

KidneyTalk[®]

Fall/Winter 2024

by Renal Support Network

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



**LARRY GREEN
ARTIST IN RESIDENCE**

**MODERN-DAY PIRATES
SCAMS & HOW TO AVOID BEING A VICTIM**

**ANNOUNCING
THE 22ND ESSAY
CONTEST WINNERS!**



3 Modern-Day Pirates: Scams & How to Avoid Being a Victim By Lori Hartwell

4 Artist in Residence
By Maxine Phoenix

6 Committing to Care: Improving Your Health and Wellbeing By Jessica Farrell, MSW, LCSW, NSW-C

8 Hyperkalemia: Understanding Its Impact on Your Health By Mandy Trolinger, RD, PA-C

10 SHPT Happens
Secondary Hyperparathyroidism Infographic

12 I Love Lucy, 1st Place Winning Essay, 22nd Annual Essay Contest, By Chelsea Roman

16 From Comic Books to Coping, 2nd Place Winning Essay, 22nd Annual Essay Contest, By Sea Krob

18 Turning Music into Triumphs, 3rd Place Winning Essay, 22nd Annual Essay Contest, By Jennifer McClung

19 Prescribed by Grey's, 4th Place Winning Essay, 22nd Annual Essay Contest, By Stacey Moore

20 Matlock is My Inspiration, President's Pick Winning Essay, 22nd Annual Essay Contest, By Ev Dove

21 Save the Date for the 26th Annual Renal Prom Party!

23 Studio Hope: Vintage, Artisan and Curated Thrift Benefiting People and Pets

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: www.RSNhope.org



Modern-Day Pirates

Scams & How to Avoid Being a Victim

By Lori Hartwell

In today's digital age, the internet plays a vital role in our daily lives, offering countless opportunities for communication, education, and entertainment. However, it also acts as a breeding ground for scams that can inflict serious emotional and financial harm on their victims.

I recently watched the movie *Thelma*, which follows the journey of Thelma Post, a determined 93-year-old woman who becomes a victim of a phone scam, losing \$10,000 to a scammer impersonating her grandson. Driven by her resolve, she embarks on a mission to reclaim what was taken from her.

The film is inspired by "grandparent scams," a deceptive scheme which preys on the emotional vulnerabilities of older adults. A scammer typically contacts the victim via a phone call or email, posing as a distressed grandchild and pleading for money, claiming they have been arrested and need funds.

Thelma vividly portrays the emotional turmoil experienced by its protagonist as she navigates the fallout of the scam. Blending comedic elements with a poignant message about her feelings of defeat, the film leaves the audience

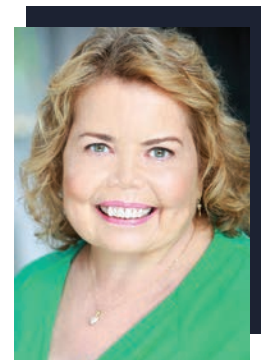
feeling a sense of vindication and a longing for revenge. Armed with her scooter, a supportive friend, and a fierce determination to recover her money, Thelma confronts her adversaries head-on.

Below are some other common scams which have deceived people.

- Phishing Scam: Attackers impersonate reputable organizations through urgent emails or messages, tricking users into providing login credentials on fraudulent websites.
- Online Ticket and Auction Scams: Fraudsters list attractive products/events on platforms like eBay, collect payments, and fail to deliver the items or tickets, leaving victims with financial losses.
- Tech Support Scam: Scammers pose as tech support from known companies, claiming that a victim's computer is compromised, then seeking remote access or payment for unnecessary services.
- Nigerian Prince Email Scam: Victims receive unsolicited emails from someone claiming to be a wealthy individual needing assistance to transfer money, often resulting in personal information loss or financial theft.
- Lottery or Prize Scam: The scammers may call, text, or email to tell the victim that they have won a prize through a lottery or sweepstakes, then asks the victim to pay an upfront payment for fees and taxes.

Continued on page 25

Lori Hartwell is the Founder and President of Renal Support Network (RSN) and the host of KidneyTalk® Podcast. Lori was diagnosed with kidney disease at the age of two and is now living with her fourth kidney transplant. She is the author of Chronically Happy and has numerous editorials and peer-reviewed articles published. She is a thought leader in the kidney community and her goal is to always improve the patient's experience of care, let her peers know they are not alone in their journey and how to advocate for themselves.



ARTIST IN RESIDENCE

By Maxine Phoenix



Larry has lived in Chicago for over fifty years. The windy city has served as home, education, inspiration, and history-keeper. Qualities of Chicago have also integrated themselves into how Larry carries himself. He is functional and persistent, with a strong artistic center—still standing after years of hardship and many

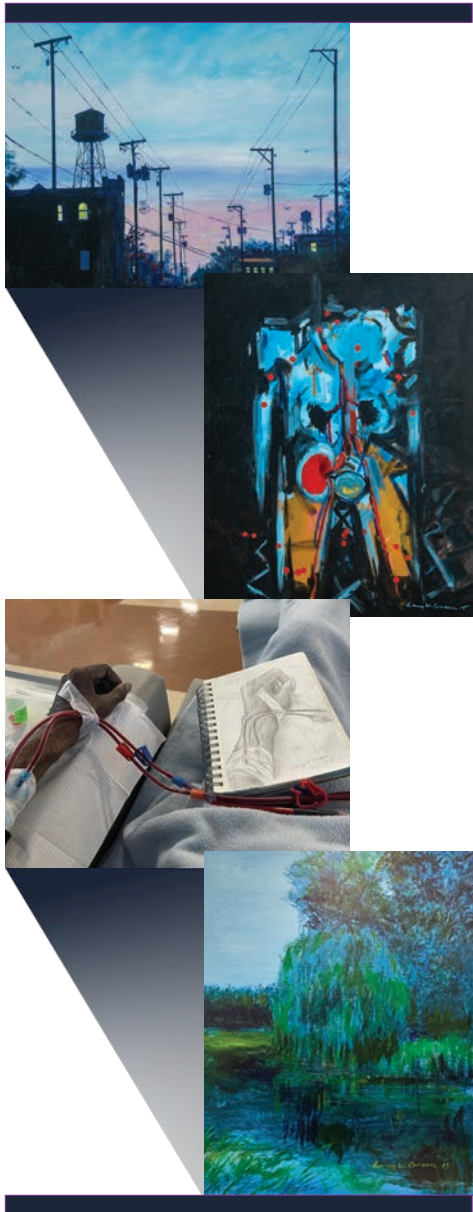
winters. New reflections of his spirit are created on the regular.

Originally, Larry hails from Terre Haute, Indiana, a small town in the southern part of the state. If he wanted to get out of rural living and try something new, he had to reach high—and he did. Accepted into the

prestigious Art Institute of Chicago, Larry received a BFA in Painting and Printmaking.

The move to the big city was a cultural shock, Larry explains. Despite his artistically stifled feeling back in Terre Haute, his hometown was a lot more integrated than how

he found Chicago. Yes, there were more opportunities, but there was also an aptly felt divide in the city. At school, Larry came face-to-face with protests and a community-wide desire for change. Vietnam and the Trial of the Chicago Seven brought black student unions rallying together toward peace. “When I was in Indiana I drew



‘pretty pictures,’” Larry shares. “My favorite artists were the Impressionists. I did portraits and still lifes. And when I got to the Art Institute, the philosophy was that you had to be an artist, and art wasn’t exactly doing pretty pictures. It was ‘finding yourself’ or being political. If you’re black, you do ‘black art.’ You had to show the

times.” Larry felt as if his inclination toward creating peaceful scenes capturing the harmony in nature was rejected by his teachers. “One [teacher] said, ‘You paint like you’re from the 16th century.’”

Larry ended up making his living not only in art, but in gardening. Which, knowing his inclination toward the Impressionist era, makes sense. He describes his job as being an “interior landscaper.” His primary artistic realm these days is in landscape paintings—he’s best known for his water towers. Larry has also created a book for grade-school children, aligning his paintings with the history of the water towers in and around Chicago.

“There used to be thousands of them. And now,” he says with a rueful tone, “there are only a few hundred left. Less and less. They were the reason that you flushed your toilet; the gravity forced water up and into the tanks.” He goes on to explain the system, built back in the 1800s, and in his voice remains the curiosity of the young man who was admonished for painting in too “old” of a style.

Larry is respectful of the past and regards it lovingly. Raised amongst farmland—pure nature—he has not lost that sense of the “old world” where things took longer, science and nature could work in harmony, and water towers were a phenomenon as fascinating as a lightbulb.

After school, Larry met the woman whom he would soon marry. They had two children, Nathan and Lizzie. Happily ever after, at least for a bit. Until Larry got sick.

He went to the hospital thinking he had the flu. After multiple examinations, he was told his kidneys were “the size of prunes.” Larry trails back into memory: “The next thing I remember was being on a gurney with people over me, trying to hold me down. I just had to go pee. And they said no.” The

experience was terrifying—from what Larry recalls, a tube was shoved down his throat, he was injected with medication, and then he passed out. Four days later, he woke up in the ICU to the news that his kidneys had fully shut down. He was then told that he had been put on emergency dialysis with a catheter. Soon afterwards, he received a fistula to replace the perma-cath. The dialysis continued.

Sadly, Larry and his wife had to sell their interior landscaping business, as Larry could not do the physical work any longer and had to commit to a dialysis schedule of three times a week. Larry was added to the wait list for a transplant, but in Illinois the wait time was between seven and ten years.

After applying for the Wisconsin list (he jokes that it’s shorter “because they don’t have motorcycle helmet laws”), Larry began an internet search. Craigslist for a kidney. Why not? He posted, and a week later, learned via his hospital that a woman had come forward. She had been called to do so by God, this anonymous woman from Haiti, and she was a match. The transplant was a success. Larry says, emotion reverberating in his voice, “It made me believe in miracles.”

The kidney lasted ten years. Three years ago, Larry’s body rejected it. Through the years, Larry had kept in touch with his donor via Facebook. “The only time I cried is when I talked to [the donor], because I felt so bad I lost her kidney.” With the transplant’s rejection, Larry had to go back on dialysis. In the years leading up to this, Larry and his wife separated. He is grateful he has his two adult children who are making their mark in the world; he could not be prouder.

There is one thing which has gotten him through the tough times, a practice that has reconnected him with his younger self, the art

Continued on page 26

COMMITTING to CARE

Improving your health and wellbeing

By Jessica Farrell, MSW, LCSW, NSW-C

Dialysis is a life-saving treatment. Attending all of your scheduled dialysis appointments and staying for the full treatment session is important to feeling your best. Committing to dialysis can be tough, but it can improve your physical health and emotional well-being. Some days may be more difficult than others, but there are ways to handle even the worst days.

It is normal to experience many feelings when you think about attending treatments. You could experience a range of strong emotions. Recognizing your feelings can help you figure out what might keep you from going to your treatments. Your social worker can help you find ways to address these feelings and also talk through any obstacles that you may identify. Sharing your thoughts and feelings with your family, friends, and others in your support network can help as well.

In addition to identifying feelings about treatment attendance, there are a variety of reasons why people on dialysis may not be able to complete their treatments as prescribed, such as scheduling, finances, or feeling unwell. Knowing what to do when you experience these challenges can help you prioritize yourself and commit to your care. Talk with your care team to address these obstacles. By taking an active role in your care and prioritizing your health, you can feel more in control.

Here are a few tips to improve your health and well-being:

If you are not feeling well...

Call your dialysis center and ask to speak with a nurse. Your nurse can talk to you about how you are feeling and whether you can attend a later treatment or complete your treatment on a different day. This can help decrease your risk of hospitalization. If you have any new or worsening medical symptoms, talk with your doctor about possible solutions.

If you are tired...

Not completing your dialysis treatment can actually make you feel more tired. You will be carrying around extra fluid which is hard on your body, and you may also miss doses of medication that help with anemia. If you are feeling anxious, depressed, or are having trouble sleeping, talk to your social worker or doctor.

If you have a doctor's appointment...

Schedule doctor's appointments around dialysis to ensure you receive your full dialysis prescription. Let your doctor's office know that you need to prioritize your dialysis treatments. If you have no other option, speak to your dialysis nurse as soon as possible about how you can complete your dialysis treatment.

If you do not have transportation...

Your social worker can connect you with community resources. It's a good idea to have a back-up plan in case your regular transportation is not available. Can a family member, neighbor or friend offer a ride? Do you know about public transportation options or shared ride services? Your back-up plan can also help in bad weather. If you can't make it, call your center and reschedule your treatment as soon as possible.

If your schedule does not work for you...

Talk to your team about options to complete treatments from the comfort of your home. Let the staff know if you have commitments such as work or family obligations and need a different time or schedule.

If you have a concern about your care or care team...

Let the center manager or administrator know. The facility has a process to investigate concerns and must inform you about the results of that investigation. The team wants you to feel comfortable about all aspects of your care.

If it's a holiday...

Check the dialysis facility schedule and your transportation provider's availability. There may be a change during the holidays. You can feel your best for the holiday by making sure to attend treatment. If you are looking for more flexibility with your plans, talk to your care team about home dialysis options.

If you are feeling alone or sad...

Your support system can listen and provide help when you feel overwhelmed. Build a stronger support system by connecting with professional organizations, asking your social worker to connect you with a dialysis peer mentor, joining a book or fitness club, or even volunteering. Talk with your social worker. They are trained to provide support through tough times. Attending treatments and following your treatment plan helps you stay healthier longer. Partner with your care team to prioritize your health and be an active participant in your own wellness journey.

Continued on page 26



The support you need, every step of the way

At Fresenius Kidney Care, we know that feeling your best goes beyond your dialysis treatment. It's about caring for the whole you. Fresenius Kidney Care offers services supporting your emotional well-being, helping you follow a kidney-friendly diet, and fitting dialysis into your lifestyle, so you can live a vibrant and more active life.



Scan here

Get valuable tips and learn about the support available to keep you thriving.

[FreseniusKidneyCare.com/Thriving-On-Dialysis](https://www.FreseniusKidneyCare.com/Thriving-On-Dialysis)

HYPERKALEMIA

Understanding Its Impact on Your Health

Mandy Trolinger, RD, PA-C

I was diagnosed with kidney disease as a child. I was on dialysis for one year and have had two kidney transplants—one from my mom and one from a deceased donor. I feel very lucky to have the gift of a kidney.

Growing up with kidney disease, I learned early on to understand my labs and became fascinated about the kidneys. You always miss what you don't have, and I was so intrigued by how food impacts your health, I decided to go to school to be a registered dietitian (RD) and specialize in renal nutrition. I found that having been on dialysis and receiving a transplant gives me street cred with my patients. About 15 years ago, I went on to become a physician assistant (PA).

A "healthy diet" for the general population contains lots of fruits and vegetables, unfortunately it does not always work with people who have chronic kidney disease (CKD) or are on a dialysis diet. We need potassium in our diet but having too much or too little can cause serious consequences to our health. Potassium is crucial for muscle and

nerve function. Healthy kidneys typically eliminate any excess potassium, allowing it to exit the body through urine. Too much potassium can lead to serious health complications. When your level is too high, it is called hyperkalemia. People with CKD face a higher risk of hyperkalemia because their kidneys are less effective at filtering out excess potassium from the bloodstream, and while dialysis does remove some potassium from your blood, it can still build up in between treatments.

People who are on dialysis or have later stage CKD must carefully monitor their potassium intake. When your potassium levels are high, you may not always notice a change in how you feel. Symptoms that have been reported are irregular heartbeat, cardiac arrest, and muscle paralysis, so it is nothing to mess around with. My patients and friends who have CKD have reported they have experienced the following when their potassium was high:

"I felt weak and dizzy all the time. It was like my body was constantly struggling to function properly."

"I experienced irregular heartbeats and chest pain. It was scary not knowing if my heart was going to give out."
"When my potassium levels were high, I felt constantly fatigued, heaviness and weak. It was as if my body was just not able to move, and I had no energy to do anything. I just wanted to lay flat."

Managing your potassium can be a two-pronged approach that involves working with your doctor on a plan that considers both a healthy diet alongside personalized treatment options. I love bananas but they are high in potassium so when I was on dialysis, I had to be mindful and learn if (and how much) I could eat based on my labs. This can be confusing, and this is where the renal dietitian can really help you choose the foods that are best for you. If your potassium is high your doctor may prescribe a medication to put in normal range. It's important to talk to your doctor, PA (advanced practitioners) and renal dietitian about your potassium.

You can learn more about hyperkalemia at UnfilteredKidneyConvos.com. For more guidance on what foods are renal-friendly, RSN has this cool nutrition calculator on their website (not an app) that can tell you the levels of potassium in foods.

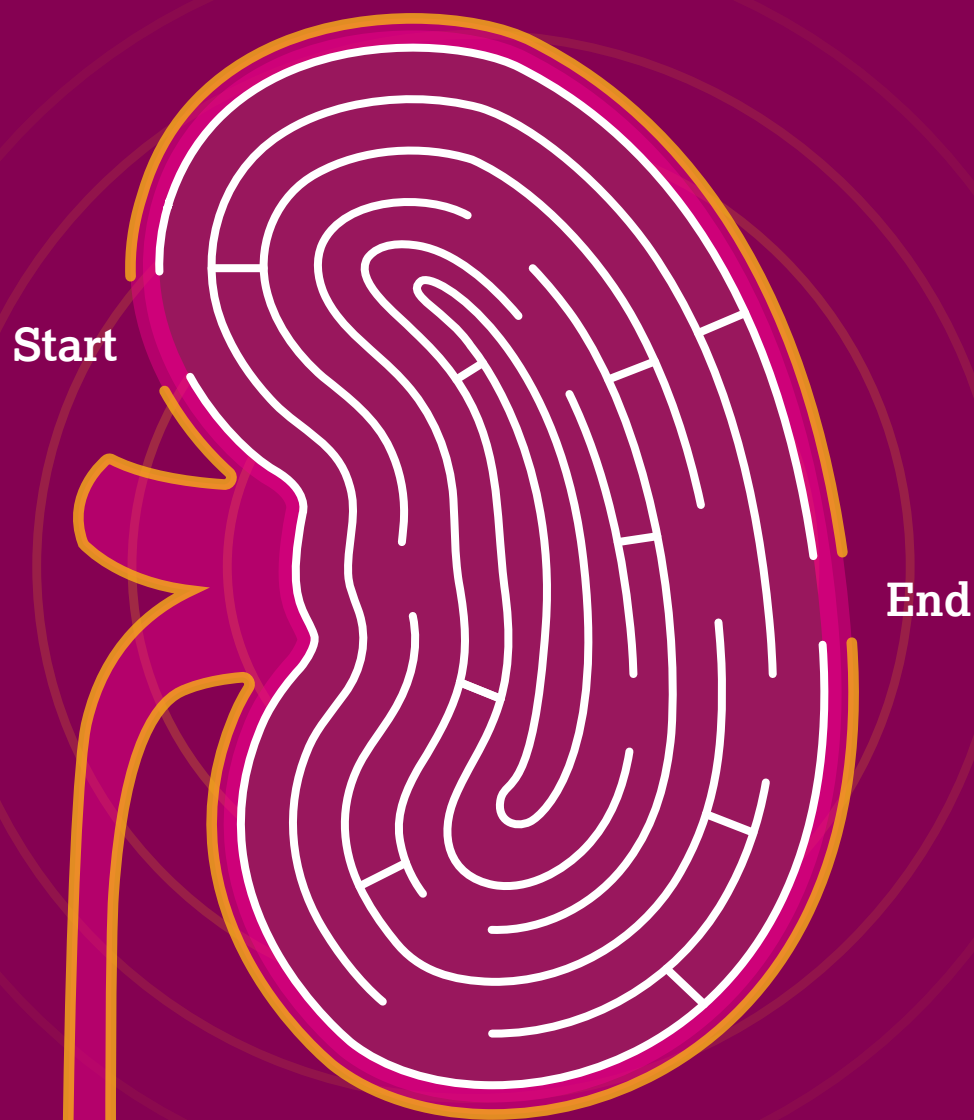
Be informed and stay well. I know I do! I have two energetic kids, a loving husband, lots of pets and a full-time job. An ounce of prevention is worth a pound of cure!

Continued on page 26

Mandy Trolinger is a physician assistant and registered dietitian, as well as a former dialysis patient and two-time kidney transplant recipient. She currently works as a nephrology physician assistant at Rocky Mountain Kidney Care in Denver, Colorado. She volunteers for many organizations, but her proudest accomplishment is her family.



Navigating the connections between **chronic kidney disease** and **high potassium**



AstraZeneca 

Learn more at <https://www.astrazeneca-US.com>

SECONDARY HYPERPARATHYROIDISM (SHPT)

SHPT HAPPENS

It is important to treat secondary hyperparathyroidism to prevent it from causing serious health problems.

WHY DOES SHPT OCCUR IN PEOPLE WITH KIDNEY DISEASE?

High blood phosphorus levels

Kidneys cannot make active vitamin D that the body needs to absorb calcium

Low blood calcium levels

WHAT ARE THE SYMPTOMS OF SHPT?

Weak, broken bones or joint pain

Feeling nauseated, loss of appetite, tired and weak

Kidney Stones

Itching

WHAT CAN YOU DO TO MINIMIZE RISK OF SHPT?

Take medication as prescribed

Don't miss a dialysis treatment

Follow dietary phosphorus recommendations

WHAT TESTS DETERMINE IF YOU HAVE SHPT?

Parathyroid hormone (PTH)

Calcium (Ca)

Phosphorus (P)

Calcium-phosphorus product (Ca x P)

HOW IS SHPT TREATED?

Vitamin D, calcium supplements or Calcimimetics

Surgery to remove parathyroid glands

WHAT HAPPENS IF SHPT IS LEFT UNTREATED?

Calcium builds up in your blood vessels causing narrowing and impeding blood flow

Calcium builds up under your skin causing skin wounds that are painful

Calcium build-up leading to weak and brittle bones



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1st Place Winning Essay, 22nd Annual Essay Contest
By Chelsea Roman

In the quiet hours of the night, when the world outside slept, I found solace in the familiar rhythms of my home dialysis routine. For two years now, my life had revolved around the gentle hum of the machine, the beeping alarms, and the sterile smell of the medical equipment. Chronic kidney disease had barged into my life uninvited, demanding attention and reshaping my days.

Each evening, I settled into my routine. I would meticulously prepare the dialysis machine, checking and rechecking the connections, ensuring everything was just right. The process was painstaking but necessary, a lifeline that kept me going when my own kidneys could not.

But amidst the clinical precision and the steady whirring of the machine, I found respite in an unexpected place: the classic episodes of "I Love Lucy." The old black-and-white sitcom had become my nightly companion, a source of laughter and warmth that cut through the monotony of my treatment.

I had discovered the show when I was a young girl during one restless night,

flipping through channels in search of something to distract me from the tedium of dialysis. The antics of Lucy Ricardo, the quirky redhead with a penchant for mischief, drew me in immediately. There was something timeless about the humor, the slapstick comedy, and the endearing relationships portrayed on screen.

As I settled into my chair, the soft glow of the TV casting shadows on the walls, I found myself transported to a different era. The laughter that echoed through my small room drowned out the mechanical sounds of the treatment. For those precious moments, I wasn't a patient tethered to a machine; I was simply someone enjoying a good show.

Night after night, I eagerly awaited my rendezvous with Lucy Ricardo and her escapades. Whether it was Lucy getting into yet another harebrained scheme or Ricky's exasperated but loving reactions, each episode brought a smile to my face. The simplicity of the humor and the genuine camaraderie of the characters created a comforting familiarity that eased the weight of my illness.

Through the ups and downs of my health, I found strength in the resilience of the characters I had come to love. Their antics became a reminder that life, despite its challenges, could still be filled with laughter and unexpected moments of joy.

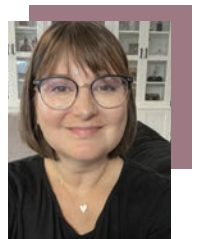
One particular episode stands out in my memory. It was an episode where Lucy Ricardo, in her relentless pursuit of fame and fortune, found herself inadvertently causing chaos in a television studio. As I watched, I couldn't help but see parallels to my own life—striving for normalcy amidst the unpredictability of illness, occasionally stumbling but always persevering.

But it wasn't just the humor that touched my heart; it was the love story between Lucy and Ricky Ricardo that resonated deeply with me. Their on-screen chemistry, their playful banter, and their unwavering support for each other mirrored the kind of love and companionship I myself yearned for, especially in the midst of my health struggles.

As the months passed, my appreciation for "I Love Lucy" grew into something more profound. The show became a lifeline—not just a distraction, but a source of comfort and inspiration. It reminded me

Continued on page 23

Chelsea Roman is a previous solo home hemodialysis patient and self-described #dialysiswarrior who has dealt with kidney disease her entire life.



Over the past few years, she has become a proactive source of information, hope, and inspiration for others who battle kidney disease and are looking for ways to live a healthier, more fulfilling life. Her sense of humor, positive outlook and never-quit attitude are contagious and uplifting. Chelsea was transplanted in November 2019 at UC Davis Medical Center in Sacramento, California, for which she is forever grateful.

Having trouble getting phosphorus to goal?

XPHOZAH[®]
(tenapanor) tablets

A different way to lower your phosphorus is here.

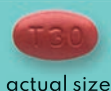
As add-on therapy for patients on dialysis in whom a phosphate binder does not work well:

- ◆ 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.



Scan or visit [XPHOZAH.com](https://www.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.



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 (C_{max}) 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.
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Patent: www.XPHOZAH-patents.com

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FROM COMIC BOOKS TO COPING

2nd Place Winning Essay, 22nd Annual Essay Contest
By Sea Krob

Growing up, my dad and his brothers all read comic books. This was in the '70s and '80s when comics were not seen as “cool” and there was not a basic cultural knowledge of the characters outside of the big ones. My dad had a treasure trove of comics from his youth that my siblings, cousins, and I got to enjoy. Because these comics were always around, I thought it was just dorky.

The X-Men comic book series is about people called mutants who have superpowers due to genetic mutations, and explores themes of inequality and segregation, pulling from rights movements. When the first X-Men movies came out in the early 2000s, my dad went to the midnight showings. He would tell me how cool it was because people dressed up in character. I was so embarrassed. I teased him, “Why would you even do that?!”

Shortly after the movies, the video game *X-Men Legends* came out during my peak middle school energy, which I begrudgingly played with my dad and brother because we didn't get to see my dad often. What got me interested, and then hooked on X-Men specifically, was that I started to see so much of my

experience reflected. I carry the diagnosis of autosomal dominant polycystic kidney disease (PKD), a genetic disease inherited from my dad. Conflicts that play out within the X-Men universe among humans and mutants relate to the experience of having a genetic kidney disease. I strongly identified with the character Rogue as a young teen. She absorbs people's energy and mutants' powers through touch, but often she feels like her power is something to be fixed even though she is so badass.

After we finished the game, I wanted the story to keep going, so I started reading my dad's X-Men comic books and then buying my own once I had devoured all of his.

From 2007 to 2018, my dad was on dialysis. His stamina went down to the point where walking around the block was pushing himself, pain due to his enlarged kidney was constant, and he was generally lethargic. He talked about how it was hard adjusting because of how quickly his body changed. As a way to spend time together, we would watch comic book movies and talk about them. It became a shared ritual for us to connect, and

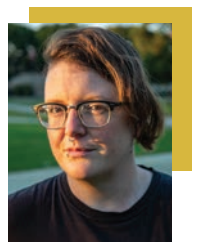
we looked forward to comic book movies coming out. In 2018, the movie *Avengers Infinity War* came out in theaters while my dad was in the hospital, and we never got to see it together.

When I think about my grief of being diagnosed with a “chronic disease,” a condition where there is no “cure,” I think about the dynamics in the X-Men universe. I apply Kubler-Ross' five stages of grief to myself as someone with a genetic kidney condition. While I continually process what it means to have that diagnosis, I flip through the stages as new symptoms in my own body arise. I think about how in the comics, they show how young mutants process the new knowledge of their diagnosis.

As I grow older, I find myself reflecting on Storm and Wolverine and their relationship to their bodies and powers. Storm views her powers as a part of her, that her powers shape her lived experience and that there is nothing to “cure.” Whereas Wolverine was defined by how other people view their own power, and the struggle Wolverine faces is to be able to define who they are outside of people medicalizing their body for personal gain. Wolverine both embraces their body and powers as a part of their experience and tries to forge ahead with defining what being a mutant means to them.

Continued on page 23

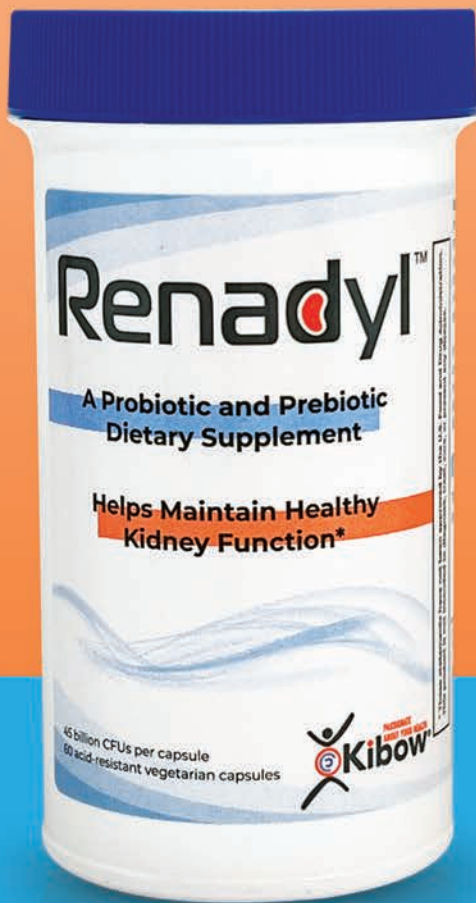
Sea Krob (they/them) is a photographically rooted artist based in Los Angeles. Their work undulates between the personal and the societal as they take in new perspectives and question how the other side shifts, focusing specifically on the body at the intersections of the medical industrial complex/disability/gender/race/class. Their art is a direct conversation with the viewer, shifting them from a witness to an active participant in dialogue.



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TURNING music INTO TRIUMPHS

3rd Place Winning Essay, 22nd Annual Essay Contest

By Jennifer McClung

As far back as I can remember, music has been a huge part of my life. Both my mom and dad loved music. My dad listened to music by Simon and Garfunkel, including Peter, Paul and Mary. He even had one of the original recordings from Woodstock. My mom listened to songs by Elton John, Neil Diamond, and John Denver. I remember getting my first cassette tape when I was ten. My dad took me to the bank with him and the song “Pretty Woman” came on and I loved it! Two days later, my dad came home with a cassette tape with the song “Pretty Woman” on it. This started my music collection.

Then at age 16 I was placed on dialysis. Music helped bring me comfort and inspiration. I was very pain-sensitive and hated having my blood drawn. So my parents got me my first CD player. I put on headphones and listened to music to zone out during those times. I started to search for songs with a positive message or lyrics to help inspire me to keep going, such as “Hold On” by Wilson Phillips, which reminded me things could change. “A Little Bit Longer” by Nick Jonas told me I’ll be fine. “The Climb” by Miley Cyrus helped encourage me to not give up.

But then I needed a song to help me get through one of the hardest times in my life.

I was at the dialysis unit and was hooked up to the machine. I received a phone call from University of California San Francisco (UCSF). The person on the phone told me the transplant team had decided to take me off the transplant list because my heart was not strong enough to handle the surgery. It was recommended that I have a heart and kidney transplant. I hung up the phone and was in shock. I turned to my playlist of music to find something to inspire me to take on this new medical challenge I would be facing. I found nothing outside of “I Left My Heart in San Francisco” by Tony Bennett. Which definitely wasn’t helpful at this moment!

My dialysis nurse came to me and asked how I was doing. I put on a brave face and said I’m okay, just can’t wait to get off the machine. My nurse looked at me and said, “Jenn, we know what’s going on.” I burst into tears. I didn’t know how I was going to get through this. Another nurse who had just gotten off duty came and sat by me for the rest of my treatment. She reassured me that I could do this and that everyone here would support me.

After my treatment was finished, I drove straight to my mom’s house. I needed a hug and to be around my family. A few hours later I decided to

drive home. I got in my car and put on the radio as I normally would. I was about halfway home and a new song came on that I had never heard before. Once I got home, I had to look this song up. The song was called “Fight Song” by Rachel Platten. This was exactly what I needed!

About a month later, I started being tested for a heart transplant. I had to go through so many difficult tests. The transplant team tested my lung capacity by having me pretend to blow a candle out. They asked me to keep blowing until I could no longer feel the air leaving my mouth. I also needed a stress test on a treadmill. The nurses connected me to many wires and had me wear an odd-looking face mask. If I felt scared or thought I couldn’t get through this, I put on the “Fight Song.” It became my anthem throughout the time I tested for a heart transplant.

In the end, I did not need a heart transplant. The test results showed my heart was just good enough to be able to handle the surgery for a kidney transplant.

The “Fight Song” continues to be my anthem to this day. Not only for any medical challenges that I may face in the future but also as I advocate for the kidney community. To quote a line from the “Fight Song”: “Cause I’ve still got a lot of fight left in me.”

Jennifer McClung was 16 when she was diagnosed with end-stage kidney failure. For 17 years, Jennifer was on both peritoneal dialysis and hemodialysis, then received a transplant in 2015. Jennifer educates the public about kidneys, encourages people to be organ donors, and speaks to legislators in Washington, DC, about bills which will help the kidney community. She also uses her story to inspire others. She believes a positive mindset and a bit of humor can help people get through whatever challenges they may face.



PRESCRIBED BY GREY'S

How a TV Show Became My Lifeline with Chronic Kidney Disease

4th Place Winning Essay, 22nd Annual Essay Contest

By Stacey Moore

It's hard to narrow down what I consider to be my favorite anything, but there is one show that has helped me cope with chronic kidney disease. I wrestled a little with this decision because it almost sounded cliché. In the end, the answer was clear. Grey's Anatomy was indeed the show that helped me navigate life with kidney disease.

For those who have been living under a rock for nearly twenty years, Grey's Anatomy is a medical drama which provides a closer look into what it is to be a resident, surgical intern, and attending both in and outside of the hospital. I was late to Grey's fandom, having started watching out of boredom one night in 2016, but I was quickly hooked.

Combine attractive doctors with the drama on and off the operating table, and you have a recipe—or maybe a prescription—for a great show. Seeing all the sick people coming in and out of the hospital, along with people who had kidney disease, made me strangely feel a sense of normalcy.

Having been diagnosed with kidney disease at the age of 25, I felt like an outcast. My friends from college and family members were leading normal lives. They couldn't relate to the weekly doctor's appointments,

bloodwork, or dialysis treatments. Starting on dialysis at that young age I almost felt isolated. I was even the youngest person at my center at the time, so I didn't have many people my age to talk to.

When I watched Grey's, I saw people I could relate to. I could relate to the character who was itching to get out of the hospital after an extended stay who longed for the doctor to tell them they were being discharged. I sympathized with the patient who sometimes wanted to give up and just wanted one moment for their life to go back to normal. On these days, I cried with the characters on the show because I knew it was what I wanted for myself. Then there were the days when I cheered for the patient finally receiving a transplant after a long wait, knowing that I, too, wanted that for myself.

It was here that I got a basic understanding of what happens when you receive a transplant. Sometimes as a dialysis patient, a transplant is glamorized or deemed something like the Superbowl of kidney disease. It is the goal when you're on dialysis. It is as if all your problems will disappear once you're transplanted, but that's not true. There is the constant worry of rejection, the laundry list of prescriptions needed to keep that kidney from being rejected, and

constant visits to the doctor. I saw all this depicted on the show, and while it all seemed daunting, it was also enlightening.

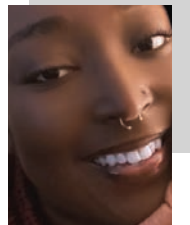
After dealing with all the heaviness and the drama on the show and in my actual life, I had something of a realization. I didn't have to let kidney disease run my life or become my entire personality. I could still live a life of normalcy; it would just have to be a new normal. My new normal was going to dialysis three times a week, but after dialysis, I could still do the things that I would normally do. I can still spend time with my mom and my fur baby Papí, cook, and do anything else I thought I couldn't do before.

When I watched the show, I realized that while I was dealing with serious problems, there were other people in the real world having to cope with a multitude of health problems that left them unable to live normal lives. A normal life that you and I may take for granted.

As I get older, I learn to appreciate the simple things in life. I enjoy spending time with the people who matter most to me. I enjoy cooking and I'm grateful that I can do so because there were times when I was too weak to even walk down the steps into the kitchen. Lastly, I still enjoy binge-watching the latest season of Grey's once it hits Netflix.

Continued on page 23

Stacey Moore is 32 years old and lives in Baltimore, MD. She has been on dialysis for seven years, and also has t-cell lymphoma. Despite her health challenges, she earned a bachelor of science in psychology and a master's degree in forensic studies. She dotes on her eight-year-old Shih Tzu, Papí Chulo, and loves to cook and hang out with her mom. She hopes to someday work in the mental health field to help people who have chronic kidney disease and cancer.



Matlock *is My Inspiration*

President's Pick Winning Essay
22nd Annual Essay Contest
By Ev Dove

Web ID: 5101

I love the television series titled "Matlock." In the show, Attorney Ben Matlock is sagacious to say the least. He is so down-to-earth on the show; however, he is full of wit and wisdom. No matter what situation arises, Matlock will figure out the solution. While detectives, officials, and others are working hard to

biggest house or drive the most expensive car. He still lives in the same old house he had before his wife died. And he drives an old car that, though nice, may need a jump or a push from time to time. Ben does not care about luxury. But he does have a social life. He has a loyal best friend and a lady he likes a lot.

"The journey has had some hard spots and some hurtful spaces. But I have grabbed on to the good people who have been placed in my path."

figure out who committed the crime and find the perpetrator, Matlock methodically focuses on the little details and pieces together the big picture.

Matlock also knows what he likes and sticks to that. Just because he is a millionaire lawyer, he does not feel like he has to live in the

He prefers plain old hot dogs to filet mignon, with lots of cut-up raw onions. Me too.

Matlock is also a simple dresser. He wears the same old suit style and color all the time. Though they tease him about it on the show, he refuses to spend his money on expensive, showy, dark pin-striped suits. He

doesn't need to look rich to win his cases. But mind you, his suits do come from a men's tailor shop, not just any old store. So, Ben Matlock does recognize quality. He is my kind of guy.

Matlock inspires me to think critically and to be positive. No problem is too large to tackle bit by bit. When I was diagnosed with kidney challenges, I wanted to just give up. But my sons, my sister, my brothers, and others rallied around me to urge me to climb this mountain. I watched an episode of "Matlock" in which he and his housekeeper found themselves lost. His car wouldn't start, of course, so he asked her to drive him to a dinner in his honor. Somehow, she got turned around and didn't know where they were. Disaster, right?

Matlock figured out strategies to get them out of that mess. They hitched a ride back to town and reached their destination. But wouldn't you know it, the dinner in his honor had ended. Determined and unbowed, Matlock gave his speech to the room of empty chairs anyway. That is how I have tackled my kidney challenges. The journey has had some hard spots and some hurtful spaces. But I have grabbed on to the good people who have been placed in my path. And when I have a disappointing day, I sit down to my Netflix TV my sons gave me and watch Matlock re-runs with my sister. Then, things look up.

Ev Dove writes an inspirational column for her nonprofit PathChoice. She majored in English at UNC-Chapel Hill in the 1970s. Helping others be positive in the face of adversity is something Ev does often.

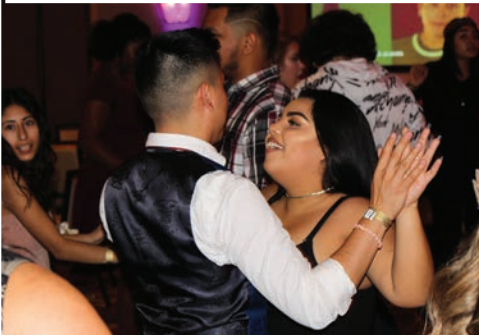


"We all have a cross to bear, and we can all help each other travel life's path with lighter steps," she says. Ev's hobbies include doing Word-Circle puzzles and going to look at the ocean. She believes ocean waves bring about healing. She is proud to be a United States Air Force Veteran.



SAVE THE DATE FOR RSN'S 26TH RENAL PROM PARTY Sunday, February 16, 2025



If you had kidney failure as a child or if you are currently aged 16 to 24, you are invited to join the prom—a celebration of life! We all share the common challenges of living with kidney disease in our youth. Let's come together to celebrate life, meet new friends and have a great time! Learn more at RSNhope.org/PROM



• • • • • 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.

Renal Support Network Presents
THE HOME HEMODIALYSIS EXPERIENCE

Video: Watch as Rachel Cluthe Shares a Home Hemodialysis Treatment From Start to Finish
RSNhope.org Web ID 2023HHD

Renal Support Network Presents
THE PERITONEAL DIALYSIS EXPERIENCE




Video: Watch as Kristin Rice Shares a Peritoneal Dialysis Treatment and Catheter Site Care
RSNhope.org Web ID 2024PD

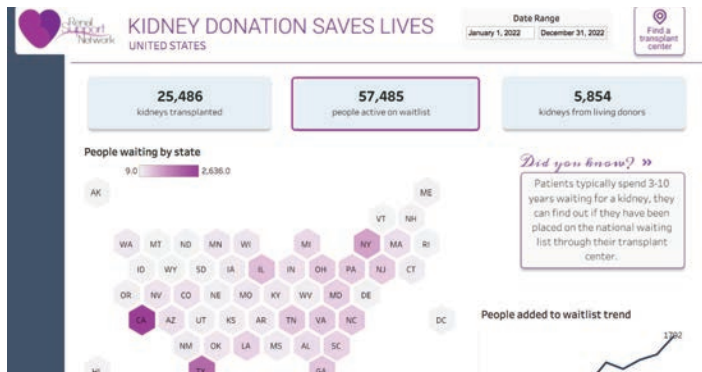
DESIGNING YOUR ROOM FOR HOME TREATMENT

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



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

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

KidneyTalk Podcast Listen wherever you are!



RSN's KidneyTalk® is an informative, inspirational, and entertaining online, half-hour radio talk show that 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



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



Kidney Diet Recipes Tasty and kidney-friendly!



We've compiled a collection of recipes that we find are tasty and also kidney-friendly. At the bottom of each recipe you will find nutritional guidelines to help you stay in line with your personal needs. Find them at RSNhope.org, Web ID RD100.



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I Love Lucy Continued from page 12

that even in the darkest of times, there were moments of light and laughter waiting to be discovered.

One evening, after a particularly challenging day of dialysis, I found myself rewatching my favorite episode. The familiar jokes and familiar faces wrapped around me like a warm blanket, soothing my tired spirit. And then, something unexpected happened.

In the final moments of the episode, as Lucy Ricardo and Ricky shared a tender moment, I felt a tear slip down my cheek. It wasn't sadness, but a profound sense of gratitude—for the show that had brought me so much joy, for the strength it had given me to face each day with renewed determination, and for the reminder that beauty could be found even in the most unlikely places.

That night, as I turned off the dialysis machine and settled into bed, I

carried with me a newfound sense of peace. The echoes of laughter from "I Love Lucy" lingered in my mind, filling the quiet corners of my room with warmth. Despite the challenges I faced, I knew that as long as I had laughter and love, I could weather any storm.

And so, with the gentle rhythm of my own heartbeat and the echoes of Lucy Ricardo's infectious laughter still ringing in my ears, I closed my eyes and drifted off to sleep, grateful for the reprieve that "I Love Lucy" had given me and for the beautiful moments it had brought into my life.

From Comic Books to Coping Continued from page 16

When I think about my grief of watching my dad through his life/death journey with his kidneys, I apply Worden's four tasks of mourning. Worden's tasks were crafted for people grieving the death of a person, not their own death, like Kubler-Ross. The X-Men franchise, in book and media forms, gives me

a way to maintain the connection to my dad as I continue on with life, which is task number four.

I don't think my dad meant to have the X-Men play such a role model figure in my life. Through this fiction, the X-Men gave me words and language about alternative ways of seeing myself and body than either the medical model or charity model of disability would have people think about my experience.

Prescribed by Grey's Continued from page 19

The series has shown me that I'm not alone, and even though the show is fictionalized, it depicts what it's like having to adjust to a new normal. I'm grateful for what the show has taught me about the practice of medicine, and myself.



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.



Through the experience of hosting many support groups, RSN has learned that it is important to have a strong leader with compassion and patience who can help keep the group on track. This allows meetings to be productive, helpful, and hopeful. RSN's Support Group Masterclass consists of 8 training modules to guide you toward holding your first peer support group meeting. The training videos will walk

you through each step of the process to make sure you feel prepared to host your first meeting. Learn more and sign up at RSNhope.org, Web ID: RSNMC.



We're about to start anew in DC with the 119th United States Congress.

Being a Champion of Kidney Care means you want to get involved and make a difference! Only one thing can help change the course of this disease, and that is for anyone who is affected by it—whether patient, family member or renal professional—to get involved.

Join us in educating your elected officials about how they can help with legislation relating to kidney disease. We will make sure you are up to date on all current and upcoming legislation which has an impact on people living with kidney disease, are on dialysis, or have a kidney transplant. We will also provide you with the tools you need to reach out to your elected officials and educate them about these issues.



Sign up for Champions of Kidney Care updates. Learn more at RSNhope.org, Web ID: CKC

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Modern-Day Pirates

Continued from page 3

Newer Scams:

- **Get a Kidney Scam:** This fraudulent scheme deceives people into thinking they can secure a kidney by providing their insurance information and paying fees.
- **Owe Money Scam:** A scammer may contact the victim via phone, email, or text message that appears to be from the victim's bank, medical office, or utility company. The scammer may claim that there is a problem with a transaction or payment and ask the victim to send money via Zelle to resolve it.
- **Debt Collection Scams:** Scammers pose as legitimate debt collectors, threatening people with debt they do not owe. Someone contacts the victim, often by phone, but also by text message, fax, mail, or email, and claims that they owe a debt. The debt may be completely fake. The scammers' tactics can be very intimidating.

When someone falls victim to such deception, their initial reaction is often one of shock or disbelief. Victims may struggle to comprehend how they were misled, replaying the events repeatedly in their minds. This tendency to blame themselves can result in feelings of shame and embarrassment, making it difficult for them to share their experiences with others. However, Thelma was not concerned about that; all she wanted was her money back. This is just a story, and not a good idea to pursue in real life.

Experiencing a scam is a distressing ordeal, but there are effective steps to take to address it. First, remain calm and gather all relevant information, such as emails, receipts, and screenshots. Report the scam to your bank or credit card company, especially if you suffered a financial loss, to secure your accounts and potentially reverse any

unauthorized transactions. Keep a close watch on your financial accounts, change your passwords, and consider enabling two-factor authentication for added security.

Fostering an environment of awareness can help alleviate both emotional and financial repercussions, making online spaces safer. Reflect on your experience so you can identify warning signs and educate yourself and others about common scams in order to prevent future occurrences. If the scam is severe, inform local authorities or consumer protection agencies, and report any suspicious activities. Additionally, if the scam occurred online, notify the platform involved to help protect others.

If you see something, say something. And do not go chasing anyone down like Thelma did!

Ways to Protect Yourself from a Scam: Limit Personal Information Sharing

Exercise caution regarding the information you share on social media and other online platforms, as scammers often create fake profiles to harvest personal details. Avoid participating in games where participants are asked for personal details, such as your pet's name or favorite color, as scammers can gather this information to guess password or security questions.

Adjust Your Privacy Settings

Take control over who can see your posts and profiles and ensure your friend list is concealed on social media.

Recognize Suspicious Messages

Remain vigilant against phishing emails or texts which may appear legitimate but aim to deceive you into providing personal information. Watch for indicators such as poor grammar, generic greetings, urgent requests, or a bogus sender email address, and always verify unfamiliar requests through official channels. You can also do an online search

to check if others have reported the email or text as a scam.

Use Strong Passwords

Construct strong, unique passwords for your accounts which include a combination of letters, numbers, and symbols. Steer clear of easily-guessable passwords like birthdays or names. Whenever possible, activate two-factor authentication for added security.

Website Credibility

To assess the credibility of a website, check for a secure SSL certificate, which is indicated by a padlock icon in the URL bar. You can perform a "Whois" lookup to verify the ownership of the domain. Additionally, ensure that the website has a clear privacy policy and provides its physical address and contact information. You can also consult social media to gauge public opinions about the website.

Confirm Identity

If you receive a suspicious call, always verify the caller's identity and request their contact information. Do not return the call using their number; instead, use a number from a reliable source, like your credit or insurance card, to check for legitimacy. Legitimate debt collectors typically have detailed information about you, while scammers often ask for personal details instead. If they seem unaware of essential information, it is likely a scam.

Trust Your Instincts

If an offer appears too good to be true, exercise skepticism. Deals which promise easy money, unrealistically low prices, or a kidney are often scams. Take the time to investigate before acting on any suspicious offers.

Here are more tips from the Consumer Financial Protection Bureau:
<https://www.consumerfinance.gov/ask-cfpb/what-are-some-common-types-of-scams-en-2092/>

Artist in Residence Continued from page 5

student. Larry has been keeping an art journal for the days he does dialysis (currently, three times a week), wherein he draws his arm. Every day he is on the machine, Larry does a drawing. His dialysis access in his forearm is the primary subject, all the blood lines that connect to the machine, and each time it is a little different. More details some days on the bandages, the needles, the tubes. "And I write little notes about the weight and blood pressure and all that," he adds. Right now, he has about six of these



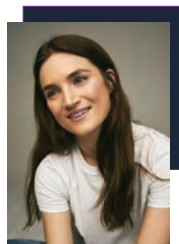
art journals. Nearly 500 drawings. "I post them on my Instagram," Larry shares.

Sometimes it is hard for Larry to find things that make him happy. He feels grief toward losing, in his eyes, the great outdoors; he used to take trips periodically to Michigan, go fishing, be out in nature. These days, he watches cartoons which make him laugh, and he enjoys immersing

himself in science fiction. He gardens when he can, which gives him that connection to nature. He is working on selling more of his art and is interested in creating another series soon—possibly something linked to dialysis, or maybe another landscape set.

It has been a long road for Larry, but he has never lost his artistic soul. Even in the way he speaks of his history, he paints landscapes, filling in the details of sorrow and curiosity. The shadows, the pockets where light filters through. Larry is the true "artist in residence," looking at the world around him like the "en plein air" painters of the 19th century. Sitting, observing, reflecting what he sees, and making meaning of the life held within the stillness. In the sadness and in the joy. Truth and beauty in the whole of the journey. The entire landscape.

Maxine Phoenix is a freelance writer and she also volunteers for RSN.



Hyperkalemia: Understanding Its Impact on Your Health Continued from page 8

Unfiltered Kidney Conversations
<https://www.unfilteredkidneyconvos.com/hyperkalemia.html>

Nutrition Information
for the Kidney Diet
<https://www.rsnhope.org/nutrition-data-information-for-the-kidney-diet/>

You can watch a video of me sharing my story at <https://www.rsnhope.org/2020-hope-week/mandy-trolingers-inspiring-journey/>


Committing to Care Continued from page 6

Jessica Farrell, MSW, LCSW, NSW-C is the Senior Manager of Social Work Services at Fresenius Medical Care for the Eastern and Western North Carolina Regions. Jessica leads a team of 100 social workers and has spent her entire 20-year career devoted to kidney and dialysis patients. Jessica received her MSW from Virginia Commonwealth University in Richmond in 2004 and has been a member of the Council of Nephrology Social Workers, a Board Member of the Nephrology Social Worker Certification Board, and a member of the National Kidney Foundation Spring Clinical Meetings Planning Committee. Jessica strongly believes in the importance of collaboration and partnership, having worked in multiple capacities as a dialysis facility level social worker, dialysis social work manager and a kidney transplant social worker at Duke University Hospital. Jessica's passion is teaching others the techniques of Motivational Interviewing to allow a person-centered approach to care.



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An illness can feel insurmountable when faced alone; however, connecting with others who have walked a similar path can instill a sense of optimism. That hope is vital—it reminds people that, despite the challenges, they are not alone on this journey.

Please consider contributing financially: through a one-time donation, a monthly recurring donation, a personal fundraiser, a tribute donation, or a legacy donation.

For more information, please visit RSNhope.org/Donate.

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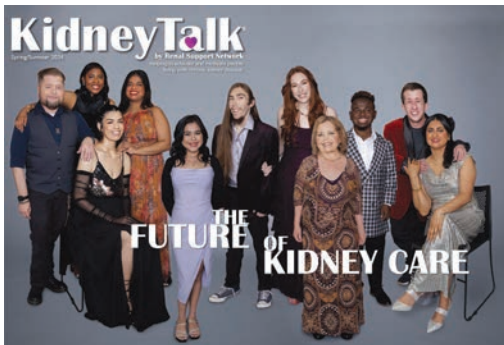
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HOPEline

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Call (800) 579-1970
Monday - Friday

If you are a person who has chronic kidney disease, a family member, or caregiver, and don't know what to expect, call us.

Connect with another person who has lived with kidney disease and can share their experience, strength and hope with you. Learn what they have done to successfully navigate this illness.

About RSN

The Renal Support Network (RSN) is dedicated to empowering people who are diagnosed with kidney disease. If this describes you, know that you're not alone; we understand how challenging this experience can be. One important truth we have learned is that by becoming informed about your condition and taking a proactive approach to your care, you will discover that there is plenty of hope on the horizon. In fact, some of us have managed to live with kidney disease for over 50 years and are still thriving.

Connecting with others who have navigated this journey is essential. We will guide you on what questions to ask, what to expect, and how to manage lifestyle changes. Plus, by joining our community, you'll have the chance to make new friends along the way.

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