given how challenging it can be for dialysis patients to control their phosphate levels, it is worth asking, what is the basis for how we treat hyperphosphatemia? From dietary counseling to phosphate binder choices to the serum phosphate targets we aim to achieve, observational studies mostly guide physician recommendations for treatment. These studies suggest that higher blood levels of phosphate are worse for dialysis patients when it comes to cardiovascular disease and survival. Is this a strong basis for how we treat?

Unfortunately, the short answer is no. Observational studies are not the most reliable type of study. As the name suggests, observational studies passively observe the outcomes of patients who get one treatment or another. Researchers use complicated analytical and statistical tools to try to distill a given treatment's effects from all other factors that influence patients' outcomes. It can be difficult for researchers to determine if a difference in one group's outcome is caused by a given treatment or by other factors that were also different between the groups.

When deciding if one treatment approach is better than another, the most reliable study type is the randomized clinical trial. In randomized clinical trials, patients consent to participate and are randomly assigned to one or another treatment being compared in a given study. If observational studies are passive, randomized clinical trials are proactive.

When a large number of patients are included in a randomized clinical trial, randomization creates a balance between the two groups in their characteristics at the start of the study. For example, the average age, gender mix, rates of diabetes, serum phosphate, and all other variables will usually be equal between the two groups. This is important because it means any differences in future outcomes between the groups are due to the treatment under study and are not related to other factors; for example, one group being healthier than the other at the start of the study.

Why do we rely on observational studies when randomized clinical trials provide much stronger evidence to determine whether one treatment is superior to another? Randomized clinical trials are labor intensive and can be extremely expensive. There are simply too many unknown clinical questions to answer with a dedicated randomized clinical trial. This is true in the area of dialysis, where we have many open questions and few randomized clinical trials.

To address this limitation, a new type of randomized clinical trial, called a **pragmatic clinical trial**, is being used increasingly.

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Pragmatic clinical trials are conducted by patients and their health care teams within day-to-day clinical practice. Pragmatic clinical trials aim to be cost-effective. If we can make clinical trials less expensive, more of them can be done. Pragmatic clinical trials aim to be as inclusive as possible, and only a few criteria limit which individual patients can participate. The main goal of pragmatic clinical trials is to generate **real-world answers to real-world clinical questions**. The answers can be readily incorporated into clinical practice after the study ends and the results are known. Many of these characteristics differentiate pragmatic clinical trials from usual clinical trials. Usual clinical trials are administered by a separate group of dedicated research study staff, often include only a subset of patients who meet specific criteria, and usually involve extra study visits and extra data collection. Sometimes, these trials' results don't materialize when they are moved back into real-world practice because they were done in such a specialized way.

This is where the **HiLo study** comes in (<https://hilostudy.org>). HiLo is a pragmatic randomized clinical trial sponsored by the National Institutes of Health (NIH) that aims to address an important, unanswered question about the management of hyperphosphatemia in patients receiving dialysis. HiLo is testing whether aiming for a higher serum phosphate (6.5 mg/dl or higher) or a lower serum phosphate (less than 5.5 mg/dl) will improve survival and lower hospitalization rates for dialysis patients.

Initially, HiLo was designed as a cluster-randomized trial. This means that dialysis facilities were randomly assigned to either the Hi or Lo group. Practically speaking, patients who consented to participate in HiLo were asked to adhere to the serum phosphate target to which all consenting participants in their dialysis facility were assigned. HiLo started recruiting facilities and patients in March of 2020 and to

date, recruited 555 patients from 30 DaVita dialysis facilities.

Upon reviewing the characteristics of the first 555 patients who joined HiLo, the HiLo Steering Committee observed that patients enrolled in the Hi group were, on average, younger and had higher serum phosphate levels when they entered the study compared to patients who enrolled in the Lo group. This could have been due to chance, but we worried that patients who historically struggled to keep their phosphate lower were more likely to agree to participate in HiLo if they were dialyzing in a facility that was assigned to the Hi group. Likewise, we worried that patients who historically have had lower serum phosphate levels were more likely to enroll in HiLo if it meant that they would be asked to be in the Lo group. Whatever the cause, the imbalances we observed could “bias” the final results of HiLo and limit the conclusions we would be able to make in the future when the trial would have been completed.

To prevent this potential problem, the study team spent the last year modifying the design of HiLo from a cluster-randomized to an individual-level randomized trial. This means that instead of randomizing whole dialysis units as we did initially, we are now randomizing individual patients one by one to either the Hi or Lo groups. Everything else about HiLo remains unchanged. We still aim to recruit over 4,000 dialysis patients. We are still comparing serum phosphate targets of less than 5.5 to at least 6.5 mg/dl. We are still comparing the effects of the Hi versus the Lo targets on hospitalization rates and survival. While making this significant update, we have encouraged and welcomed all participants who have already enrolled in HiLo to remain in the study.

In March 2022, the study resumed enrollment. While still early, we are encouraged by patients' initial willingness to participate. We hope that

Continued on next page

we will be able to replicate our previous successful enrollment.

In the initial phase of the study, approximately 51.4 percent of dialysis patients who were offered inclusion into the study agreed to participate.

Interested in learning more about the HiLo Study?

If you would like to learn more about HiLo, please visit our website at <https://hilostudy.org/>. If you are undergoing dialysis in a DaVita facility and would like your site to consider participating in HiLo, please let us know at HiLo@dm.duke.edu, and please discuss this with your dietitian and nephrologist. We welcome your participation!



Acknowledgments

The Duke Clinical Research Institute (DCRI) recognizes and thanks members from the following organizations who are volunteering their time, energy, and expertise to help conduct the HiLo Study – National Institutes of Health/ National Institute of Diabetes, Digestive, and Kidney Diseases (NIH/NIDDK); DaVita Clinical Research; Davita, Inc. Dietitians; Northwestern University; University of Pennsylvania; and the American Association of Kidney Patients' Center for Patient Research and Education.



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conducts laboratory-based and patient-oriented research focused on calcium and phosphate homeostasis across the spectrum of kidney disease. Dr. Wolf is Principal Investigator of the HiLo trial, which is supported by a grant from the National Institutes of Health to the Duke Clinical Research Institute.

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Rozelle Callangan, AAKP Global Ambassador

By Deborah Pelaez, aakpRENALIFE Independent Writer

Rozelle was born with underdeveloped, small kidneys. As a baby, Rozelle suffered from numerous urinary tract infections and was diagnosed with kidney disease. She recounts that when her mom changed her diaper, she would often hold her breath until she turned blue because of the pain.

Rozelle and her family lived in Prince Rupert, British Columbia, where there were no urologists or nephrologists at the time, only emergency care and family care doctors. Her parents had to drive Rozelle two hours to see a urologist. Rozelle's care was transferred to the Children's Hospital in Vancouver when her urologist moved away, a 16-hour drive for the family. The family drove there several times a year.

In 2000, when Rozelle was five years old, her family decided to move from Prince Rupert to Vancouver, Canada, to be closer to medical care. This was a big move for the family, who originally migrated from the Philippines to Prince Rupert in the 1990s. Rozelle's father was a tradesman and found work

in Vancouver first, then her family followed several months later. Rozelle, her parents, younger sister, and paternal grandparents moved into a small two-



bedroom apartment and started a new life.

Rozelle's doctors discovered that her urethra was twisted and scheduled her for surgery. The family thought this would be a cure, however, she continued to have infections. In 2005, Rozelle was diagnosed with type 2 diabetes (T2D) and was put on insulin.

Rozelle shared that she was a "bigger girl" and started to be bullied and teased at school because of her size. Often, she felt on edge. "No one knew I was dealing with health problems inside because I looked fine on the outside. I had to put a brave face on and ignore them," Rozelle told AAKP. Rozelle changed schools several times in attempt to avoid bullying and get a fresh start. She finished her last year of high school in adult education, where she graduated and received her diploma.

After high school, her kidney function continued to decrease. She was in stage three kidney disease, and her kidney function went from 49 percent to 21 percent. She transitioned from pediatric care to adult care, which she recounts



Continued on next page

being very difficult. “I thought I’d be staying at Children’s Hospital forever,” she said.

Rozelle became rebellious and reckless due to the transition. “I felt like it was going to high school all over again. I did not know anyone in adult care and it was not welcoming,” she said. Being out of her comfort zone and separated from the friends and medical team she had trusted at Children’s Hospital, Rozelle stopped caring. “My first day there, I was the only young adult there. I remember being asked, ‘Are you here with your grandma?’,” she said. Rozelle did not care what anyone thought of her, nor if the doctors liked her. She would try to go in, see the doctor, and get out as quickly as possible.

Rozelle’s health continued to decline during this time. She started feeling very fatigued and found it difficult to do anything. Her kidney function would fluctuate between 21 and 15 percent. She often got urinary tract infections from her diabetes, had high sugar levels, and grew frustrated. “Even when I tried to do better, no one seemed to see it,” she said.

In 2015, Rozelle started hemodialysis and began to feel better. “Dialysis was a positive note for me,” she explained. Rozelle was on hemodialysis for three years, but began to have fistula problems after only a few months, developing nerve damage and carpal tunnel. Her hand and arm stopped functioning, and she was switched to a catheter for dialysis treatments. However, the catheter was problematic because it would get frequent infections, as catheters are prone to. Her doctors lectured her about keeping it clean, and Rozelle was doing her best, but still got many infections and was hospitalized frequently.

“I was 21 years old, going to the hospital three to four days a week for six to eight hours at a time, all while my classmates were off living their lives. It was rough,” Rozelle explained. She built trust and support at her dialysis clinic, which helped her through the hemodialysis years.



Rozelle was able to get on the kidney transplant list for a deceased donor.

Her mom and sister also tried to see if they could donate, but her sister was too young, and her mom was a caregiver to her dad who had a brain injury in 2011.

One Monday morning, after completing a round of antibiotics the week before, Rozelle got the call and found out that a kidney was available for her. Rozelle was in shock. She told her mom and a few friends, then went directly to the hospital. When she arrived, everyone was congratulating her and only then did it start to feel real to her.

Rozelle had kidney transplant surgery on June 19, 2018. She explained the kidney transplant process happened very quickly; she was transplanted in less than 24 hours after the call. After surgery, it hit her, and she thought, “Holy smokes, no more dialysis. I am free!”

Rozelle is now four years post-transplant and doing great. She said the first year, especially the first three months, were the most critical. She went to the clinic two to three times a week to be monitored and tested, but says everything she has been through was worth it. With a renewed look on life after going through those difficult years, she looks forward to advocating and sharing her story to help others battling kidney disease.

Continued on next page

Rozelle as an AAKP Global Ambassador

Rozelle found AAKP through Instagram in 2016. She started using social media to talk about her health issues. She was looking for support and people her age to engage with. She found AAKP Board Member and Ambassador Jim Myers, a social media guru who connected her with AAKP's Erin Kahle to become AAKP's first Global Ambassador!

Rozelle's specialty is the transition from pediatric to adult care, and wants to help young people between the ages of 18 and 30. She does not want anyone to feel alone, but instead have resources and support.

National High Potassium Awareness Day

Rozelle is a great supporter of the AAKP's "Are You O-K+" campaign recognizing National High Potassium Awareness Day (May 1) and encourages fellow patients to learn as much as possible about high potassium and the kidney diet. She struggled with sticking to her kidney-friendly diet over the years. High potassium (hyperkalemia) affected her several times throughout her kidney disease journey. Before dialysis, she had to take powder medication to lower her potassium, and remembers it tasting very bad. Thankfully, she did not have to take it after she started dialysis.



However, one time while on dialysis, she was visiting her godmother who made a homemade Filipino dessert, Banana Spring Rolls. Rozelle ate it without thinking about her kidney diet modifications. Later, when it was time for her to get up and leave for her dialysis treatment, she could not get up. The family had to call the ambulance to pick her up and take her to dialysis. She was told her potassium levels were very high, and recalls it being scary, but was fine after dialysis. After this, she realized how important it is to monitor your kidney-friendly diet, even when on dialysis!

Additional Resources:

Resources for transition from Pediatric Care to Adult Care:

<https://bit.ly/AAKPwebinarAdultCareTransition>

AAKP Ambassador Program information:

<https://bit.ly/AAKPAmbassadorInfo>

National High Potassium Awareness Day educational resources: www.areyouok.org

National High Potassium Awareness Day

Learn about high potassium and kidney disease this May. Share your knowledge.



Visit ➔ areyouok.org
#areyouok5point1



National High Potassium Awareness Day takes place each year on May 1.

This awareness day, founded by the American Association of Kidney Patients in 2020, helps educate kidney patients about high potassium, also known as hyperkalemia, through the "Are You O-K+?" campaign.

We invite you to learn more about potassium and kidney disease through patient stories and by accessing educational resources from the "Are You O-K+?" campaign website all year long. Resources include: high potassium fact sheet, high potassium infographic, pocket guide to managing high potassium, recipes from the new *AAKP Delicious!*, patient stories, recorded virtual events, and more!

AAKP Delicious! 6th Edition

Did you know the 6th Edition of *AAKP Delicious!* recipes was released as part of this year's National High Potassium Awareness Day campaign? Gain access to all 12 kidney-friendly recipes by visiting the campaign webpage at www.AreYouOK.org or www.aakp.org/shop.



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