# KidneyTalk®

Spring/Summer 2025

by Renal Support Network

Helping to educate and empower people living with chronic kidney disease.

## TWENTY YEARS LATER
## A KIDNEY GIFT FROM THE HEART
BY ANN LOPEZ

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WHO HAS FALLEN IN?

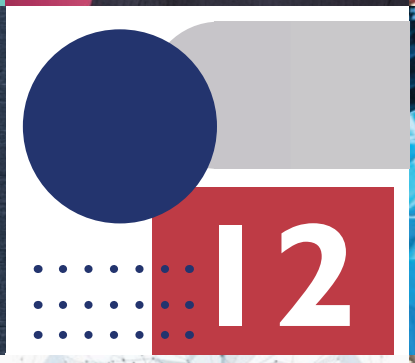
## NEW DEVELOPMENTS IN KIDNEY TRANSPLANTATION

## ENJOY NEW KIDNEY-FRIENDLY SUMMER RECIPES


















*KidneyTalk® Magazine is a program of Renal Support Network (RSN). Articles are written by people who have kidney disease and by healthcare professionals. Those with kidney disease share their knowledge and experiences about living a full life in spite of their disease. KidneyTalk™ Magazine subscriptions are offered at no charge to people who have kidney disease and their families. Join RSN at RSNhope.org to subscribe. Current issue, printable version, articles, and archives can be found at RSNhope.org. Cover and cover story photo credit: Brad Everett Young @bradley206*

Web ID: 44095

# THE PITT

# WHO HAS FALLEN IN?

By Lori Hartwell

I am a fan of the new HBO series "The Pitt" and believe it is poised to win multiple awards this Emmy season. The show resonates with me, illustrating the dedication of healthcare professionals and their collaborative efforts to save lives. Having spent time in the emergency room (ER), watching this series has given me a fresh perspective on the immense challenges faced by healthcare professionals. The staff can be overwhelmed, particularly given the nursing and physician shortages impacting the country.

> *This whole scenario could have been a scene on "The Pitt."*

**A memorable ER visit.**
A few years ago, I experienced a hematoma in my right groin after a procedure to replace my right aortic valve. During the procedure, a wire was inserted through my groin to facilitate the placement of the new valve. After a stay in the hospital, I complained of pain in my groin area to the "attending doctor" and he advised me to apply ice to reduce the swelling and take Tylenol, and he sent me home.

Later that evening, after I ate dinner, watched some TV, took a shower, and headed to bed, I felt a sudden pop in my right groin along with a warm liquid sensation. Alarmed, I immediately sat down and told my husband to call 911. Fortunately, the fire station is around the corner and the paramedics arrived within seconds. I could hear the sirens drawing closer, a sound that always makes me tear up because help is on the way.

Knowing that a bleed can be life-threatening, I asked the paramedic to place a sandbag on my groin and told him about the hematoma. He promptly followed my request; anyone who has undergone femoral catheter removal understands that a sandbag on the site is necessary, and one must lie flat with a sandbag while it clots.

Given my recent valve replacement, the focus shifted quickly to my heart. I desperately needed an IV as my blood pressure was low, and I also needed fluids. My recent hospitalization and the many pokes made it extremely difficult to establish an IV line in my already compromised veins. Since I had an oxygen mask on, I motioned to the ER doctor with my hand indicating I had something to say. He lifted the mask slightly so he could hear me. In a low whisper I told him to insert the IV into my neck. He said, "Okay," and was able to establish a line quickly. I was so glad he listened to me. As a long-time patient, I have found that this is not always the case in a new healthcare setting where I am not known.

Continued on next page

*Lori Hartwell founded Renal Support Network (RSN) in 1993 and is the host of KidneyTalk® Podcast. Lori was diagnosed with kidney disease at the age of two, spent 13 years on dialysis and is now doing well with her fourth kidney transplant. She is the author of* Chronically Happy *and has numerous editorials and peer-reviewed articles published. Lori lives with her husband Dean, four dogs and a parrot. She loves to spend her free time being creative by making jewelry and painting.*

Blood transfusions were ordered stat to replenish my red blood cells. Amidst the chaos and being very scared, one of the most challenging aspects was feeling like I was freezing to death. Eventually, I was stabilized and transferred to the ICU for a surgical evaluation of the hematoma site. There, I was provided with warm blankets, and the nurse had more time to make me comfortable now that I was stable and not losing blood.

This whole scenario could have been a scene on "The Pitt."

While waiting in the ER to be seen, they asked me a series of important questions regarding my allergies, surgeries, and medications. I can be a bit loopy from pain or a fever so sometimes those details can be difficult to remember.

After many years of hospital experiences, I have realized how important it is to be prepared before heading to the ER. If possible, it is beneficial to have someone accompany us, especially since we often seek care when we are in pain or are not feeling our best. Having a list of doctors, medications, and allergies readily available can make a significant difference. Even if I typically visit the same hospital where my records are kept, having backup information is good idea. I am aware that every visit will possibly be a training session.

My patient portal is an invaluable resource; it contains all the information I need. I share my portal password with a few trusted friends and my husband, allowing them to access my information and advocate on my behalf. Additionally, I maintain a one-page summary of my medical history, diagnoses, and surgeries. This documentation is particularly crucial given my history of multiple dialysis access points. It is essential to be aware of what is happening to make sure the medical team avoids placing a blood pressure cuff on the wrong arm or using an IV in a potentially problematic location. Although I have older access points that are no longer functional, this also can be confusing for healthcare workers. If they are unaware of my history, they will err on the side of caution and choose to avoid that arm altogether. Since I have notoriously difficult veins for blood draws or IV placement, having all options available is helpful.

Being prepared not only alleviates my stress and that of my friends and family but also empowers me to navigate the healthcare system and advocate for myself. I just have to remember my username and password. The older I get, the harder that seems!

So many experiences have heightened my appreciation for the hard work and commitment that healthcare providers dedicate to our care. I always remember it is a medical practice, and doctors are practicing medicine on me. The more we can be our own advocate, the more healthcare professionals can effectively do their job.

"The Pitt" effectively portrays the emotions and challenges faced in a day at the emergency room. While I find Noah Wyle, who plays Dr. Robb, to be both handsome and intelligent, my favorite character is Dr. King, played by Taylor Deardon. She consistently strives to learn as much as possible from her patients, and most importantly, she listens. Head nurse Dana Evans (Katherine LaNasa) reminds me of the caring nurses I grew up with. I love her. The entire cast is exceptional. If you don't have HBO, they offer a 30-day free trial, making it well worth a watch.

## What to Bring if Admitted to the Hospital

- Identification and insurance card(s)
- Emergency contacts
- A list of your current medications, allergies, doctors, and any relevant medical conditions, as well as information found in your online patient portal
- Medications you may need during your wait
- A drink or snack
- A book, phone charger, blanket, or personal care items to help you feel more comfortable while you wait
- Medical devices such as hearing aids, glucose monitor, or CPAP machine
- Passwords for online patient portals
- Do not bring valuables
- Be prepared to explain your symptoms and when they began

Web ID: 44096

# ANATOMY OF ANEMIA

**Understanding anemia and its impact can empower people with kidney disease to work with their care team and take proactive steps to stay healthy.**



**Symptoms of Anemia** include fatigue, weakness, shortness of breath, dizziness, pale skin, cold hands and feet, difficulty concentrating.

Healthy kidneys produce **erythropoietin (EPO)**, a hormone which signals the bone marrow to make RBCs. People with **kidney failure** produce little or no EPO, leading to anemia (low RBC count).

**Red blood cells** (RBCs) carry oxygen from the lungs to the rest of the body. **Hemoglobin**, a protein in RBCs, binds to oxygen and delivers it to tissues.

**Treatments to Help Increase Red Blood Cell Production**

- Erythropoiesis-stimulating agents (ESAs), subcutaneous injection or IV
- Iron supplements, Oral or IV
- Hypoxia-inducible factor prolyl hydroxylase inhibitors, oral
- Blood transfusions via IV

**Proactive Steps to Take**

**Know Your Numbers** Check your labs and know your hemoglobin levels.
**Work with Your Care Team** Your nephrologist will adjust treatments based on your labs.
**Stay on Track** Don't miss a dialysis treatment or a prescribed medication dose.
**Speak Up** Say something to your healthcare team if you have symptoms.

Web ID: 44097

# *Twenty Years Later*
# A KIDNEY GIFT FROM THE HEART

By Ann Lopez

*photo credit: Brad Everett Young @bradley206*

Twenty years ago, the most amazing thing happened to me: I became a living kidney donor. My former husband George Lopez was always very healthy. It came as a complete surprise when he had surgery for a popped Achilles tendon and his blood work showed an elevated creatinine level. His doctor sent him to a urologist. Let's just say this doctor did not have the best bedside manner. He came in the room, slapped George's x-rays on the light box and said, "Mr. Lopez, you are sick, very sick. By the age of 45 you will need a kidney transplant."

George and I just looked at each other in shock and I said to him, "I'll give you mine." That is how our transplant journey began.

George had narrowing of the ureters which had gone undiagnosed. This problem made the urine back up into the kidneys, causing irreversible and severe kidney damage. For the next six years we tried every preventative measure, such as stents, to keep his native kidney working as long as possible. We also told no one!

> ***My answer was always that the greatest thing about organ donation is that you are giving a family back a mother, a father, a sister, etc. That would shut them up.***

In Hollywood you can be an alcoholic or a drug user and they will hire you. But twenty years ago, they would not hire you if you had an illness. We could not risk that the show would be canceled. It was a difficult time because each year George's kidney function would deteriorate further, and we had to keep it a BIG secret.

I remember the moment when the doctors informed us that it was finally time to begin the testing process for George's kidney transplant, something we had managed to postpone for six years. His kidney condition had deteriorated rapidly, making it urgent to act to avoid dialysis.

I had so many emotions: determination, fear for George, and anxiety about telling our daughter, wondering if the transplant will work, and if we can keep it private. Our daughter Mayan was nine years old. George was in the middle of filming the fourth season of the *George Lopez* television series. So many people depended on him, and no one working on the show knew George was dealing with any of this. We were able to wait until the season wrapped, but just barely. At that time, George was at 17 percent kidney function.

I had an alias at Cedars Sinai and all my testing was done under the name Ann Ace, and George was Tom Ace after our daughter's favorite movie *Ace Ventura*. When George was in the recovery room and starting to wake up after the transplant, the nurse said, "Mr. Ace, can you hear me? Tom, open your eyes." George said he forgot his alias and kept wondering why they were calling him Tom!

Becoming a living kidney donor is a specific process. You cannot simply decide to donate a kidney. You have to have your own team of doctors, and you undergo health evaluations to make sure your body can handle the stress of surgery. You also have other testing done to see if you are a match. If the operation would pose any risk to your health you will not be approved to be a donor.

I also had to go through psychological counseling, and they brought up things I had never thought about such as how would I feel if my kidney got rejected or if we got a divorce. I said I would be very disappointed if my kidney was rejected, but knowing we had tried was important to me.

*George, Ann, and Mayan Lopez*

As for divorce, which ultimately occurred, it obviously brought a great deal of pain. However, what mattered most was that my daughter would still have her father in her life. Nothing is more important than that. Unfortunately, during the divorce a false news article said that George was divorcing me, the woman who gave him a kidney. The truth is, I am the one who made the decision to end our marriage and file for divorce. Many of the less reputable news outlets picked up the rumor, and like wildfire it became a false narrative we could not contain. George still faces a lot of flak and hate because of this false narrative. I am not claiming that he is without fault, but it is not for that reason.

I remember the doctors trying to tell me that the odds were incredibly low for me to be a good match, yet in my heart I knew I was going to be George's donor. So when I found out I was a match for George, I was ecstatic! It felt like we had won the donor

Continued on next page

lottery. Back then, it was uncommon for spouses to match. I am grateful for the advancements in transplantation over the last 20 years which have allowed more couples to donate to each other.

After the transplant, George felt so much better when my kidney kicked in! The media went wild over the story. We were in *People Magazine, The New York Times, The Los Angeles Times*, and countless newspapers around the country. We sat down with "Dateline," "Good Morning America," and other television shows, and we did a satellite tour talking to news outlets all over the country. Suddenly there was a dialogue about live kidney donations. We heard from so many people who had decided to donate one of their kidneys after hearing our story. That made George and me so happy to be able to shine a light on living organ donation.

A transplant is major surgery and there was pain afterward. I was also very tired. It took about six weeks for me to get back to normal. These discomforts were a small price to pay to help my husband. I had no complications after surgery, and my health since the transplant has been great. Today, I work out, I hike, I bike, and I eat a balanced diet. The transplant did not impact my own health in any way. I do have a few scars which I consider my bad-ass mementos for being an organ donor and saving a life!
We celebrated the 20th anniversary of our kidney transplant on April 19, 2025. Mayan has her dad, George has his health, his fans have him. I have George as a dear friend and the father of my only child. It is just such a miracle! Every year on the anniversary Mayan writes a beautiful post about what organ donation means to her and how grateful she is to still have her dad in her life.

Mayan grew up on the set of the *George Lopez* show. She always wanted to visit her dad on the set. Mayan was always following the director around and they finally made her "Kid AD" because she wanted to work on the show. On show night she had a headset, and she would bring the actors from hair and makeup to the set. She loved it. George and I paid her $20 each show night.

Twenty years later it is so amazing to see Mayan and George star in a television series together. *Lopez vs. Lopez* originated from a series of comedic TikTok videos by Mayan. It is the first show to be created from a TikTok. To see Mayan with her own show and doing what she always wanted to do is so special. To be doing it with her dad makes it doubly so. The fact that George is healthy, thriving, and being so darn funny is just a blessing. Mayan and George have truly created something very special. Some of the people working on *Lopez vs. Lopez* worked on the original show and have known Mayan since she was five years old. It is a full circle moment in so many ways.

We had so many friends reach out to us when the news of the transplant came out. Clint Eastwood was the very first to call us, Sandra Bullock sent us weeks' worth of yummy food, Damon Wayan sent us a barrel of kidney beans, Freddie Prinze Jr. came over and made us laugh. And there were so many more sweet moments and acknowledgments. It was so special to feel so much love from our friends.

I have been working with Renal Support Network (RSN) for over ten years. I worked on the poker and bingo tournament, the Renal Teen Prom, and now at Studio Hope Thrift Store in Burbank. The Renal Teen Prom just celebrated its 26th year. Mayan and I would get dresses donated to the prom from friends. On the day the girls came to pick their prom dresses, we would be there to help these special young ladies pick their dresses. Mayan was a junior in high school and I felt it was very important that she was volunteering for an event so special to kids her own age living with kidney disease. Mayan loved sharing this special time with the girls. I think it is so important to get children and young adults to volunteer and start them on a path of philanthropy.

Mayan and I would also attend the prom. Mayan helped encourage quite a few of the shy kids to get out on the dance floor. During the pandemic Mayan and I hosted a Zoom version of the prom as well as a Zoom bingo game night. She and George also did a "live" Zoom tour at Ripley's Believe It or Not. The pandemic didn't keep RSN from connecting with these amazing kids who are so full of courage, resilience, and aspirations.

People ask me if they should donate a kidney. I say do it if you can! It is the ultimate recycling. Seriously, besides giving birth to my daughter, being a living kidney donor has been the most profound experience of my life. We all need to continue to spread the word. The more people who share their living donation experiences, the greater the impact we will have. I also feel more representation of organ donation in an accurate manner on television and film will bring even wider awareness to a larger audience.

To be able to extend the life and give health to another human being is just a mind boggling and humbling experience. George is alive and in good health. Mayan has her dad. That makes me so grateful. It is a feeling like no other.

*Ann Serrano Lopez is a producer, actress, and organ donation advocate. As an actress she has been seen in* Curb Your Enthusiasm, Arrested Development, *and* Life with Bonnie, *and has appeared in over 60 television commercials. She executive produced the TV movies* Naughty or Nice *for The Wonderful World of Disney,* Mr. Troop Mom *for Nickelodeon, the documentary* Carlos Almaraz: Playing with Fire *for Netflix, and various other television specials and short films.*

Web ID: 44098

# SPEAK OUT FOR INNOVATION IN DIALYSIS CARE

By Jeffrey Silberzweig, MD

When I walk into a dialysis unit today, it looks much the same as it did when I entered nephrology practice in 1995. Yet if I were to walk into a cardiac care unit or a cancer treatment suite, it would look dramatically different. The medications have changed so much that those who taught me about heart disease or cancer in the 1980s and 1990s would not be able to teach the students and residents of today.

Why is there such a disparity in innovation between nephrology and other medical fields? The ability to make money drives entrepreneurs and "sharks" to invest their creativity, drive, and money to a field. When the United States Government amended the Social Security Act in 1973 to permit Medicare payment for patients requiring dialysis, they paid $138 per treatment; an equivalent payment based on inflation would be $1,033 in 2025. The base rate paid today is $273.82.

Recognizing the lack of drivers of innovation, the kidney community banded together and asked Congress and the Centers for Medicare and Medicaid Services (CMS) to consider additional payment for new, innovative medications and equipment which could improve the quality of life and outcomes of patients requiring dialysis. In 2016, CMS introduced two payment pathways: the Transitional Drug Add-on Payment Adjustment (TDAPA) and the Transitional Add-on Payment Adjustment for New and Innovative Equipment and Supplies (TPNIES).

***Often patients feel ill-equipped to talk to their representatives, but it is precisely patient stories and experiences that are needed.***

These programs provide payment of 65 percent of the average sales price of new products. The first products to qualify for TDAPA payment were calcimimetics, medications which mimic the action of calcium on the parathyroid gland, reducing the incidence of bone complications of chronic kidney disease. When initially introduced, the IV form (etelcalcetide or Parsabiv) was thought to represent a significant advance compared with the oral form (cinacalcet or Sensipar) and widespread use was anticipated. However, over the two-year TDAPA period, providers and physicians found little difference between the two forms of the medication, so when a generic form of cinacalcet was introduced in 2018, its use dramatically surpassed that of etelcalcetide. At the end of the two-year TDAPA period, payment for etelcalcetide was reduced further and its use was even more limited.

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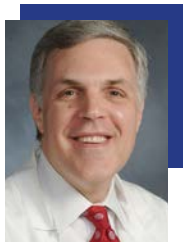

*Jeffrey Silberzweig, MD is the Chief Medical Officer of The Rogosin Institute, leads the dialysis programs at New York-Presbyterian Hospital as Chair of the Dialysis Executive Council and is the medical director of the dialysis units at the Weill Cornell and Lower Manhattan Hospital Campuses. He has been a nephrologist and leader in the community for over 25 years and has received many prestigious awards.*

# What's in the DIALYSIS BUNDLE

Medicare is a government program which pays for dialysis treatment for people who are eligible and covered under Part B with the ESRD PPS (End-Stage Renal Disease Prospective Payment System). The ESRD PPS is a "dialysis bundled payment" made to a dialysis facility on behalf of Medicare beneficiaries for their treatment. The "Dialysis Bundle" includes the dialysis treatment, laboratory tests, supplies, all drugs, biologicals and services provided for the dialysis treatment.

## Treatment

Maintenance dialysis treatments done at an approved facility or in a patient's home.

## Labs

Laboratory tests ordered for ESRD-related conditions.

## Oral/IV Drugs

Oral or other forms of drugs and biologicals which are for the treatment of ESRD.

## Clinic Staff

Includes all nurses, technicians, social worker, and dietitian.

## Innovation

Medicare establishes a time frame for the inclusion of new ESRD medications and medical equipment within its coverage. Medicare determines a set price per treatment to be added to the bundle after a 2-year trial period.

## Home Training & Treatment

Home hemodialysis or peritoneal dialysis supplies and equipment. It also includes the training time from clinic staff.

## What's not in the dialysis bundle

- Nephrologist (kidney doctor) professional services
- Medications taken outside of the dialysis treatment (covered by Medicare Part D)
- Preventive vaccines and administration
- Labs relating to transplantation
- All costs associated with emergency room visits and hospitalization including dialysis and labs
- Procedures necessary to maintain vascular access



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# BE A CHAMPION OF KIDNEY CARE

*To foster innovation and improvements in kidney care, it is vital for everyone to express their concerns. Establishing relationships with elected officials and sharing personal experiences can significantly raise awareness. Here are three things you can do to get started.*

1

Stay Informed: Keep yourself updated on news regarding kidney care and healthcare legislation.

*"I always follow the news about xenotransplantation as I think it's incredible my peers took this risk and are doing the research for us. One step closer." – Cher T.*

2

Engage with Members of Congress: Reach out to your state's senator and representative to share your concerns. Personal stories can have a profound impact, influencing your elected official's stance on relevant issues, particularly regarding the effects of kidney disease on individuals and families.

*"When I'm asked about polycystic kidney disease (PKD), I explain that it is a genetic disorder that causes cysts to grow and damage the kidneys. If one parent (or both parents) carries the abnormal gene, a child has a 50 percent chance of having the disease." – Julie P.*

3

Attend Local Events: Participate in town halls or forums in which healthcare policy will be on the agenda. These gatherings provide excellent opportunities to pose questions and share your opinions directly with decision-makers.

*"I asked my representative if they knew that kidney disease is a silent illness which goes undetected until in the later stages, when damage is already done. Early testing is needed." – Marjorie M.*

***Take our survey to share what you think should be the top priorities in kidney care innovation. Scan the QR code or visit RSNhope.org and search for "Web ID 44099."***

***We look forward to hearing your story about innovation in our essay contest. See page 24 for more information.***

Note: As of this printing, the Trump administration has proposed tariffs on all medications, citing a national security threat. We hope the medication and medical supplies tarifs will be reconsidered, as they will lead to increased prices and hinder access to care.

***Find your representatives at RSNhope.org Web ID: Lookup or scan this QR Code:***

FRESENIUS KIDNEY CARE

# Stay home. Stay in control.

If your needs are changing with peritoneal dialysis, home hemodialysis (HHD) may be a great option. Many people think switching from PD means moving to in-center dialysis, but HHD lets you continue treatment at home—with more flexibility and control.

## HHD may offer:

- More freedom to dialyze on your schedule
- Better health outcomes and symptom management
- Travel-friendly options

Learn more about your home hemodialysis options.

**Scan here**

Thrive On

Web ID: 45000

# New Developments in KIDNEY TRAN

***There have been numerous time periods in kidney transplantation where one could argue that not much has changed. Thankfully, we are currently in an era where there are new developments either already happening or on the near horizon. Major changes are on the way!***

### *Organ Procurement/Allocation*

If you are on a kidney transplant waitlist or seeking to be added to one, you should be aware of the significant recent changes in this area. Many have felt that the existing system was inefficient and in need of reform. To address these concerns, in 2024 Congress initiated a modernization project focused on organ procurement and allocation. This initiative aims to enhance quality measures, streamline operations, increase data transparency, and leverage technology. From the patient's perspective, there is hope for greater transparency from the organ transplant community and ultimately an increase in the availability of organs. Another significant initiative expected to benefit patients and their families is the Improving Organ Transplant Access (IOTA) project, which will be launched by the Centers for Medicare and Medicaid Services (CMS) this summer. This mandatory pilot project will involve 50 percent of U.S. transplant centers, aiming to increase the volume of transplants while ensuring good patient outcomes through an incentive, and penalties to transplant centers if they do not perform to quality standards.

### *Xenotransplantation*

You may not be familiar with the term "xenotransplantation," but you have likely come across it in your reading. Xenotransplantation refers to the transplantation of tissues or organs from one species to another, typically from animals to humans. When I first learned about this concept over 20 years ago, I believed it might never become a reality or that it was far off in the future. However, that future has arrived, as you may have seen on the internet or television. There have been recent transplants being performed of a genetically engineered pig kidney. Although we are still in the early stages of this therapy with clinical trials yet to be completed, there is no doubt that we will see more developments in this exciting field. It holds the potential to help alleviate our significant organ shortage, especially as wait times continue to increase. I am also frequently asked about alternatives to transplantation, including artificial kidneys, stem cells, and other treatments. These technologies are progressing as well, and I remain hopeful that there will come a time when patients with advanced kidney disease have access to a range of effective options.

### *Diagnostic Testing*

For people who have a working transplant, the constant fear of organ rejection is a reality. The most common method for detecting this serious complication is a kidney biopsy. Fortunately, there are several less invasive tests available

# SPLANTATION

By Rafael Villicana, MD

which can assist your clinical team in assessing the risk of rejection. If we can detect rejection early, we can get ahead of it and help prevent it. While these tests are not foolproof, they can help determine whether a biopsy is necessary, or equally important, whether it can be avoided or postponed. Most of these assessments are blood-based, although urine tests are also in development.

### *Immunosuppression*

As many of you may know, after receiving a transplant, it is essential to take medications routinely to prevent rejection throughout the life of the transplant. Unfortunately, while these medications are effective in preventing rejection, they also come with numerous side effects which can adversely impact the transplant or cause other health issues. This might partially explain why the incidence of early rejection episodes has decreased, but the longevity of transplants has not improved at the same rate. Immunosuppressive therapy is an area of transplantation which has experienced fewer recent advancements compared to other fields, with the last significant development occurring nearly 15 years ago. Nonetheless, there have been many advances in treating chronic rejection and preventing initial rejection, which we hope will ultimately lead to longer-lasting transplants.

### *What You Can Do Now*

To maintain your transplanted kidney health, always take your immunosuppressant medications, ensure you have an adequate supply, and keep up with doctor appointments and lab tests. Regularly monitor your blood pressure, temperature, and weight, and report any health changes to your doctor, such as pain or fever. Prioritize a healthy diet, exercise, and hydration. Use your healthcare portal to check lab results and medications and stay in touch with your healthcare team whenever you experience nonemergency issues. And most importantly, stay informed and ask questions! If you are waiting for a kidney transplant, ensure that all your tests are up to date and that your transplant team has your current contact information. If you are unsure if they have your current information, send a message though your portal. It is important to always answer your phone, as the call for a kidney transplant may come from a number you do not recognize. Transplantation is an increasingly sought-after treatment for kidney failure, which is why the waiting list continues to grow each year.

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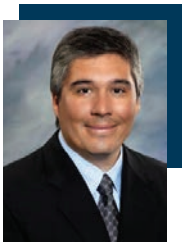


Rafael Villicana, MD, is a transplant nephrologist and the medical director of the kidney transplant program at Loma Linda University (LLU) Transplantation Institute. His interests include kidney and pancreas transplantation, living kidney donation, and ABO /HLA incompatible kidney transplantation.

Web ID: 45001

# Kidney-Friendly Summer

Eating well while managing phosphorus, potassium, and sodium levels does not mean missing out on summer favorites! Here are a few kidney-friendly foods and refreshing drinks for those hot, sunny days. These menu ideas will help you stay cool, nourished, and confident as you enjoy the flavors of the season. Recipes on pages 20-21.

**GRILLED CHICKEN**
High in protein, low in phosphorus

**RICE SALAD**
Low potassium alternative to potato-based salads

**CUCUMBER & ONION SALAD**
Light and refreshing

**HOMEMADE LEMONADE**
Low in potassium if made with fresh lemons

**GRILLED SALMON**
High-quality protein, low in sodium, rich in omega-3 fatty acids

**CUCUMBER INFUSED WATER**
A refreshing way to drink water; try lemon, mint, or frozen fruit

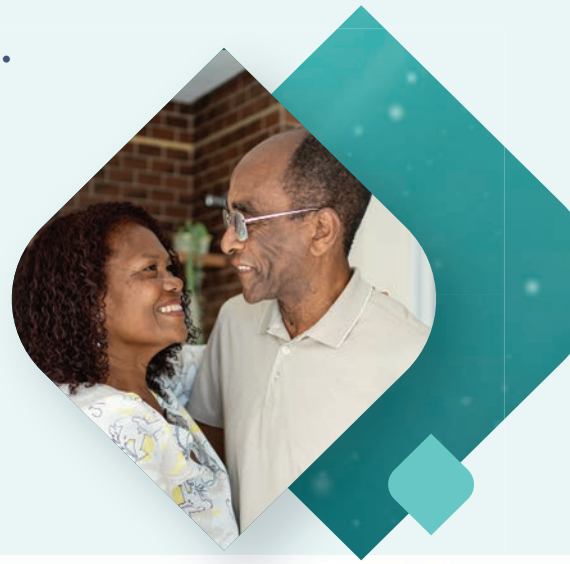
# Having trouble getting phosphorus to goal?

XPHOZAH®
(tenapanor) tablets

## A different way to lower your phosphorus is here.

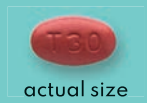
As add-on therapy for patients on dialysis in whom a phosphate binder does not work well:

- XPHOZAH can help reduce serum phosphorus in adults
- XPHOZAH is not a binder, it's a blocker
- XPHOZAH blocks phosphorus throughout the day when taken just before your first and last meal



## Ask your healthcare provider about XPHOZAH.

**One pill, twice a day.**



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**Scan or visit XPHOZAH.com to learn more**

## INDICATION

XPHOZAH (tenapanor) 30 mg BID is a prescription medicine used to reduce serum phosphorus in adults with chronic kidney disease (CKD) on dialysis as add-on therapy when phosphate binders do not work well, or when phosphate binders cannot be tolerated.

## IMPORTANT SAFETY INFORMATION

**The most important information about XPHOZAH is:**

- XPHOZAH may result in softer and/or more frequent bowel movements.
- Do not give XPHOZAH to children who are less than 6 years of age

**Do not use XPHOZAH in:**

- Children who are less than 6 years of age
- Patients who have a suspected bowel blockage

**Before taking XPHOZAH, tell your healthcare provider about all of your medical conditions, including if you:**

- are pregnant or plan to become pregnant
- are breastfeeding or plan to breastfeed

Do not use XPHOZAH with stool softeners or laxatives. **Tell your doctor about all the medicines you take**, including prescription and over-the-counter medicines, vitamins, and herbal supplements.

**XPHOZAH can cause serious side effects, including:**

Diarrhea is the most common side effect of XPHOZAH, and it can sometimes be severe. Call your doctor if you develop severe diarrhea.

These are not all the possible side effects of XPHOZAH. Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088. You may also report side effects to www.fda.gov/medwatch.

**Please see Brief Summary of the full Prescribing Information on the following pages.**

ardelyx®

**XPHOZAH (tenapanor) tablets, for oral use**
**Brief Summary of Prescribing Information**

## 1 INDICATIONS AND USAGE

XPHOZAH is indicated to reduce serum phosphorus in adults with chronic kidney disease (CKD) on dialysis as add-on therapy in patients who have an inadequate response to phosphate binders or who are intolerant of any dose of phosphate binder therapy.

## 4 CONTRAINDICATIONS

XPHOZAH is contraindicated in patients under 6 years of age because of the risk of diarrhea and serious dehydration *[see Warnings and Precautions (5.1), Use in Specific Populations (8.5)]*.

XPHOZAH is contraindicated in patients with known or suspected mechanical gastrointestinal obstruction.

## 5 WARNINGS AND PRECAUTIONS

### 5.1 Diarrhea

Diarrhea was the most common adverse reaction in XPHOZAH-treated patients with CKD on dialysis *[see Dosage and Administration (2) in the full Prescribing Information, Contraindications (4) and Adverse Reactions (6.1)]*. In clinical trials, diarrhea was reported in up to 53% of patients, reported as severe in 5%, and associated with dehydration and hyponatremia in less than 1% of patients. Treatment with XPHOZAH should be discontinued in patients who develop severe diarrhea.

## 6 ADVERSE REACTIONS

### 6.1 Clinical Trial Experience

Because clinical trials are conducted under widely varying conditions, adverse reaction rates observed in the clinical trials of a drug cannot be directly compared with rates in the clinical trials of another drug and may not reflect the rates observed in practice.

The safety data described below reflect data from 754 adults with CKD on dialysis taking XPHOZAH in clinical trials as monotherapy and in combination with phosphate binders. Among the 754 patients, 258 patients were exposed to tenapanor for at least 26 weeks and 75 were exposed to tenapanor for at least one year. *[see Clinical Studies (14) in the full Prescribing Information]*.

Most Common Adverse Reaction

Diarrhea, which occurred in 43-53% of patients, was the only adverse reaction reported in at least 5% of XPHOZAH-treated patients with CKD on dialysis across trials. The majority of diarrhea events in the XPHOZAH-treated patients were reported to be mild-to-moderate in severity and resolved over time, or with dose reduction. Diarrhea was typically reported soon after initiation but could occur at any time during treatment with XPHOZAH. Severe diarrhea was reported in 5% of XPHOZAH-treated patients in these trials *[see Warnings and Precautions (5.1)]*.

## 7 DRUG INTERACTIONS

### 7.1 OATP2B1 Substrates

Tenapanor is an inhibitor of intestinal uptake transporter, OATP2B1 *[see Clinical Pharmacology (12.3) in the full Prescribing Information]*. Drugs which are substrates of OATP2B1 may have reduced exposures when concomitantly taken with XPHOZAH. Monitor for signs related to loss of efficacy and adjust the dose of concomitantly administered drug as needed.

Enalapril is a substrate of OATP2B1. When enalapril was coadministered with XPHOZAH (30 mg twice daily for five days), the peak exposure (Cmax) of enalapril and its active metabolite, enalaprilat, decreased by approximately 70% and total systemic exposures (AUC) decreased by 50 to 65% compared to when enalapril was administered alone *[see Clinical Pharmacology (12.3) in the full Prescribing Information]*. However, the decrease in enalaprilat's exposure with XPHOZAH may be offset by the inherently higher exposures observed in patients with CKD on dialysis due to its reduced renal clearance. Therefore, a lower starting dose of enalapril, which is otherwise recommended in patients with CKD on dialysis is not required when enalapril is coadministered with XPHOZAH.

### 7.2 Sodium Polystyrene Sulfonate

Separate administration XPHOZAH and sodium polystyrene sulfonate (SPS) by at least 3 hours. SPS binds to many commonly prescribed oral medicines.

## 8 USE IN SPECIFIC POPULATIONS

### 8.1 Pregnancy

Risk Summary

Tenapanor is essentially non-absorbed systemically, with plasma concentrations below the limit of quantification (less than 0.5 ng/mL) following oral administration *[see Clinical Pharmacology (12.3) in the full Prescribing Information]*. Therefore, maternal use is not expected to result in fetal exposure to the drug.

The available data on XPHOZAH exposure from a small number of pregnant women have not identified any drug associated risk for major birth defects, miscarriage, or adverse maternal or fetal outcomes. In reproduction studies with tenapanor in pregnant rats and rabbits, no adverse fetal effects were observed in rats at 0.2 times the maximum recommended human dose and in rabbits at doses up to 15 times the maximum recommended human dose (based on body surface area) *[see Nonclinical Toxicology (13.1) in the full Prescribing Information]*.

The estimated background risk of major birth defects and miscarriage for women with CKD on dialysis with hyperphosphatemia is unknown. All pregnancies have a background risk of birth defect, loss, or other adverse outcomes. In the United States general population, the estimated background risk of major birth defects and miscarriage in clinically recognized pregnancies is 2% to 4% and 15% to 20%, respectively.

Animal Data

In an embryofetal development study in rats, tenapanor was administered orally to pregnant rats during the period of organogenesis at dose levels of 1, 10 and 30 mg/kg/day. Tenapanor doses of 10 and 30 mg/kg/day were not tolerated by the pregnant rats and was associated with mortality and moribundity with body weight loss. The 10 and 30 mg/kg dose group animals were sacrificed early, and the fetuses were not examined for intrauterine parameters and fetal morphology. No adverse fetal effects were observed in rats at 1 mg/kg/day (approximately 0.2 times the maximum recommended human dose) and in rabbits at doses up to 45 mg/kg/day (approximately 15 times the maximum recommended human dose, based on body surface area). In a pre- and post-natal developmental study in mice, tenapanor at doses up to 200 mg/kg/day (approximately 16.5 times the maximum recommended human dose, based on body surface area) had no effect on pre- and post-natal development.

### 8.2 Lactation

Risk Summary

There are no data available on the presence of tenapanor in either human or animal milk, its effects on milk production or its effects on the breastfed infant. Tenapanor is essentially non-absorbed systemically, with plasma concentrations below the limit of quantification (less than 0.5 ng/mL) following oral administration *[see Clinical Pharmacology (12.3) in the full Prescribing Information]*. The minimal systemic absorption of tenapanor will not result in a clinically relevant exposure to breastfed infants. The developmental and health benefits of breastfeeding should be considered along with the mother's clinical need for XPHOZAH and any potential adverse effects on the breastfed infant from XPHOZAH or from the underlying maternal condition.

### 8.4 Pediatric Use

Risk Summary

XPHOZAH is contraindicated in patients less than 6 years of age. In nonclinical studies, deaths occurred in young juvenile rats (less than 1-week old rats; approximate human age-equivalent of less than 2 years of age) and in older juvenile rats (approximate human age-equivalent of 2 years of age) following oral administration of tenapanor, as described below in Juvenile Animal Toxicity Data.

The safety and effectiveness of XPHOZAH in pediatric patients have not been established.

Juvenile Animal Toxicity Data

In a 21-day oral dose range finding toxicity study in juvenile rats, tenapanor was administered to neonatal rats (post-natal day (PND) 5) at doses of 5 and 10 mg/kg/day. Tenapanor was not tolerated in male and female pups and the study was terminated on PND 16 due to mortalities and decreased body weight (24% to 29% reduction in females at the respective dose groups and 33% reduction in males in the 10 mg/kg/day group, compared to control).

In a second dose range finding study, tenapanor doses of 0.1, 0.5, 2.5, or 5 mg/kg/day were administered to neonatal rats from PND 5 through PND 24. Treatment-related mortalities were observed at 0.5, 2.5, and 5 mg/kg/day doses. These premature deaths were observed as early as PND 8, with majority of deaths occurring between PND 15 and 25. In the 5 mg/kg/day group, mean body weights were 47% lower for males on PND 23 and 35% lower for females on PND 22 when compared to the controls. Slightly lower mean tibial lengths (5% to 11%) were noted in males and females in the 0.5, 2.5, and 5 mg/kg/day dose groups on PND 25 and correlated with the decrements in body weight noted in these groups. Lower spleen, thymus, and/or ovarian weights were noted at the 0.5, 2.5, and 5 mg/kg/day doses. Tenapanor-related gastrointestinal distension and microscopic bone findings of increased osteoclasts, eroded bone, and/or decreased bone in sternum and/or femorotibial joint were noted in males and females in the 0.5, 2.5, and 5 mg/kg/day dose groups.

In juvenile rats administered tenapanor at 0.03, 0.1, or 0.3 mg/kg/day on PND 5 through PND 61, treatment-related mortalities were observed at 0.3 mg/kg/day. Lower mean body weight gains were noted in the 0.3 mg/kg/day group males and females compared to the control group primarily during PND 12–24 but continuing sporadically during the remainder of the dosing period; corresponding lower mean food consumption was noted in this group during PND 21–33. As a result, mean body weights were up to 15.8% and 16.8% lower in males and females, respectively, compared to the control group; the greatest difference was on PND 24 for males and PND 21 for females. Mean body weight in the 0.3 mg/kg/day group males was only 3.9% lower than the control group on PND 61. There were no tenapanor-related effects on mean body weights, body weight gains, or food consumption in the 0.03 and 0.1 mg/kg/day group males

and females. A dosage level of 0.1 mg/kg/day was considered to be the no-observed-adverse-effect level (NOAEL) for juvenile toxicity of tenapanor *[see Contraindications (4), Warnings and Precautions (5.1)]*.

In a 21-day oral dose range finding study in older (weaned) juvenile rats administered tenapanor at 0.1, 1, or 5 mg/kg/day on PND 21 through PND 41 (approximate human age-equivalent of 2 to 12 years of age), treatment-related mortalities or moribundities were observed during the first two days of the study in the 1 mg/kg/day males and the 5 mg/kg/day males and females. Watery feces, decreased food consumption, and lower mean body weight were also observed in the 1 and 5 mg/kg/day groups.

In weaned juvenile rats administered tenapanor at 0.1, 0.3, and 0.7 (males) or 1 (females) mg/kg/day on PND 21 through PND 80, no mortalities were observed. Significant decreases in mean body weights were observed in the 0.3 and 0.7 mg/kg/day males throughout the dosing period (up to 20.3% lower than control) and in the 1 mg/kg/day females between PND 23 to 35 (up to 16.7% lower than control), with food consumption notably decreased on PND 21 to 29. There were also reductions in tibia length between PND 76 and 80 in the 0.3 and 0.7 mg/kg/day males, and between PND 36 and 64 in the 0.7 mg/kg/day males, which were not observed during the 14-day recovery period. The NOAEL was considered to be 0.1 mg/kg/day for juvenile toxicity of tenapanor.

### 8.5 Geriatric Use

Of 1010 adult patients with CKD on dialysis randomized and treated in two randomized, double-blind, placebo-controlled randomized withdrawal clinical trials for XPHOZAH (TEN-02-201 and TEN-02-301) as well as a third randomized, double-blind, placebo-controlled trial (TEN-02-202) for XPHOZAH in combination with phosphate binders, 282 (28%) were 65 years of age and older. Clinical studies of XPHOZAH did not include sufficient numbers of patients aged 65 and older to determine whether they respond differently than younger patients.

## 10 OVERDOSAGE

No data are available regarding overdosage of XPHOZAH in patients. Based on nonclinical data, overdose of XPHOZAH may result in gastrointestinal adverse effects such as diarrhea, as a result of exaggerated pharmacology with a risk for dehydration if diarrhea is severe or prolonged *[see Warnings and Precautions (5.1)]*.

## 17 PATIENT COUNSELING INFORMATION

Advise Patients:

Diarrhea

Instruct patients to contact their healthcare provider if they experience severe diarrhea *[see Warnings and Precautions (5.1)]*.

- Instruct patients not to use stool softeners or laxatives with XPHOZAH.

Administration and Handling Instructions

Instruct Patients:

- To take XPHOZAH just prior to the first and last meals of the day *[see Dosage and Administration (2.2) in the full Prescribing Information]*.
- Patients should be counseled not to take XPHOZAH right before a hemodialysis session, and to take XPHOZAH right before the next meal, as some patients may experience diarrhea after taking XPHOZAH.
- If a dose is missed, take the dose just before the next meal. Do not take 2 doses at the same time *[see Dosage and Administration (2.2) in the full Prescribing Information]*.
- To keep XPHOZAH in a dry place. Protect from moisture. Keep in the original bottle. Do not remove desiccant from the bottle. Keep bottles tightly closed *[see How Supplied/Storage and Handling (16) in the full Prescribing Information]*.


Manufactured for and distributed by Ardelyx, Inc.
400 Fifth Avenue, Suite 210 Waltham, MA 02451 USA



US-XPH-0161 11/23

**Kidney Friendly Summer**
**Continued from page 16**

## Grilled Salmon

### Ingredients (2 servings)

2 4-ounce salmon fillets

1 tablespoon olive oil

1 teaspoon fresh lemon juice

1 teaspoon fresh dill (or ½ teaspoon dried)

½ teaspoon garlic powder

½ teaspoon onion powder

¼ teaspoon black pepper

1 teaspoon honey for slight sweetness (optional)

1 clove garlic, minced (optional)

### Instructions

Soak salmon in water for 1–2 hours before cooking to lower potassium.

In a small bowl mix olive oil, lemon juice, dill, garlic powder, onion powder, black pepper, and honey (if using).

Brush the marinade evenly over both sides of the salmon fillets.

Put the salmon in the refrigerator for about 15–20 minutes.

Heat a grill to medium and lightly oil the grates to prevent sticking.

Place the salmon on the grill skin side down.

Cook for about 4–5 minutes per side, or until the fish flakes easily with a fork.

Serve immediately.

### Nutritional Facts (per serving)

Calories: 241
Protein: 22 g
Total Fat: 14 g
Saturated Fat: 2 g
Cholesterol: 62 mg
Carbohydrates: 4 g
Calcium: 20 mg
Phosphorus: 234 mg
Potassium: 583 mg
Sodium: 50 mg

## Refreshing Cucumber & Onion Salad

### Ingredients (4 servings)

2 cucumbers, thinly sliced

¼ red onion, thinly sliced

2 tablespoon apple cider vinegar

1 tablespoon olive oil

1 teaspoon sugar

¼ teaspoon black pepper

### Instructions

Combine all ingredients in a bowl.

Toss well and let sit for ten minutes before serving.

### Nutritional Facts (per serving)

Calories: 57
Protein: .97 g
Total Fat: 3 g
Saturated Fat: .5 g
Cholesterol: 0 mg
Carbohydrates: 5 g
Calcium: 23 mg
Phosphorus: 34 mg
Potassium: 221 mg
Sodium: 3 mg


## Rice Salad

### Ingredients (4 servings)

2 cups cooked white rice (rinsed to reduce potassium)

½ cup red bell pepper, finely diced

¼ cup cucumber, peeled and finely diced

¼ cup red onion, finely diced

¼ cup fresh parsley, chopped

2 tablespoons olive oil

1 tablespoon apple cider vinegar (or lemon juice)

½ teaspoon garlic powder

½ teaspoon onion powder

¼ teaspoon black pepper

1 teaspoon honey (optional)

### Instructions

Prepare white rice according to package instructions, then rinse under cold water to cool and reduce potassium.

Dice the bell pepper, cucumber, and red onion (soak onion in water for 10 minutes if you prefer a milder taste).

In a small bowl, whisk together olive oil, vinegar (or lemon juice), garlic powder, onion powder, black pepper, and honey.

In a large bowl, mix the rice, diced vegetables, and dressing.

Toss well to coat evenly.

Refrigerate for at least 30 minutes to allow flavors to blend.

Serve chilled or at room temperature.

### Nutritional Facts (per serving)

Calories: 180
Protein: 3 g
Total Fat: 7 g
Saturated Fat: 1 g
Cholesterol: 0 mg
Carbohydrates: 27 g
Calcium: 20 mg
Phosphorus: 50 mg
Potassium: 120 mg
Sodium: 5 mg

## Grilled Lemon Herb Chicken

**Ingredients: (4 servings)**

4 skinless, boneless chicken breasts

2 tablespoons olive oil

Juice of 1 lemon

1 teaspoon garlic powder

1 teaspoon dried oregano

1/2 teaspoon black pepper

**Instructions**

In a bowl, mix together olive oil, lemon juice, garlic powder, oregano, and black pepper.

Brush marinade on chicken.

Allow the chicken to marinate for 30 minutes.

Grill on medium heat for 6-7 minutes per side until fully cooked.

**Nutritional Facts (per serving)**

Calories: 196
Protein: 24 g
Total Fat: 9 g
Saturated Fat: 1 g
Cholesterol: 72 mg
Carbohydrates: 1 g
Calcium: 15 g
Phosphorus: 242 mg
Potassium: 444 mg
Sodium: 131 mg

## Homemade Lemonade

**Ingredients (4 servings)**

4 cups water

Juice of 2 lemons

1/4 cup sugar (or to taste)

Ice cubes

**Instructions**

Mix water, lemon juice, and sugar.

Stir well and serve over ice.

**Nutritional Facts (per serving)**

Calories: 51
Protein: .05 g
Total Fat: .06 g
Saturated Fat: 0 g
Cholesterol: 0 mg
Carbohydrates: 13 g
Calcium: 25 mg
Phosphorus: 2 mg
Potassium: 25 mg
Sodium: 5 mg

## Cucumber Infused Water

**Ingredients (4 servings)**

4 cups filtered water

½ cucumber, peeled and thinly sliced

3–4 fresh mint leaves (optional)

1 teaspoon lemon juice (optional)

Ice cubes (optional)

**Instructions**

Peel the cucumber to reduce potassium, then slice into thin rounds.

In a pitcher, add the cucumber slices, mint leaves (if using), and filtered water.

Let the mixture sit in the refrigerator for at least 1–2 hours (or overnight for stronger flavor).

Pour over ice and enjoy!

**Nutritional Facts (per serving)**

Calories: 5
Protein: .25 g
Total Fat: 0 g
Saturated Fat: 0 g
Cholesterol: 0 mg
Carbohydrates: 1 g
Calcium: 14 mg
Phosphorus: 5 mg
Potassium: 56 mg
Sodium: 12 mg

Every person is different and each meal may need adjusting depending on your situation, so please be sure to check with your dietitian or medical team if you're not sure about a recipe.


## Cooking For Your Kidney Health Online Nutrition Information Tool

RSN's Nutritional Information Database is a great resource for people who have chronic kidney disease, are on dialysis, or have a kidney transplant. Learn more at RSNhope.org, Web ID: NTData

Web ID: 45002

# 8 Tips FOR SELF-CARE

PRIORITIZE SELF-CARE AND MAKE TIME FOR THESE ACTIVITIES AS THEY CAN HAVE A POSITIVE IMPACT ON YOUR WELL-BEING.

MOISTURIZE YOUR ENTIRE BODY WITH YOUR FAVORITE LOTION, WHETHER IT'S UNSCENTED, INEXPENSIVE, OR LUXURIOUS. APPLY IT GENEROUSLY TO NOURISH YOUR SKIN.

WEAR CLEAN AND COMFORTABLE CLOTHES, INCLUDING YOUR FAVORITE UNDERWEAR. DON'T HESITATE TO DON THOSE QUIRKY BOXERS YOU GOT AS A GIFT.

ENGAGE IN SMALL CLEANING TASKS LIKE ORGANIZING A DRAWER, WASHING A FEW DISHES, DOING LAUNDRY, OR SCRUBBING THE BATHROOM SINK.

BOOST YOUR MOOD BY PLAYING UPBEAT MUSIC THAT MAKES YOU WANT TO DANCE AND SING ALONG, EVEN IF YOU'RE NOT PARTICULARLY TALENTED AT EITHER.

CREATE SOMETHING ARTISTIC SUCH AS WRITING A SHORT STORY OR POEM, DRAWING OR COLORING PICTURES, FOLDING ORIGAMI SHAPES, CROCHETING OR KNITTING A BLANKET, OR SCULPTING WITH CLAY.

SPEND TIME OUTDOORS BY TAKING WALKS IN NATURE, SMELLING THE FLOWERS IN YOUR NEIGHBORHOOD, OR EATING A PICNIC LUNCH AT A PARK.

IF YOU HAVE PETS, CUDDLE THEM, WALK THEM AND EXPRESS THE FEELINGS YOU HAVE TO THEM.

COMMUNICATE WITH OTHERS: CALL LOVED ONES/FRIENDS/FAMILY MEMBERS OR ATTEND RSN SUPPORT GROUPS. CONNECTING WITH OTHERS, EVEN IN SMALL WAYS, CAN HELP UPLIFT YOUR SPIRITS.

# RENAL SUPPORT NETWORK CONTENT SPOTLIGHT:
## *Knowledge at Your Fingertips!*

### KidneyTalk® Podcast
**Listen wherever you are!**

RSN's KidneyTalk® is an informative, inspirational, and entertaining online radio talk show which provides the audience with practical advice on how to live a full and productive life despite CKD. The show features healthcare professionals and people living successfully with kidney disease who share personal experiences and wisdom. Listen in on the website. Stream or download on Apple, YouTube, Amazon, and on iHeart Radio. Learn more at RSNhope.org, Web ID: 159

### Transplant Dashboard
**National and state statistics at a glance**

RSN's Kidney Transplant Dashboard makes it easier for patients, families, and friends to understand the options with an interactive map. The dashboard shows how many people are active on the waiting list, what type of transplants each center performs, and the number of kidney transplants done by each hospital. Learn more at RSNhope.org, Web ID: TXData

### Online Support Groups & More
**Spend Quality Time with Your Kidney Kin**

RSN's Zoom support groups are a great way to connect with others living with kidney disease all across the United States, make new friends, and learn new things.

Our online meetings are informative and so much fun! Topics include kidney disease support groups, exercise, hobbies, diet tips, and more. There are no fees. Sign up for online meet-ups with your kidney kin today at RSNhope.org, Web ID: RSNOSG.

### What is a Web ID?
**How to Quickly Locate RSN Website Content**

Each article in the magazine has a unique Web ID number, which is assigned to all content, both print and online. To find content on the website, users can click the magnifying glass icon on the homepage and enter the Web ID. Healthcare professionals can simplify sharing resources with patients by compiling lists of prescription articles and podcasts using these Web IDs as short codes.

You can also scan the QR code to access the linked content. Simply point your phone's camera at the QR code. A notification or pop-up will appear, typically displaying the link. You can then tap it to open the webpage or access other related information.

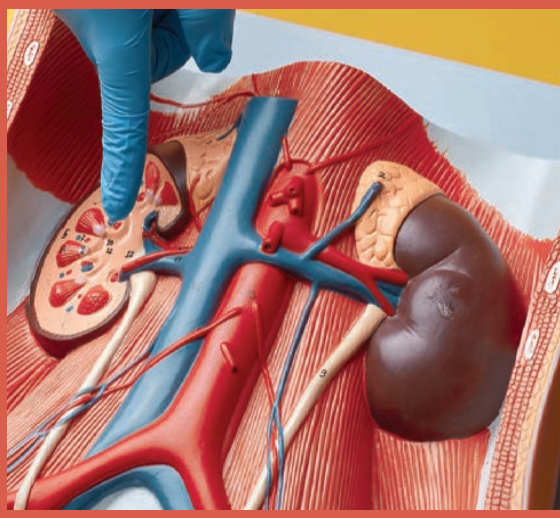
ENTER RENAL SUPPORT NETWORK'S

# 23RD ANNUAL ESSAY CONTEST

# INNOVATION

## PAST, PRESENT & FUTURE

Share a story about an innovation in kidney care from which you benefited or describe an innovation you are looking forward to in the future.



**Submissions are open to anyone in the United States who has kidney disease.**

**Essays are due by August 10, 2025.**

**Cash prizes awarded to 1st, 2nd, and 3rd place winners.**

**Learn more and enter at RSNhope.org/essay-contest**




JOIN US FOR
RENAL SUPPORT NETWORK'S

# KidneyTalk® LIVE


## 32ND ANNUAL PATIENT EDUCATION AND LUNCHEON MEETING

**Discover inspiring updates in kidney care, gain life-saving tips, connect with your peers, enjoy lunch and have a chance to win raffle prizes!**



**We are excited to announce that we will be meeting in-person this year in Burbank, California with two additional virtual days! The in-person meeting will be followed by a social gathering at Studio Hope Boutique.**

## THERE ARE NO FEES TO ATTEND!

**In-Person Meeting Sunday, June 29, 2025 · 10:00am – 3:00pm PT**
**Elks Lodge, 2232 N Hollywood Way, Burbank, CA 91505**

**Virtual Meeting Sunday, July 20 and Sunday, August 17, 2025**
**12pm - 2:30pm PT (zoom link available upon sign up)**

**REGISTRATION IS REQUIRED. LEARN MORE AND SIGN UP TO ATTEND AT RSNHOPE.ORG**

**Speak Up For Innovation In Dialysis Care**
**Continued from page 10**

Another product, Korsuva (difelikefalin) was introduced in 2021 for treatment of itching associated with kidney disease. Because of the side effects of other medications used to treat itching like Benadryl (diphenhydramine), Korsuva was thought to be a tremendous advance. However, physicians used very little Korsuva because there was no pathway to permanent payment and they knew patients would not be able to pay for it after the TDAPA period ended. When TDAPA ended, CMS determined, based on use and pricing, to add nine cents for its ongoing use. Since the payment was sufficiently inadequate, Korsuva was withdrawn from the market in 2024.

A new drug called XPHOZAH (tenapanor) has been approved by the FDA to help lower phosphorus levels in people undergoing dialysis. The developers are seeking to ensure its continued availability for patients through legislative changes or adjustments to the payment system. If these changes do not occur, access to this medication may also be at risk.

So far, TDAPA and TPNIES have not spurred innovation for patients requiring dialysis. The best way for patients to change the programs to gain more innovation is to talk about what they need, and talk to anyone who will listen: friends, other patients, doctors, dialysis unit staff, representatives at the local, state, or federal level, and officials in the department of health at the local, state, and federal level.

Often patients feel ill-equipped to talk to their representatives, but it is precisely patient stories and experiences which are needed. Since these programs were created to serve patients, those who oversee them need to understand where the programs work and where they fall short of reaching their goals.

Talking to officials may seem intimidating at first, but after a couple of meetings it will feel much more routine. Talking with your representatives alongside others in the kidney community—whether patients, physicians, or representatives of dialysis providers—may make these meetings feel easier.

New medications and equipment have the potential to improve the lives of people who have kidney disease. However, people who are impacted by these innovations need to make their voices heard. You can find support and help from organizations like the Renal Support Network. It is our voices which will force changes in a system that has changed little over the past 50 years!

As a physician, I will continue to speak up about the flawed payment system that does not spur innovation in treatment, and I hope you will join me!

**New Developments in Kidney Transplantation**
**Continued from page 13**

Living donation provides additional options for people who may not be a match for their known donor. Swaps, paired donations, and vouchers can enhance opportunities for those in need. Some of these options have taken place a few times at my center. If someone you know in your community passes away and they are eligible to be an organ donor, their kidney could be directed to you. You need to be active on the waiting list, allowing you to potentially skip the waiting list if it is a match. The deceased donor family will need your name and the name of transplant facility. They must inform the local Organ Procurement Agency of their wishes.

It is important to consult your healthcare team if you have questions or do not understand something, join a support group, and do your own research to learn more about these options.

## HOME DIALYSIS SPOTLIGHT

If you are curious about what doing dialysis at home might be like, these two videos are for you! Watch as Rachel Cluthe of Houston, TX, and Kristin Rice of Baltimore, MD, share a candid look behind the scenes during home hemodialysis and peritoneal treatments.

Watch as Rachel Cluthe of Houston, TX, along with her husband and two daughters demonstrate a home-hemodialysis treatment from start to finish. RSNhope.org Web ID 2023HHD

Watch as Kristin Rice of Baltimore, MD, demonstrates her own peritoneal dialysis treatment and catheter site care. RSNhope.org Web ID 2024PD

## DESIGNING YOUR ROOM FOR HOME TREATMENT

We created a tool to help you get started on planning your treatment space using your own room size and furniture. Our guide comes with a printable PDF with a blank room layout grid and mock-up scaled to the grid for just about everything you might have in a living room or bedroom plus standard home dialysis machines. RSNhope.org, Web ID 4069

# Empower the Lives of People Who Have Kidney Disease!

Photo Credit: RSN's Renal Prom Party

## Make a Tax-deductible Donation Today

We ask you to consider making a financial contribution, whether through a one-time donation, a monthly recurring donation, a personal fundraiser, a tribute donation, or a legacy donation. Your support makes a difference.

RSN is a national organization dedicated to providing peer support, education, advocacy, and hope for people who have kidney disease and their families. The demand for RSN's services has never been greater, and we rely on financial contributions to continue offering our various patient-centered programs at no cost.

Facing an illness can feel overwhelming when you are alone; however, connecting with others who have experienced similar challenges can foster a sense of hope and optimism. This sense of hope is crucial—it serves as a reminder that, despite the difficulties, no one has to navigate this journey alone.

Mail:
Renal Support Network
1146 North Central Ave. #121
Glendale, CA 91202

Phone:
(818) 543-0896
We accept all
major credit cards.

PayPal:
Donation@RSNhope.org

To donate, please visit RSNhope.org/Donate.

*Renal Support Network is a 501c3 tax-exempt non-profit organization (EIN #95-4672679).*

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Another Way to Donate: RSN's Studio Hope Boutique in Los Angeles, where we gladly accept donations. Visit us to explore our curated thrift items, vintage pieces, and handmade jewelry and artwork created and donated by Lori Hartwell. See page 8 for details.

***"An Illness is Too Demanding When You Don't Have HOPE!" – Lori Hartwell***

Renal Support Network
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Service to those affected by chronic kidney disease
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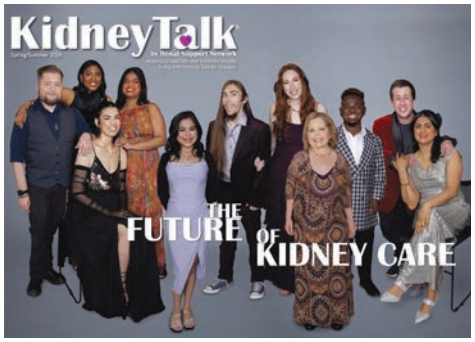




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## About RSN

Lori Hartwell established the Renal Support Network (RSN) in 1993 with the mission of empowering her peers who have kidney disease. Diagnosed in 1968, she underwent 13 years of dialysis and is doing well with her fourth transplant.

### Editorial Team

Editor-in-Chief: Lori Hartwell
Creative Direction: Suzette Maffi
Distribution: Cher Thomas & Isela King
Copy Editor: Shari Gilford

### Contact Information

Renal Support Network
1146 North Central Ave. #121
Glendale, CA 91202
info@RSNhope.org

818-543-0896
E-Fax: 818-484-2070
9 AM–5 PM Pacific Time
Monday–Friday

RSNhope.org