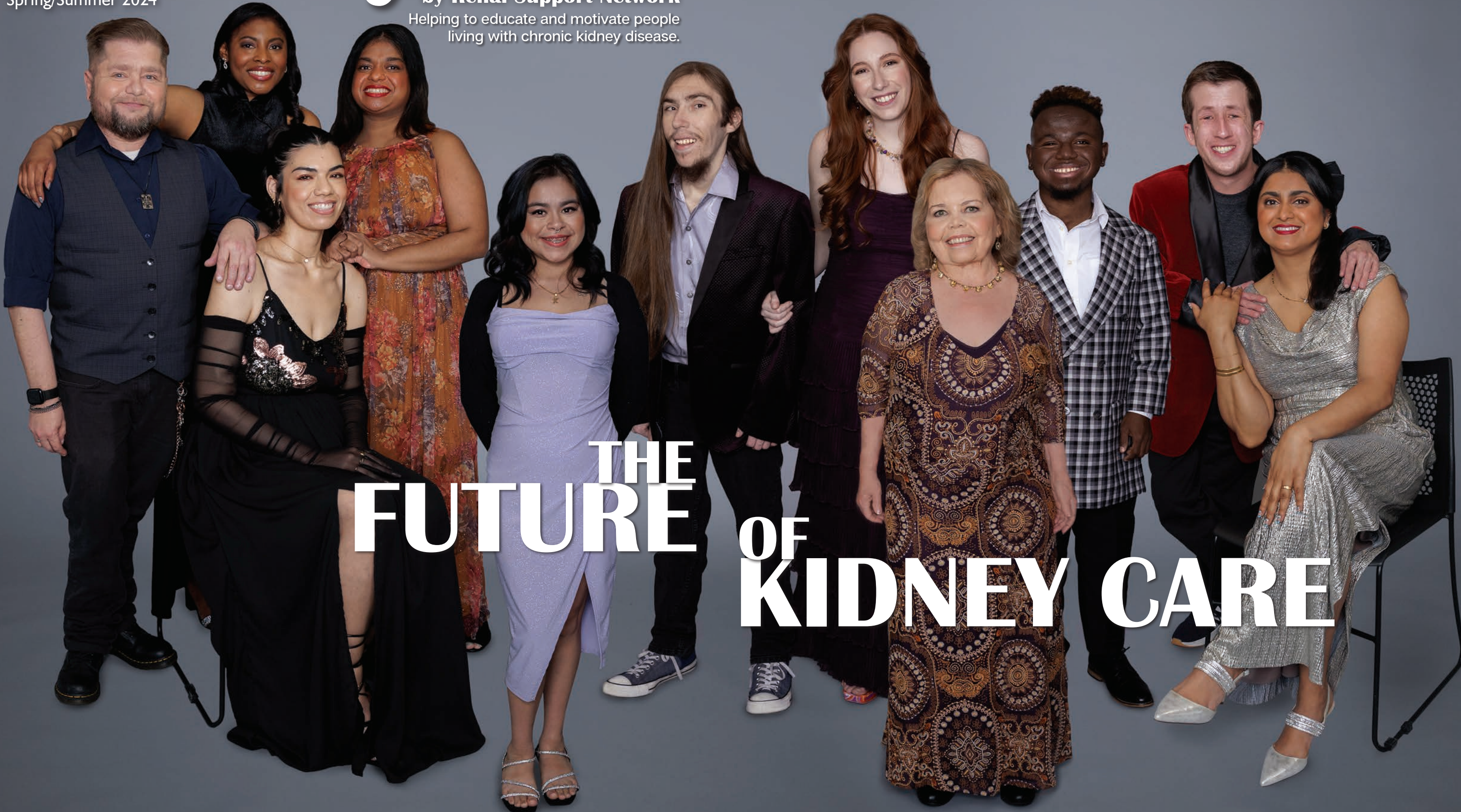


# KidneyTalk<sup>®</sup>

Spring/Summer 2024

by Renal Support Network

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



## THE FUTURE OF KIDNEY CARE





# SHAPING THE FUTURE OF KIDNEY CARE

By Lori Hartwell

The RSN Renal Teen Prom has been a labor of love for me and countless volunteers, as we recently hosted our 25th prom. Over the course of more than two decades, I have had the privilege of meeting and getting to know an incredible group of youth who battle kidney disease and are winning the fight. Their resilience and positive outlook on life have taught me so much, and they motivate me to continue advocating on their behalf.

It fills my heart with joy to see many young adults whom I have come to know not only pursuing their dreams but also seeking ways to help others. I spent 13 years on dialysis and had my fourth transplant 13 years ago. By sharing my own story of living with this illness, I let them know that they too can lead long lives. They can get married, own a home, have a meaningful career, have a family, enjoy a household full of loving pets, and pursue their dreams. They have promising futures ahead of them.

RSN is thrilled to share “Capturing Dreams”—stories which highlight the journeys of some amazing people. When we were doing the photo shoot for the cover of this magazine, it felt like we were having a family reunion! We have a common bond and consider each other kidney kin.

Natalie is definitely a badass when it comes to overcoming adversity. Reading her story made me think that it should be made into a movie. She displays so much courage and understanding for her family, and she has a lot to teach others.

Trent has the biggest heart ever. As a recipient of kidney and heart transplants, he maintains an unwavering attitude of optimism toward life.

Mihi’s story always brings a smile to my face. I have always enjoyed Taylor Swift, but Mihi’s article of how this superstar inspires her takes it to a whole new level. I think I am a Swiftie now.

I have watched Austin grow up since we first met at the 12th prom in 2011. He is an advocate with a compassionate ear and a naturally kind disposition. I hope he chooses a leadership role in some capacity since he was born to lead. Maybe President of the United States?

Asha is wise beyond her years, and her quiet calmness and curiosity will take her to great places. She remains composed in a stressful environment where she is helping people who may have possibly committed a crime understand their options.

I have witnessed Meghna grow up, get married, and choose a career. Being a long-time attendee of the prom, I am delighted to see her develop her interests and fall in love with a wonderful guy. She is very creative and always ready to lend a helping hand.

Michael attended the very first prom and many thereafter. Having a similar story has always allowed me to connect with him, and I admire his zest for life. I will never forget his expressive moves on the dance floor. Those moves were at the level of Dancing with the Stars. His journey to sobriety and finding true love exemplifies resilience. Joey and Vinnie are forever connected, as their moms have become best friends through their

babies’ diagnosis. I love this story as it shows that not only do people with illnesses need to make friendships, but caregivers need a connection as well. Joey can bust a move too.

When I first met Isela, she had just learned she had kidney disease at the age of 16 during a physical examination. She was a student at Notre Dame High School and decided to volunteer for the prom, and now she works for RSN full time. She is an amazing person, and I am excited to work with her every day to further the mission of RSN.

Finally, Jasmine became friends with Reyna at a prom, and they have been BFFs ever since. When I read this story, I realized that the mission I started 30 years ago is thriving. These incredible individuals, along with many other stories of hope and the power of overcoming adversity, are showcased on our site.

To thrive, we need a kidney healthcare system which is easy to navigate, has enough healthcare professionals, fosters innovation for improved care, and most importantly, acknowledges that the only way for people who have a chronic illness to be able to effectively communicate our needs is by expressing how we feel. Much of the correspondence we receive at RSN comes from people who need to express their feelings of depression, fatigue, loneliness, and confusion surrounding their diagnosis, often feeling immobilized by these emotions. It is essential to remember that patient-centered care hinges on listening to and responding to patients when they express their feelings.

When I established RSN 30 years ago, I understood that mental health was crucial for my overall well-being because it influences every aspect of my life. Greater emphasis should be given to mental health as it is the most crucial aspect of overcoming the multitude of challenges presented by a serious illness.

Connecting with peers is paramount to navigating this illness. Online forums provide a pathway for this connection. We know that the most influential and impactful connections occur face-to-face. After all, humans are inherently social beings. Getting support from people who have “been there” is the glue that helps many people cope emotionally. One friend can make a difference.

In order to ensure a promising future, it is crucial to have a healthcare system in place which caters to our needs.

As I invest more time in learning about the policies regarding kidney disease care, I am becoming more aware of the intricate and complex nature of the subject. It is imperative for all of us to actively engage and advocate for a healthcare system that serves our needs.

The future is upon us, and I have had the privilege of witnessing my peers embody the epitome of the human spirit. These exceptional people have demonstrated immense strength, courage, and resilience. Their very existence hinges on the healthcare policy choices we make today.



# CAPTURING DREAMS: RENAL TEEN PROM

" I am happy to share "Capturing Dreams" stories, which highlight the journeys of these amazing  
Learn more and read their stories at [RSNhope.org/Prom](https://RSNhope.org/Prom)." –Lori Hartwell.



*Keep Your Head Up*  
Asha's Story



*The Princess in Scrubs*  
Breck's Story



*The Patient's Politician*  
Austin's Story



*The Hopeful,  
Loving Badass*  
Natalie's Story



*A Swiftie Enters  
Her Own Era*  
Mihi's Story



*Connection Heals*  
Rayna & Jasmine's Story

As we prepare for RSN's 26th prom on February 16th, 2025, we are making changes and extending an invitation to all youth over 16 who have chronic kidney disease. If you experienced kidney failure as a child, you are invited. It is a unique perspective to grow up as a child/youth with kidney disease and to make the transition to the adult world. We all serve as beacons of hope and resilience for the generations of youth to come and make connections that last a lifetime. Learn more and read their stories at [RSNhope.org/Prom](https://RSNhope.org/Prom).



# STORIES OF RESILIENCE AND HOPE

*people by Maxine Phoenix.” Learning their stories has given me a great deal of knowledge.*



**Healing in Nature  
Isela's Story**



**A Tale of Two Mothers  
Joey & Vinnie's Story**



**The Gardener in Love  
Meghna's Story**



**It's a Wonderful Life  
Michael's Story**



**The Mighty Trent,  
On Ice!  
Trent's Story**



**The Prom Queen  
Lori's Story**

*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 has published numerous peer reviewed articles and the book Chronically Happy. She is a thought leader in the kidney community and her goal is to always improve the patient's experience of care and to let her peers know they are not alone in their journey.*





Cover and Cover Story Photo Credits Photographer: Transplant recipient Michael Anthony Hermogeno (IG @8x10proofs) Make-Up: Stephanie Lawrence Mazumdar

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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](http://RSNhope.org) to subscribe. Current issue, printable version, articles, and archives can be found at: [www.RSNhope.org](http://www.RSNhope.org)



# Enter Renal Support Network's 22<sup>nd</sup> ANNUAL ESSAY CONTEST



For this year's theme, we ask that you share a story about how a favorite form of entertainment media which helps you cope with the challenges of living with kidney disease.

Submissions are open to anyone in the US who has kidney disease.

Essays are due by August 10, 2024.

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

Learn more and enter at [RSNhope.org/essay-contest](https://RSNhope.org/essay-contest)





# TRANSITIONING from PEDIATRIC to ADULT CARE

By Mark Hanudel, MD, MS, FASN

For patients with chronic kidney disease, transitions of care can be challenging, stressful times. Some transitions of care and changes of providers are inevitable, such as when pediatric patients with chronic kidney disease (CKD) transition to adult nephrology care. Other transitions of care are more unexpected, such as when adults with CKD may have to change providers due to relocation or changes in insurance. For both anticipated and unanticipated transitions, there are things to keep in mind which can help facilitate smooth transfers of care.

Pediatric patients with CKD

transition to adult nephrology care around 18 to 21 years of age. However, it is recommended that the preparation for transfer of care begin earlier, at around 11 to 14 years of age. Longer, more thorough preparation for transfer to adult care can ensure a more seamless transition and help prepare young people for full autonomy with medical visits.

As noted in the 2024 KDIGO (Kidney Disease Improving Global Outcomes) CKD guidelines, several resources are available to help guide the transition from pediatric to adult care, and to help assess readiness to do so: TRxANSITION; Youth

Quiz from the On Trac program; Transition Readiness Assessment Questionnaire (TRAQ); Readiness for Transition Questionnaire (RTQ); and Got Transition tools (<http://www.gottransition.org>).

For pediatric nephrologists, seeing adolescent patients without caregivers for at least part of the clinic visit can help young people practice interacting with healthcare providers independently. Doing so also provides privacy for the discussion of sensitive topics. Also, allowing older adolescent patients to visit the adult clinic prior to transfer of care can be helpful.

Continued on page 22

“young adult patients are navigating not only a transition of care and change of healthcare providers, but also the larger transition from childhood to adulthood”





## Thrive on with transplant

Kidney transplant is considered one of the most effective treatments for end stage kidney disease (ESKD) and may offer many benefits including a chance for a longer, healthier life.



Our free kidney disease education class can help you better understand your treatment options—including transplant. Wherever you are on your journey, our in-person or online class can help you thrive.

 Scan to learn more or visit [FreseniusKidneyCare.com/Class](https://FreseniusKidneyCare.com/Class)



# REVOLUTIONIZING

# TREATMENT

## Innovations in Kidney Care

By Isela King, MPH

Picture this: a future where kidney diseases are no longer a dreaded problem, where treatments are not just effective but also revolutionized to improve patients' overall well-being. It is no longer just a daydream. Cutting-edge breakthroughs are now becoming a reality.

In the United States alone, there are an estimated 37 million people who have chronic kidney disease (CKD), and I am one of them. Back in 2015, when I was a sophomore in high school, I was first referred to a nephrologist. During a regular physical with my pediatrician, which included a urine test, it was discovered that I had protein in my urine. This abnormality prompted my pediatrician to recommend seeing a nephrologist at Children's Hospital Los Angeles, where I underwent a blood draw

and another urine test. After the results from these tests came back, my nephrologist ordered a biopsy on my kidney, which led to my diagnosis of IgA nephropathy (IgAN). As a teenager, all of this was overwhelming, as neither I nor my parents had ever considered the possibility of kidney disease. What made it even more surprising was that I did not feel sick at all. It was a revelation to learn that kidney disease often presents with little to no symptoms.

CKD is an escalating public health issue in the United States, with various reasons contributing to kidney failure, such as genetic factors or rare diseases. However, the primary causes of CKD are diabetes and high blood pressure. Innovation is crucial for improving patient outcomes, addressing unmet needs of those with kidney disease,

enhancing access to care, and promoting personalized medicine. I want to highlight three innovations in the treatment of kidney disease: a new drug for IgAN, two new medications for lupus, and advancements in stem cell-based therapy. These innovations give me hope for the future as someone with kidney disease, knowing there are advancements being made to improve our outcomes and quality of life, with the hope that they will eventually become widely accessible for all patients.

IgAN, an autoimmune disease characterized by deposits of the antibody IgA in the kidneys, currently has no cure. However, an exciting development in IgAN management received full FDA approval in 2021, offering renewed hope for people like me. This new treatment targets



the gut, where the antibody IgA is produced, and reduces the amount of this antibody. A study has shown that this treatment leads to a significant reduction in protein in the urine. Additionally, another non-immunosuppressive therapy for IgAN received FDA approval in 2023.

I have a vivid memory of attending American Society of Nephrology's (ASN) Kidney Week last year in Philadelphia. It was evident that there was a significant surge in interest and advancements related to IgAN, which was truly encouraging. Witnessing such progress instilled a sense of optimism and hope not just for my own future but also for my peers who are fighting this illness.

Lupus nephritis, a form of kidney disease caused by systemic lupus erythematosus (SLE), can worsen over time and result in kidney failure. Two new therapies approved in 2021 offer hope for better treatments specifically targeted to address lupus and lupus nephritis. Unlike older medications which suppress the entire immune system, these new drugs target specific molecules. One therapy, taken orally, inhibits the activation of T cells responsible for autoimmune responses, effectively reducing kidney inflammation. Clinical trials have shown its superiority in preventing kidney inflammation compared to standard treatment. The other therapy, administered intravenously, blocks type I interferon (IFN-I) activity which triggers inflammation. These advancements in lupus treatment provide hope for improved outcomes and can help save people's kidneys.

For those with end-stage renal disease (ESRD), the current treatment options are transplantation or dialysis. I am grateful to have options. However, dialysis can be burdensome, and transplantation is limited by organ shortages and is not a cure, it is

”

These exciting advancements in kidney care should inspire us to remain informed and engaged in our own treatment.

“

just another form of treatment. Stem cell-based therapy research offers a potential alternative. Stem cells, particularly mesenchymal stromal cells, have shown promise in regenerating damaged kidney tissue, reducing inflammation, and improving cell survival. While early human trials have demonstrated safety, replicating the positive results seen in animal models remains a challenge. Ongoing clinical trials will contribute to our understanding and determine the effectiveness of stem cell-based therapy in kidney diseases.

Genetic variations in the APOL1 gene are linked to a higher risk of kidney disease among African Americans. These variations are only found in people with African ancestry and offer increased immunity against African trypanosomes. If both parents have this gene, the likelihood of developing kidney failure is elevated. Genetic testing can be done to identify individuals with a higher risk of kidney disease.

It is reassuring to know there are ongoing innovations in all stages of kidney research. These exciting advancements in kidney care should inspire us to remain informed and engaged in our own treatment. It is important to communicate with our doctors and explore available options. Medication adherence and routine doctor visits are crucial for maintaining good health, and

Continued on page 22

*Isela King, MPH, is the administrative coordinator at Renal Support Network. She was diagnosed with IgA nephropathy in 2015 when she was a sophomore in high school. This is the same year she began volunteering at RSN's Renal Teen Prom. She received her Master of Public Health degree from the Keck School of Medicine and hopes to use it to continue to serve her peers in the kidney community.*





# UNLOCKING HOPE

## Exploring Kidney Donor Vouchers and Innovative Strategies for Finding a Donor

By Karol Franks

I would like to share an amazing program called the donor voucher program. Are you familiar with it? This paired exchange program offers an innovative way to encourage living kidney donations and save lives. The program is associated with the National Kidney Registry, and most transplant centers offer this option to potential living donors. This program differs from a typical swap or paired exchange transplant program.

The donor voucher program is a unique initiative which allows individuals to donate a kidney in advance. The donor gives the voucher to a person who is in immediate need of a kidney who can then choose to use the voucher for themselves, or if they receive a deceased kidney instead, can pass it on to a loved one in need for future use.

Another type of voucher allows a prospective donor to receive a voucher for a family member who may need a kidney in the future. This is particularly beneficial in cases where a parent wants to donate to their child who may need a transplant in the future, but the parent wants to donate now to make sure the child has a backup.

Unfortunately, transplants are only a form of treatment, and many long-term kidney survivors require more than one kidney transplant.

The idea for vouchers came about back in 2014, when retired judge

Howard Broadman asked UCLA's Kidney Transplant Program a unique question: If he donated a kidney to a stranger, could his 4-year-old grandson, who had kidney disease, get priority for a transplant in the future? Broadman's grandson's kidney disease was expected to lead to kidney failure in 10 to 15 years, requiring a transplant. By that time, Broadman would be about 80 years old, too old to qualify as a donor. Broadman's December 2014 donation initiated a chain with three recipients.

There are two significant advantages to the voucher program. First, the donor can schedule the surgery at a time which is convenient. Secondly, the recipient who they donate on behalf of receives priority in the kidney donor pool, increasing the chances of finding a suitable match more quickly.

Here is one scenario. Let's say I am interested in donating my kidney to help someone but I do not know anyone in immediate need of a kidney. Instead of donating directly to a specific individual, I can donate through a designated transplant center. In return, they will issue a voucher which can be transferred to someone else in need, whether it be a family member, friend, or even an anonymous recipient.

In another scenario, let's consider a person who initially intended to donate a kidney to a friend or family member. However, due to a

change in the intended recipient's medical condition, the recipient became ineligible to receive the kidney. However, the donor still wants to donate to another person in need. The donor can start a chain of life-saving donations.

I remember reading a story which illustrates this situation. A person was unable to donate a kidney to their own mother due to changes in the mother's transplant eligibility. Instead, the donor chose to honor their mother by participating in the voucher program and donating their kidney to someone who needed it sooner.

You may wonder why someone would donate a kidney without knowing the recipient. The brilliance of this program lies in its cascading impact. By making an upfront kidney donation, it can initiate a series of kidney transplants for those in need.

Vouchers are an incredible concept which can change someone's life. Thanks to living donors and the voucher program, two of my family members have received kidney transplants.

The voucher program requires a living donor who is willing to donate a kidney. The most effective way to find one is to ask family and friends, since they are often more willing to help. However, other methods

Continued on page 22



# Having trouble getting phosphorus to goal?

**XPHOZAH**<sup>®</sup>  
(tenapanor) tablets

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

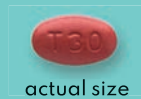
As add-on therapy for patients on dialysis in whom a phosphate binder does not work well:

- ◆ 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](https://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<sub>max</sub>) 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

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Patent: www.XPHOZAH-patents.com

US-XPH-0161 11/23



# ROOTED IN

## 25 Years of Transplant Survival

In March of 1999, my brother generously donated his kidney to me. At that time, my medical team told me that a kidney transplant could last on average ten years. I had been on peritoneal dialysis (PD) for a year and was excited to get the transplant. I am incredibly thankful that my kidney is still functioning after twenty-five years, with a creatinine level of 1.53. Maintaining its health has been a top priority of mine. I believe that being proactive has contributed to its long-term success.

When I reflect on my experience twenty-five years ago, I remember that cyclosporine was still widely used as an immunosuppressive medication, as well as prednisone. And everyone I met had to begin dialysis before they could be eligible for a transplant. Although I had read about preemptive transplantation, it wasn't commonly practiced. I am glad that more people are aware of this option now.

In 1999, there were plenty of new things on the transplant horizon which gave me hope but had not come to fruition yet. Today we are finally seeing advancements, and the following ones give me the most hope for the future.

### **Immunosuppressive Drug Therapy**

Before my transplant, my healthcare team discussed my options for immunosuppressive

therapy. They explained that the goal was to suppress my immune system just enough so that I did not reject my kidney, but not suppress it so much that I might catch every opportunistic infection I was exposed to. It was explained there would be a lot of tweaking in my medications initially and some fine tuning which might take as long as a year. It was imperative that I took my medication regularly as prescribed.

I am glad there are more medication options available now, considering that certain medications can result in side effects. A new immunosuppressive medication, delivered via intravenous drip (IV) monthly, is now an option. Post-transplant immunosuppressive therapy is highly individualized. Today, some transplant centers offer steroid-free therapy if you are a candidate. Each transplant center is different and it is important to know your options and discuss them with your doctor.

### **Stem Cell Transplantation**

Even before my own kidney transplant, the idea of receiving a stem cell transplant prior to surgery was in its infancy. The goal of this type of transplant is to utilize stem cells from the kidney donor to help the recipient's body accept the transplanted organ. Standard immunosuppression therapy can have unwanted side effects and this treatment can work to eliminate

them. Some transplant centers are developing a kidney transplant tolerance program which utilizes donor cells and targeted radiation therapy to help the recipient's body accept the transplanted organ as if it were its own. Not being required to take daily medications is very exciting to me.

### **Xenotransplantation**

Pigs are widely regarded as the most suitable source of organs for xenotransplantation due to their organ size, physiological metabolism, and immune system, which closely resemble those of humans. Genetically modifying the donor pig reduces or prevents attack by the human immune system, and thus achieves compatibility with the human body. In March 2024, Richard Slayman, aged 62, became the inaugural recipient of a kidney from a genetically modified pig. The transplant team reported that a mere two weeks after the operation, he had recovered sufficiently to be released from the hospital. This story made national headlines.

### **Rejection Detection**

I have undergone periodic biopsies on my transplanted kidney. One of the goals of these biopsies is to detect any rejection of the kidney. There are two types of rejections: acute and chronic. Acute rejection can usually be treated and potentially reversed.

# RESILIENCE

## and the Journey Ahead By Cher Thomas, RDH

On the other hand, chronic rejection is more challenging to handle, and the creatinine test does not promptly detect rejection. If your immune system targets the kidney, it becomes difficult to slow the damage.

Recently, there have been advancements in blood tests, such as molecular diagnostic testing, which can provide earlier detection of kidney injury and is less invasive than a biopsy. It is just a simple blood test to detect the presence of antibodies in your blood which may harm your transplant. There are several companies which offer this technology, called a rejection biomarker test. The test can be ordered by your nephrologist.

### Laparoscopic or Robotic Surgery

I have experienced a number of scars throughout my life, and the priority of minimizing invasiveness and pain is of utmost importance to me. The introduction of laparoscopy and robotic surgery has completely transformed the field of surgical procedures. Previously, many surgeries which required an "open surgical technique" would leave a large scar on the living organ donor's body. Both my brother and I underwent full open surgeries when he donated, which left each of us with a lengthy scar post-operation which took longer to heal. However, nowadays, most donor surgeries are performed using the laparoscopic approach, resulting in reduced pain,

shorter hospital stays, and lower instances of wound infections. Kidney recipients can now also be a candidate for laparoscopic surgery.

### Shortening the Wait for a Kidney

When on the waitlist for a kidney transplant, it is important to understand the different types of deceased donor kidneys available. Certain deceased donor kidneys are underutilized and may be a good option for you. These kidneys may not be perfect, but they can still work well. Accepting an underutilized kidney may increase your chances of getting a transplant sooner and may be better than staying on dialysis. There are two main types of underutilized kidneys: High Kidney Donor Profile Index (KDPI) and Increased Risk of Disease (IRD) kidneys. While they may not be the first choice, accepting them can offer important benefits such as shorter transplant wait times and good long-term function. Talk to your doctors about this option and know which kidneys may be offered. It is good to be prepared before you get the call for a transplant.

I consider myself very fortunate to still have the same transplant after twenty-five years, and I hope it continues to work for years to come! I may consider a KDPI kidney if I ever need another one.

Although there is no guarantee on the amount of time a kidney

transplant will last, today twenty-five years is becoming increasingly common. As a matter of fact, there are stories on the internet of transplanted kidneys which have continued to work for FIFTY years and longer!

What I believe has been very important for the longevity of my kidney is to keep in contact with my transplant team. I also do not miss appointments for lab draws, and I pay attention to the results. If I feel ill, I do not delay getting medical treatment. And most importantly, I continue to advocate for my care by communicating side effects, new symptoms, and my goals for my future health with my healthcare team. There have been a lot of changes in the world of transplant and we all need to be aware of our options.

*Cher Thomas, RDH, is a licensed dental hygienist and a kidney transplant recipient. She possesses a passion for providing peer support, assisting individuals in understanding their treatment options and advocating for optimal care. She finds solace by engaging in creative activities and spending time with her adored dogs. She resides in Galveston, Texas.*





# NO SALT SPICE BLENDS

## for a Kidney Friendly Diet

Make these spice blends ahead and store in a sealed jar so you have them on hand, ready to use anytime. Feel free to experiment with your own take on these blends. Turn the heat up or down by adding a bit more or a little bit less of the hot spices.

### Multipurpose



- 1 tbsp garlic powder
- 1 1/2 tsp dried basil
- 1 1/2 tsp dried parsley
- 1 1/4 tsp dried savory
- 1 1/4 tsp dried thyme
- 1 tsp dried mace
- 1 tsp onion powder
- 1 tsp ground black pepper
- 1 tsp dried or ground sage
- 1/4 tsp cayenne pepper

### Fish·Pork·Poultry



- 5 tsp onion powder
- 1 tbsp garlic powder
- 1 tsp paprika
- 1 tbsp ground mustard
- 1 tsp dried thyme
- 1/2 tsp pepper
- 1/2 tsp celery seed

### Italian



- 1 tbsp dried oregano
- 1 tbsp dried parsley
- 1 tbsp dried rosemary
- 1 tbsp dried thyme
- 1 tbsp dried basil
- 1 tbsp black pepper
- 1 tbsp garlic powder

### Smoky Blend



- 1 tbsp smoked paprika
- 1 tbsp paprika
- 1 tbsp garlic powder
- 1 tbsp black pepper
- 1 tbsp ground cumin
- 1 tbsp turmeric
- 1 tbsp onion powder

### Hot & Spicy



- 1 tbsp chili powder
- 2 tsp garlic powder
- 2 tsp onion powder
- 1 1/2 tsp ground cumin
- 1 tsp dried Mexican oregano
- 1 tsp smoked paprika
- 1/2 tsp cayenne pepper
- 1/2 tsp black pepper

### Cajun



- 2 tbsp paprika
- 1 tbsp garlic powder
- 1 tbsp onion powder
- 2 tsp white pepper
- 1 1/2 tsp black pepper
- 1 tsp cayenne pepper
- 2 tsp dried thyme
- 1 tsp dried oregano

## Renal Support Network Presents THE HOME HEMODIALYSIS EXPERIENCE



Video: Watch as Rachel Cluthe Shares a Home Hemodialysis Treatment From Start to Finish

*Performing hemodialysis at home has significantly increased my flexibility and convenience. I can schedule my dialysis sessions around my daily activities, whether it's spending time with family, pursuing hobbies, or maintaining my career. Home hemodialysis adapts to my lifestyle, rather than the other way around," says Rachel.*

RSNhope.org Web ID 2023HHD



*Kristin says, "Before I started on peritoneal dialysis (PD) I was terrified of it and did everything I could to avoid it. Now that I've been doing it for a while, I've come to realize that it's really not that bad. Once I figured out how much time I needed to add to my morning and evening routines, PD fit into my schedule pretty seamlessly. I'm able to work full time, spend time with friends and family and I've even done some local travel."*

RSNhope.org Web ID 2024PD



## Renal Support Network Presents THE PERITONEAL DIALYSIS EXPERIENCE



Video: Watch as Kristin Rice Shares a Peritoneal Dialysis Treatment and Catheter Site Care

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# Protein NEEDS EXPLAINED

By Lubna Akbany, RD, CSR

*"What should I eat?" is the most frequently-asked question to dietitians from people with chronic kidney disease (CKD). The renal diet can appear to be very confusing. I had kidney failure back in the late 1980s and became a registered dietitian (RD) in 1993. I have been a vegetarian for the past 25 years, and have had a transplant for 15 years. So I understand the struggle. I have found that the more I learn, the easier it gets. Food is something we can control and it can make a huge difference for our health.*

*Renal diets are based on kidney function. The primary components of a renal diet which need to be monitored are protein, salt, potassium, and phosphorus. Hopefully, the following will address the general dietary requirements of protein for people with CKD. Protein requirements for people who have kidney disease may vary over time.*

## Why is Protein Important?

Protein is an essential nutrient for the body as it plays a crucial role in numerous bodily functions. It is the building block for cells, tissues, and organs, and is involved in vital processes such as muscle repair, hormone production, neurotransmitter synthesis, and immune system function.

Your kidneys are your body's filters. When you have any stage of CKD, your kidneys are less and less able to rid the body of nitrogenous protein waste from food and beverages. This waste then starts to accumulate in the bloodstream, which is called uremia. Symptoms of uremia include nausea, bad taste in the mouth, loss of appetite, and weakness.

## CKD and Post-Transplant Protein Intake

To maintain kidney health, it is important for individuals with CKD to consume enough protein from the

right sources without overburdening the kidneys. Consuming excessive protein can lead to the accumulation of waste products in the blood, worsening the condition. A reduced protein intake can help to decrease the progression of kidney disease.

## Types of Proteins

There are two types of protein: protein from animals, and protein from plants.

- Sources of animal protein include fish, chicken, eggs, shellfish, and dairy products.
- Sources of plant protein include beans, legumes, soy, and tofu.
- Protein powder supplements are often made of whey and are not advised for low-protein diets, unless they are from plant sources such as peas.

## CKD Stages 3-5

Unfortunately, as the disease progresses to CKD stages 3-5

(GFR 59 or lower) you will need to reduce your protein intake considerably. According to recent studies, maintaining protein intake to 0.55–0.60 grams per kilogram of body weight can postpone the deterioration of kidney function. For instance, if you weigh 68 kg (150 lbs), your daily protein requirement is 40 grams (68 x 0.6 g/kg). This is roughly equivalent to 4-6 ounces of plant- or animal-based protein each day. It is preferable to consume more plant-based protein when your glomerular filtration rate (GFR) begins to drop since plant protein digests more slowly than animal protein. You may determine the ideal kind and quantity of protein for you with the assistance of a renal dietitian.

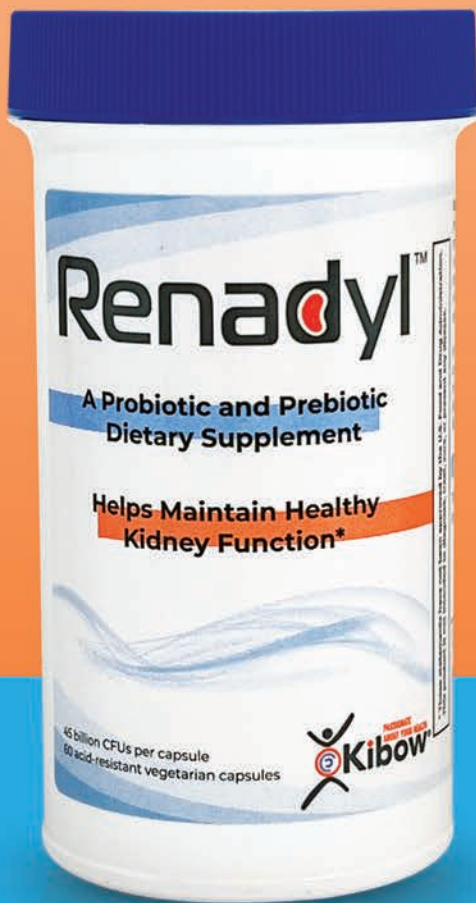
In order to prevent malnutrition, a doctor may occasionally recommend keto acid analogs to supplement a very low-protein diet. Grains

Continued on page 21

# Renadyl™

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# Mental Health Daily Practices



Living with chronic kidney disease (CKD) can be challenging, both physically and emotionally. Taking care of your mental health is just as important as taking care of your physical health, especially when living with CKD.

Incorporating mindfulness practices into your daily routine can help improve your mental health and well-being. Experiment with different techniques to find what resonates with you, and remember to be gentle and patient with yourself as you explore these practices. Bear in mind that it is okay to have difficult days and to seek support when needed.

Here are some daily mental health practices which can be helpful for people who have kidney disease. There is most likely a smart phone/tablet app for all of these suggestions.

**Meditation:** Spend a few minutes each day practicing mindfulness meditation. Find a quiet and comfortable space, sit or lie down, and focus on your breath or a specific mantra. Meditation can help reduce stress and anxiety, and promote a sense of calm and solace.

**Yoga:** Participate in gentle yoga sessions tailored to your physical capabilities. Yoga can help improve flexibility, strength, and balance while also calming the mind and reducing stress. Look for kidney-friendly yoga routines or consult with a yoga instructor who understands your specific needs.

**Ambient Sounds:** Listen to soothing ambient sounds such as nature sounds, white noise, or calming music. You can use apps or websites which offer a variety of ambient sounds to help you relax, focus, or sleep better. Experiment with different sounds to find what works best for you.

**Guided Imagery:** Practice guided imagery exercises where you visualize peaceful and calming scenes. Close your eyes, imagine yourself in a serene environment like a beach or a forest, and focus on the sensory details such as the sound of waves or the rustle of leaves. Guided imagery can help promote relaxation and reduce anxiety.

**Deep Breathing:** Incorporate deep breathing exercises into your daily routine. Take slow, deep breaths in through your nose, hold for a few seconds, and then exhale slowly through your mouth. Deep breathing can help activate the body's relaxation response, reducing stress and promoting a sense of serenity.

**Mindful Walking:** Practice mindful walking by taking slow, deliberate steps and paying attention to each movement and sensation. Focus on the feeling of your feet touching the ground, the rhythm of your breath, and the sights and sounds around you. Mindful walking can help ground you in the present moment and reduce stress.

# Do You Have a Creative Outlet?

Art, crafts, music, and writing are powerful mediums which have the ability to evoke and express emotions in profound ways. These forms of creative expression provide a way for people to communicate and process complex feelings, improving emotional well-being.

Engaging in artistic activities such as painting, drawing, or sculpting provides an outlet for self-expression and exploration.

Listening to music allows individuals to connect with certain emotions or experiences, providing solace or validation.

The act of crafting involves working with one's hands to create something tangible, whether it is through knitting, woodworking, or pottery. Engaging in crafts can be a calming and interactive process which allows people to focus their attention on a specific task, diverting their thoughts from negative emotions.

Also, writing is a transformative tool for emotional exploration and introspection. Through writing, people can articulate and process their emotions, potentially providing a sense of relief and understanding. Journaling, for instance, allows people to document their thoughts and feelings, which can act as a self-reflective tool.

Creative outlets provide an opportunity for self-expression, emotional regulation, and self-awareness and have been shown to improve emotional well-being and resilience.

## Protein Needs, Explained Continued from page 18

and starchy foods provide limited amounts of protein, so that must also be taken into consideration.

Even though you are eating less protein, you still need to eat enough calories from other food groups to prevent weight loss and muscle wasting. There are other dietary factors to be familiar with in addition to limiting protein, depending on if you also have diabetes, high blood pressure, or hyperlipidemia.

Limiting protein could sound challenging and perhaps unattainable. However, a renal dietitian can help you plan out a diet that will work for your preferences and your lifestyle.

## When on Dialysis, Everything Changes

When undergoing dialysis treatments, protein intake becomes even more crucial as the dialysis process can result in protein loss. The recommended protein intake for individuals on dialysis varies depending on factors like weight, age, and overall health. Insufficient protein levels can lead to muscle loss, weight loss, hair loss, fatigue, increased susceptibility to infections, edema, longer hospital stays, and a higher risk of heart disease. Generally, people on dialysis are advised to consume a higher amount of protein compared to individuals with normal kidney function.

You can tell if you are eating enough protein by looking at your albumin level on lab tests. A normal

albumin level is 3.8 to 5.0 g/dL. To stay strong and healthy, check your lab values, talk to your renal dietitian, and eat the right amount of protein for your body.

*Lubna Akbany, RD, CSR, is a registered dietitian nutritionist and certified specialist in renal nutrition with over 20 years of experience. She specializes in CKD management and diabetes, focused on CKD nutrition. Lubna is a mom, a kidney transplant recipient, and an effective nutrition communicator. Lubna's goal is to empower people to slow down the progression of kidney disease with proven nutrition and supplement interventions. She quotes, "If I can give you more confidence in your diet, help you keep your kidneys, and give you more time to enjoy your life the way you want, I'll have done my job."*





## Transitioning from Pediatric to Adult Care Continued from page 6

For adult nephrologists caring for young adult patients, it is important to recognize that patients under 25 years of age with CKD are a unique population at high risk of adverse outcomes. This is at least in part due to physiologic incomplete brain maturation, as the prefrontal cortex, responsible for planning and organization, is not fully developed until approximately that age. Healthcare transitions per se are associated with adverse outcomes, including loss of follow-up, but may be even higher risk in the young adult population. Therefore, it is recommended that young adults be seen in-clinic more frequently than older adults with the same stage of CKD.

For healthcare providers, it is important to understand that adolescent and young adult patients are navigating not only a transition of care and change of healthcare providers, but also the larger transition from childhood to adulthood. Keeping this in mind, and framing clinical interactions accordingly, can help to optimize this critically important time of transition.

In addition to the pediatric-to-adult transfer of care, healthcare transitions can also occur for adults. They may also need to change nephrologists in the context of a relocation or change in insurance.

When meeting with the new nephrologist, knowing and communicating key aspects of medical history (e.g. etiology and duration of CKD, other medical conditions, etc.) is important. Additionally, knowing prescribed medications, their dosages, and why they were prescribed helps to maintain optimal care while transitioning to a new nephrologist. Especially useful to the new healthcare team is an updated,

printed list of medications, medication dosages, medication indications, drug allergies, and medical conditions. Having an up-to-date list can help to avoid sub-optimal care during a healthcare transition, as communication between the transferring and receiving care teams may not always be comprehensive or thorough.

Additionally, when meeting with a new nephrologist, it is important to discuss logistics, routes of communication, and clinical expectations. How often should in-person clinic visits occur? Are telehealth video visits an option? Who should be contacted for scheduling, re-scheduling, or cancelling appointments? How are medication refills handled? What is the best way to contact a member of the healthcare team? Is there an app used by the clinical team that can help facilitate patient-provider communication? In what time frame should a response to a phone message or app-based text message be expected?

Good communication, understanding, involvement, and preparation among healthcare providers, patients, and caregivers is paramount to facilitating seamless transitions of care for those with CKD.

*Dr. Hanudel was born and raised in Roanoke Rapids, North Carolina. He completed his undergraduate studies at Yale University in 2003, earning a degree in Molecular, Cellular, and Developmental Biology. He received his medical degree from Harvard Medical School in 2008. Dr. Hanudel then came to UCLA, where he completed his pediatric residency and completed his pediatric nephrology fellowship, and earned a Master of Science in Clinical Research degree. He joined the UCLA Department of Pediatrics faculty in 2016. He also serves on the RSN Board.*



## Revolutionizing Treatment: Innovations in Kidney Care Continued from page 9

strategies like setting reminders and sticking to a consistent schedule can help us stay on track.

I hope these advancements bring optimism to our journey and serve as a beacon of hope, not just for me but for everyone facing kidney disease. Let's stay positive and well-informed, and support the potential breakthroughs which can positively impact our lives.

## Unlocking Hope: Exploring Kidney Donor Vouchers and Innovative Strategies for Finding a Donor, Continued from page 10

exist for finding a living kidney donor. Strategies which people have used, such as sharing their stories on social media platforms like Facebook, Instagram, and TikTok, have increased the chances of successfully finding a living donor. Some have even utilized billboards, yard signs, and writing on car windows to attract attention and find potential kidney donors. These approaches have proven effective in reaching a wider audience and have gained significant media attention.

For more info about the voucher program visit [www.kidneyregistry.org/for-centers/voucher-program/](http://www.kidneyregistry.org/for-centers/voucher-program/)

For ideas to campaign for a living donor visit [rsnhope.org/rsn-blog/how-to-find-a-kidney-donor](http://rsnhope.org/rsn-blog/how-to-find-a-kidney-donor)

*Karol Franks is a passionate advocate for people with kidney disease and living donors. Three of her family members have had kidney transplants. Karol is an administrator for Living Donors Online, and an administrator for the "I Hate Dialysis" Facebook group. Karol is a long-time volunteer at RSN's Renal Teen Prom and other programs. She and her husband reside in Southern California.*



## Spend Some Quality Time with Your Kidney Kin!



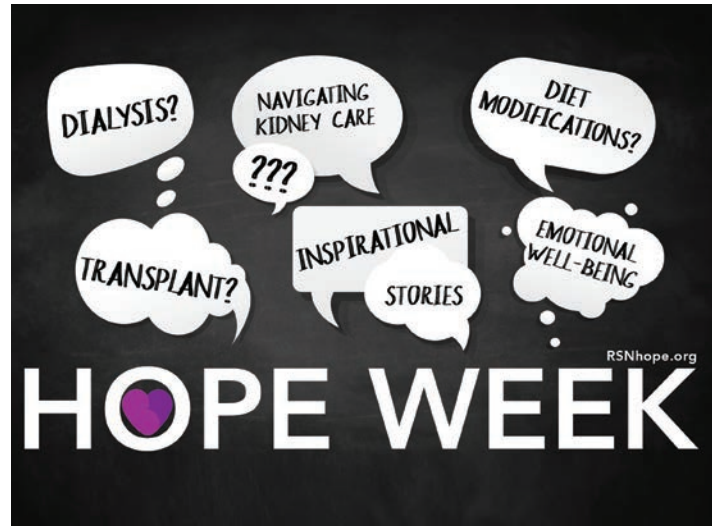
RSN's Zoom meetings are informative and so much fun! Topics include kidney disease support groups, exercise, hobbies, diet tips, and more. This is a great way to connect with others living with kidney disease, make new friends, and learn new things.

There are no fees, but registration is required in order to protect the privacy of attendees. You only need to sign up once for each class to begin receiving the Zoom link via email before the meeting date. Sign up for online meet-ups with your kidney kin today at [RSNhope.org](https://www.RSNhope.org).



## Save the Date • Hope Week

RSN's National Online Patient Education & Lifestyle Meeting for People Who Have Kidney Disease.



### October 9 - 13, 2024

For 30 years RSN has presented the Annual Patient Education Conference at no charge to people who have kidney disease and their families. Hope Week is a five-day national, virtual event. Each day will focus on a specific disease or treatment for kidney disease. Speakers will include healthcare professionals and people who have learned to live and thrive in spite of having kidney disease. See [RSNhope.org](https://www.RSNhope.org) for details.



We know kidney disease is often accompanied by anxiety, from sitting in a dialysis chair for many hours, waiting for a test result, or when you just feel overwhelmed. Let your mind and body relax while listening to comforting sounds.

Choose a soothing rainfall, a peaceful forest stream, rainforest birds, or a calming instrumental, then close your eyes and let your stress and anxiety fade away. Web ID Music01



Kidneys for Kids is an activity book that helps children understand kidney disease, dialysis, and transplant in an easy-to-understand engaging format. This book was written by Anyssa Dang to help her younger brother Kavan who was diagnosed with kidney disease and did not understand what was happening. Learn more at <https://www.rsnhope.org/kidneys-for-kids-family-activity-book>





## Champions Of Kidney Care

We don't get into politics here, but we do get into policy. As people who have kidney disease, we need to make every voice count. We are currently supporting several pieces of legislation. Help us be heard.

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, access to treatment, dialysis, transplantation, and organ donation.

### Take Action on Current Legislation that Affects People Who Have Kidney Disease

Restore Protections for Dialysis Patients Act (H.R. 6860)

Kidney PATIENT Act (H.R.5074)

Chronic Kidney Disease Improvement in Research and Treatment Act (H.R. 5027)

The Living Donor Protection Act (H.R. 2923/S.1384)

Living Organ Donor Tax Credit Act (H.R.6171)

Learn more about these bills, new legislation and regulatory opportunities and make your voice heard at [rsnhope.org/advocacy](https://rsnhope.org/advocacy).



Web ID: RSNadvocacy

*"Never doubt that a small group of thoughtful committed individuals can change the world. In fact, it's the only thing that ever has."  
—Margaret Mead*

## Watch and Share RSN's Gift of Life Music Videos

In case you missed it, RSN's "Gift of Life" music videos honor organ donation with kidney transplant recipients Aaron Battle and Alli Himer. Watch and share the videos to help raise awareness of the need for the gift of life!



## Support Group Masterclass

Have you ever wanted to help your kidney peeps? Are you a caregiver who wants to start a support group? We all know that when you are struggling with an illness it is very helpful if you can talk to someone who has been there. Peer support is essential to survival. A support group where people can share their experience, strength, and hope can help people navigate the myriad of emotions and learn about kidney disease from others. RSN is pleased to announce we have created an online masterclass at no charge to you.

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 your destination: 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.

[RSNhope.org/support-group-masterclass](https://rsnhope.org/support-group-masterclass)



## What is a Web ID?

You may have noticed that all of the articles in this magazine have a Web ID number. In fact, all of our content in print or online has a Web ID. Blog posts, KidneyTalk® podcasts, and KidneyTalk® magazine articles and more include the item's Web ID in the post. The Web ID appears at the end of every post and on the print magazine page.

You can find whatever you are looking for on our website if you know the Web ID. Just click the magnifying glass icon at the top right of the menu bar on the home page on your desktop computer or smart phone. Then enter the number in the search bar.

If you are a healthcare professional you can prepare a list of prescription articles and podcasts for your patients by using the Web IDs as a short code instead of a lengthy title.

# Studio HOPE

**Don't Sit on a Pile of Stuff You'll Never Use**



RSN is currently seeking donations for a resale boutique that we are opening in Burbank, California. If you have gently used, vintage clothing or accessories which are taking up space in your closet, or if you have unique items in your garage you don't know what to do with, consider donating them to RSN's Studio Hope. We have a list of needed items on our website. Your tax-deductible donation will directly benefit RSN's programs.

If you are interested in donating or have any questions, please contact us at [Studio@rsnhope.org](mailto:Studio@rsnhope.org). If you are in the area, we may be able to pick up your donation or we can arrange a convenient drop-off time for you. If you live outside the area and would like to send us something, please reach out to us. Please note that we can only accept shipments of boxes which can be carried by one person. We also have volunteer opportunities. Learn more at [RSNhope.org/studio](http://RSNhope.org/studio).

Follow us on Facebook and Instagram @RSN\_StudioHope





# Cooking For Your Kidney Health



## Online Nutrition Information Tool for the Kidney Diet

RSN's Nutritional Information Database is a great resource for people who have chronic kidney disease, are on dialysis, or have a kidney transplant. Here you will find the amount of sodium, potassium, phosphorus, fat, calories and more that is in just about anything you would want to stock in your pantry to make your own healthy meals. Always check with your renal dietitian before making any changes to your recommended diet.

Web ID NTData



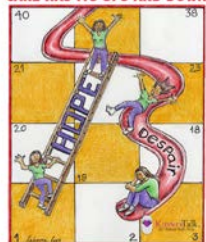
# KIDNEYTalk®

24/7 Podcast Radio Show

Listen in to these inspiring shows with host Lori Hartwell!

Listen in by scanning the QR code or enter the Web ID under each show below in the search bar on the website. All the latest shows as well as archived shows on the KidneyTalk™ page at RSNhope.org. You can also find the show on iTunes, YouTube, and iHeart Radio by searching for "KidneyTalk."

### ACCESS TO INNOVATION IN DIALYSIS CARE HAS ITS UPS AND DOWNS



Web ID: 3129 RSNhope.org

**Jeffrey Silberzweig, MD**  
Web ID 3129

Barriers to innovation for people who are on dialysis, advantages and disadvantages of the current payment system.



**Jennifer McClung**  
Web ID 3127

Tips to help make your own weight loss journey a success.



**Joy Araujo**  
Web ID 3126

Facing the challenges of growing up with kidney disease and the art of storytelling.



## WATCH NEFF & NUFF ANIMATED VIDEOS



RSN shines a light on organ donation with a clever animated video series featuring Neff and Nuff. Watch all three videos in English or in Spanish at RSNhope.org.

Web ID NN01



## SHARE YOUR SPARE KIDNEY DONATION CONVERSATION KIT

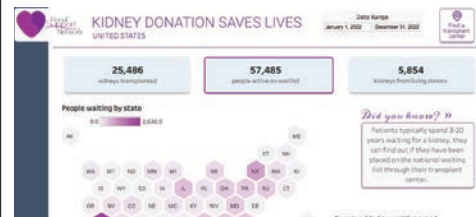


RSN's "Share Your Spare" kit brings awareness to the public about their kidneys and how to keep them healthy, kidney disease treatment options, deceased organ donation and the option of living donation. Learn more at RSNhope.org.

Web ID SYS22



## KIDNEY TRANSPLANT DASHBOARD



This tool will help you see national and state statistics at a glance. You can look up how many transplants have been done for any specific time frame. And you can locate the transplant centers in your area. Learn more at RSNhope.org.

Web ID TXData



## WE NEED YOUR SUPPORT



The Renal Support Network relies on charitable, tax-exempt contributions to make a lasting and positive difference in the lives of people who have kidney disease.

Contribute to RSN online at [RSNhope.org/donate/](https://RSNhope.org/donate/) or mail a check to:  
Renal Support Network  
1146 N. Central Ave. #121  
Glendale, CA 91202



## YOU CAN MAKE A FINANCIAL CONTRIBUTION IN SEVERAL WAYS

### One-Time or Monthly Recurring Donation

Your one-time or recurring gift of any amount via check, major credit card, or PayPal will help change lives.

### Personal Fundraiser

RSN's personal fundraiser platform makes it easy to set up your own fundraiser, track your progress, and share with friends and family on social media and/or email.

### Tribute Donation

Recognize, honor, and celebrate people and events which are important to you. RSN will send a follow-up note to your chosen recipient.

### Legacy donation

When you include RSN in your long-term estate or financial plans, you leave a legacy to people who have kidney disease. A legacy donation can include planned gifts, such as bequests, charitable trusts, insurance, or a gift of capital gains from stocks.

## CONTENT SPOTLIGHT: KNOWLEDGE AT YOUR FINGERTIPS A FEW OF KIDNEYTALK® MAGAZINE'S MOST POPULAR ARTICLES



### Designing your Room for Home Treatment - Web ID 4069

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.



### Seeking a Kidney Transplant? When to Start and What to Know - Web ID 4056

If you have decided to explore the possibility of a kidney transplant, congratulations! That is a wonderful goal. However, pursuing a transplant is a process, and that process takes time, preparation, planning, and patience. It is real work! This article and downloadable infographic shares tips to help you navigate the process more easily.



### Looks and Labs - Web ID 4029

Kidney disease and medication can have an effect on your appearance. This article and downloadable infographic contain some common symptoms along with causes and treatments you can discuss with your doctor. Simple home remedies may also provide a temporary fix.



### I Have CKD. Is it Safe to Keep My Pets? - Web ID 4019

RSN founder and president Lori Hartwell shares how the pets she has had throughout her life helped her tremendously while living with a serious illness.







Service to those affected by chronic kidney disease  
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Sign up today at [rsnhope.org/join-rsn](http://rsnhope.org/join-rsn)

# HOPEline

Peer Support Hotline

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

Lori Hartwell founded Renal Support Network (RSN) in 1993 to empower people who have kidney disease to become knowledgeable about their illness, proactive in their care, hopeful about their future and to make friendships that last a lifetime.

### CONTACT INFORMATION

Renal Support Network  
1146 North Central Ave. #121  
Glendale, CA 91202  
[info@RSNhope.org](mailto:info@RSNhope.org)

866-903-1728 Toll Free  
818-543-0896 Local  
E-Fax: 818-484-2070  
9 AM-5 PM Pacific Time  
Monday-Friday

If you have a change of address or other information, please contact us.

