

KidneyTalk[®]

Fall/Winter 2023

by Renal Support Network

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

RIYA KHAN
COOKIN' MY FEELINGS

**ANNOUNCING
THE 21ST ESSAY
CONTEST WINNERS!**

THE GREAT ESCAPE
**HOW CREATIVITY
REDUCES STRESS**

**BE KIND TO
YOUR HEART**
PREVENT FLUID OVERLOAD





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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 to subscribe. Current issue, printable version, articles, and archives can be found at: www.RSNhope.org



THE GREAT ESCAPE

How Creativity Reduces Stress

By Lori Hartwell

I have always loved to create. I think I learned to lean on the creative side of my brain when I was young and dealing with all the pressures of kidney disease. Engaging in creativity helps my brain calm down and feel more in control. Engaging in creativity provides numerous benefits for my physical, emotional, and mental well-being. As I have gotten older, creativity is like food for my soul. I always need a creative project around to give my mind a break. I leave a project out where it is easily accessible. I no longer put all my arts and crafts projects away. When I need a creative fix, they are waiting for me nearby.

Lately, I have been learning more about colors and how they interact with each other. I have learned I pick colors based on my mood, and that exploring color combination helps me to express emotions and explore my feelings. When I am painting, I see shapes or patterns appear. Over the summer, I had a few health hiccups and everything I painted seemed to have a bird symbolism in it. I took this as a sign: I will take flight again. I will get through this.

I like to make jewelry and am always looking at new designs, beads, and trends. Sparkles make

me happy. I smile when I put some crystals on my bead board and see if they want to be a necklace, earrings, or bracelet. Creativity is like a daily meditation for me.

Sometimes medication can make my hands a bit shaky, but over the last few decades my fine motor skills have remained steady. I chalk

“The worst enemy to creativity is self-doubt.”
— Sylvia Plath

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 is 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.

this up to constantly using my hands to create things. Engaging in such activities regularly can assist in maintaining or regaining dexterity and coordination.

Thinking about a creative project can provide benefits as you explore all the possibilities, even before starting it. I am fascinated with how people create things and enjoy watching other people create. Completing an arts and crafts project myself gives me a sense of achievement and it always makes me feel better. I love the challenge of learning something new.

Participating in arts and crafts can connect us with others who share similar interests, either in person or through online communities. I

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COOKIN'

my feelings



*Riya Khan pursues her love of cooking
to keep her emotions in check*

By Mary Nesfield
Web ID: 4081

Riya Khan was born in Bangladesh. In 1997, at the age of 9, her kidneys failed. By the end of August that same year, she was doing peritoneal dialysis. Two years later, at the age of 11, she decided to have a meal ready for her mother when she came home from work. She cooked up a special version of potatoes called *Aloo Bharta*. She mixed them together with chili, onions, and cilantro, then fried the mixture in a pan. She was proud of her accomplishment, and it made her feel good to know it made her mother happy. At the end of March 2001, she was transplanted with a kidney from a deceased donor. By age 15, Riya was cooking complete meals for her family. It was fun for her to see people enjoying what she created, and it made her happy.

Cooking became a good coping mechanism for her, as it helped ward off the depression that dealing with an illness can cause. She cooks not only to sustain her health, but also to create visually pleasing dishes that stimulate the taste buds.



her with opportunities that she finds interesting and gives her an option to work from home. In 2000 she attended RSN's first Renal Teen Prom. She had so much fun that she came back each year until she reached age 25. She will be attending the 25th prom as volunteer ambassador because she loves inspiring her younger peers.

Riya also has an interest in learning about different cultures, and exploring new cooking techniques leads her to discovering a variety of cultural dishes. She takes on the challenge of following complex recipes because it diverts her attention away from negative thoughts. Three of her favorite food related shows include *The Bear*, *Taste of the Nation with Padma Lakshmi* on Hulu, and *Somebody Feed Phil* on Netflix. She also likes to discover new cuisines when she travels. When she discovers a delicious dish she wants to replicate, she does a web search with the dish name to get her started.

Her favorite brunch is Turkish eggs. She makes the recipe with Greek

key to that, she says, is to cook from scratch and avoid processed foods. She reads food labels and eats balanced meals that include lots of plant-based foods. She uses sea salt, spices, and herbs to bring out the flavor in foods. "My favorite is a vegetarian diet," she says. She follows chefs on Instagram, buys seasonal produce, fresh fish and seafood at a local seafood market, and purchases hard to find ingredients online.

She is grateful her lab numbers remain stable, and her creatine level is 1.2-1.6. She knows drinking enough water contributes to the success of her transplant. She knows a transplant is not a cure and someday she may need another one, so she is mindful of maintaining a healthy lifestyle to not put any extra stressors on it.

She believes in doing everything in moderation so she can maintain a healthy weight. "It's about portion-control," she says. "Get to know your body." Exercise is an important part of her life as well; she walks 2.5 miles every day with her beloved

"When we feel down, it's because we feel that we are not in control. Cooking is being in control."



Riya attended college to earn a degree in psychology. She continued her education by studying law in Tampa, Florida, preparing meals when she had the time. Taking the bar took a lot of time and caused her a lot of stress. Since her health was her number one priority, she decided not to pursue that goal; however, her education provides

yogurt, garlic, and lemon juice, and drizzles her home-made chili butter over it. "It's one of the best dishes of all time," she says. "I cook mostly with olive oil and avocado oil. Calabrian chili oil from Italy is another one of my favorites."

How can choosing the right foods contribute to one's health? The

fur-babies, Cinnamon and Zuri.

Riya's best friend is her roommate, who is always up to trying a new culinary creation. The dogs are also her taste-testers, especially her dog Cinnamon. Her dogs have been with her through a lot.

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Cookin' My Feelings Continued from page 5

Having these furry friends around also helps keep her spirits up.

Her best friend suggested that she create an Instagram page. Riya was not convinced of its worth but did it anyway and began posting photos of the foods she was preparing. She enjoyed getting all the positive feedback. Her photos will inspire anyone to start cooking. You can look her up at @cookinmyfeelings.

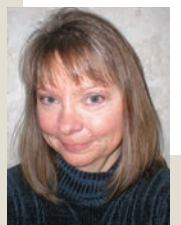
To anyone who deals with depression, she offers these words of encouragement: "When we feel down, it's because we feel that we are not in control. Cooking for me is about being in control. It's creative and takes the mind off things that get us down; it makes people happy."


How can people get started? "My advice is to start with easy recipes. Figure out what types of foods you like and build from there. Watch videos. We have so much information at our fingertips now with all these videos available online. That's how I learn," she says.

Riya stays in good spirits when she is busy or has a new recipe saved on her phone that she wants to try. Through her travels she will discover more new recipes, and that will dish up more servings of "happy" for her!

"For me, controlling depression boils down to this: Find something that makes you happy and do it often!" she says.

Mary Nesfield has enjoyed a long career in magazine publishing. She is a freelance writer and editor for Renal Support Network and works from her home in Columbia, South Carolina.



A photograph of two women standing outdoors, smiling and looking towards the right. The woman on the left has long dark hair and is wearing a white shirt under a maroon cardigan. The woman on the right is wearing glasses, a grey headwrap, and a floral patterned top. They are holding hands. The background shows green foliage and a sunset sky. The image is partially framed by a large white triangle on the left and a blue triangle on the right.

Supporting your emotional well-being

Mental health concerns like depression and anxiety are common when living with kidney disease. Learn more about the resources that can help you feel your best.

Visit [FreseniusKidneyCare.com/EmotionalHealth](https://www.freseniuskidneycare.com/emotionalhealth)





BE KIND TO YOUR HEART: Prevent Fluid Overload

By Tammy L. Bolin,
Director of Clinical Services Initiatives
Fresenius Kidney Care

Fluid management is one of the most important parts of supporting your health if you're in the early stages of chronic kidney disease (CKD) or on dialysis. Fluids may easily build up in your body. Finding a healthy balance can help you avoid a potentially serious condition called hypervolemia, or fluid overload. Not only will proper fluid management make you feel much more comfortable, but following your care team's recommendations can help you avoid health complications.

What Is Fluid Overload?

Healthy kidneys pull excess fluid out of your body and send it away as urine, but with compromised kidneys, this process is inefficient. When kidneys don't rid the body of fluid properly, you are at risk of fluid overload, which can cause congestive heart failure. Too much fluid in your body may overwork your heart, which can lead to heart problems, high blood pressure, or even further damage to your kidneys.

Signs of fluid overload include rapid weight gain, shortness of breath, and high blood pressure. You may also notice swelling in your arms, legs, hands, feet, face, or abdomen. Fluid overload can make you feel physically uncomfortable. If you're on dialysis, you may feel nausea toward the end of your sessions, and you may need additional dialysis treatments if your doctor thinks you have excess fluid in your body.

Discuss Dry Weight with Your Doctor

Estimating the safe amount of fluid removal for you depends on your "dry weight". This is your body weight without excess fluid retention, and it is close to what you would weigh with healthy kidney function. If you're on dialysis, your goal, with the help of your care team, is to return to your "dry weight" by the end of each dialysis treatment. At that time, you should feel comfortable, normally hydrated, and not thirsty.

Your doctor will determine your "dry weight" based on your weight when you have normal blood pressure, no swelling, your heart size appears normal on an x-ray, and there are no breathing sounds related to fluid overload.

A Kidney-Friendly Diet is Important

Following a healthy diet is one of the best things you can do for your kidneys and your heart. A kidney-friendly diet limits sodium and monitors minerals like potassium and phosphorus. Too much sodium causes the body to retain fluid more easily, so a low-sodium diet helps keep your fluids at a healthier level. When choosing low-sodium foods, look for “no salt added” labels. Some high-sodium foods may not taste salty to you, so be sure to check the nutrition facts. Choose foods with a percent daily value (%DV) below 10% sodium. You can also cut down on sodium by avoiding fast food and prepackaged or processed foods.

Fill up on delicious fresh fruits and vegetables to satisfy fluid cravings and get a dose of healthy vitamins and minerals. Kidney-friendly foods like whole-grain rice or pasta, beans, and lean meats like chicken, beef, or turkey are also great choices.

Meet Your Daily Fluid Goals and Stay Healthier

Talk to your doctor about setting realistic daily fluid goals so you can feel comfortable and stay your healthiest. Home dialysis can offer more flexibility with your daily fluid goals. Managing your fluid intake will help you maintain your weight and fluid balance. If you are still urinating, be sure to periodically monitor your output volume as it can change over time.

It's important to always mention any signs of fluid overload and regularly check in with your care team to be sure you're staying on the right track. Following your doctor's fluid recommendations and paying attention to your body are key to meeting your dry weight goals.

Maintaining a dry weight will put less stress on your heart and body, and you will feel better.

TIPS FOR PREVENTING FLUID OVERLOAD

You can feel your best and keep your heart healthier by taking small steps to avoid fluid overload.

- Keep track of your daily fluid intake. Write down how many ounces of fluid you're drinking and keep your records. Be sure to stick to your doctor's recommended guidelines. They will base the daily fluid intake goal on your urine output and weight.
- Cut down on salt. Fill your shopping cart with fresh foods and choose low-sodium options. You can swap the salt for flavorful spices like basil, paprika, chili powder, or rosemary. Limiting sodium reduces fluid retention and will help you feel less thirsty.
- Try strategies to manage your thirst. Managing salt intake is key, but there are other tricks for feeling less thirsty. Give fluid cravings a few minutes to pass and try taking your medications with applesauce instead of a drink. Cool down in the heat by staying in the shade, sitting near a fan, or wearing loose and light clothing.
- Watch your weight. Tell your care team if you notice weight gain or swelling in any part of your body. Dry weight has been known to change after a hospitalization or when feeling better and you have a better appetite.
- Don't miss any dialysis treatments. Missing a treatment can be dangerous for your health.

For more information on managing your fluid intake, visit [FreseniusKidneyCare.com/Fluid-Management](https://www.freseniuskidneycare.com/fluid-management).

Tammy Bolin, RN, BSN, is the Director of Clinical Services Initiatives at Fresenius Kidney Care. In this role, she supports strategic operations for home therapies. Tammy has been a nurse in the dialysis industry for over 25 years and remains passionate about supporting individuals on dialysis and those who provide their care. A resident of Oklahoma, Tammy enjoys spending time with her family and friends and working on their family ranch.



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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LANDSCAPING, GARDENING, AND FLOWERS EVERYWHERE

1st Place Winning Essay,
21st Annual Essay Contest
By John Unger

Web ID 5080

Unimaginable fatigue, like cotton candy melting and wilting on a hot day, slows the mind and body; sleep becomes an escape, but the body and mind never shed the sticky fatigue from one dialysis treatment to the next. The challenge is always to push the fatigue away. Stand up, keep moving, keep moving,

with my fistula-free arm. I roll out and cut black weed-blocker material in sections before pushing and dumping wheelbarrow loads.

As I am shoveling and dumping loads, and then spreading with a rake and shovel in mile-high sun, I am floating in imaginations of carnations which

I imagine wooden borders: large Lincoln logs, stacked just two high, marking the approximate fifteen-by-ten-foot grassy area for the dogs. I'll plant buffalo grass and some of that flower mix that hummingbirds and bees love. Other borders will be red brick and white rocks, and I will paint some four-by-fours bright red and white for dividing the already cross-fenced yard.

Tall sunflowers will stand in yellow contrast to the turquoise gate and the patchy green forests and brown/gray rock of the Sandias that rise up in the distance. Those mountains change color with the sun and clouds all day, turning a reddish color with most sunsets, often matching the pueblo red rock and dirt.

As I have been spreading dirt and rock, I have been reeling from sixteen months of designer chemo drugs for my amyloidosis (it's mine; I own it, and it me). I have also been turned down from the transplant list twice because the numbers were not low enough. Just a week ago, my oncologist told me that some miscommunication occurred; she said we would stop the chemo for a couple of months and "see what happens."

I'm a yo-yo. One day up, the next day down.

Shoveling and moving dirt and rock and sweating in the hot sun (taking frequent breaks in air conditioning) feels so normal to me, as simple as walking. My body knows these movements from an earlier me, working the fishing boats off Alaska

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keep moving. I have turned to landscaping my yard to be creative and push back against fatigue.

After clearing weeds, this first phase of the landscaping involves moving crusher-fine rock and seven-sixteenth small rock, both called pueblo red, the color of red wine and a red sky. I move this rock and dirt one shovel at a time, one wheelbarrow at a time, careful to lift the shovel

will go over there, sunflowers here, borders in strawberries, climbing roses on the wall that separates the back yard into two sections, and a five-by-four-foot pond, eighteen inches deep, near a small waterfall. Near the waterfall, I want to plant lavender all around. I am in the sunny, mile-high desert in Albuquerque, New Mexico, so I have to think about water-usage when I am choosing plants. A few are indulgences.

John Unger is a former college English teacher (College ESL; Adult Transitional Literacy), Navy Veteran, and former deckhand on commercial fishing boats in the northern Pacific, Gulf of Alaska, and Bering Sea. He now lives in Albuquerque, NM, with his two dogs, Aristotle and Oliver.





UNFILTERED KIDNEY
CONVERSATIONS

Questions to Ask Your Doctor about High Potassium



How can I
find out my
potassium
level?



Are there lifestyle
changes that can help to
manage high potassium
in addition to treatment?



What
treatments
are available
for high
potassium?



What are the symptoms
of high potassium?



What
should be
my 'goal'
potassium
level?



Can my HK be managed
by reducing my potassium
intake?

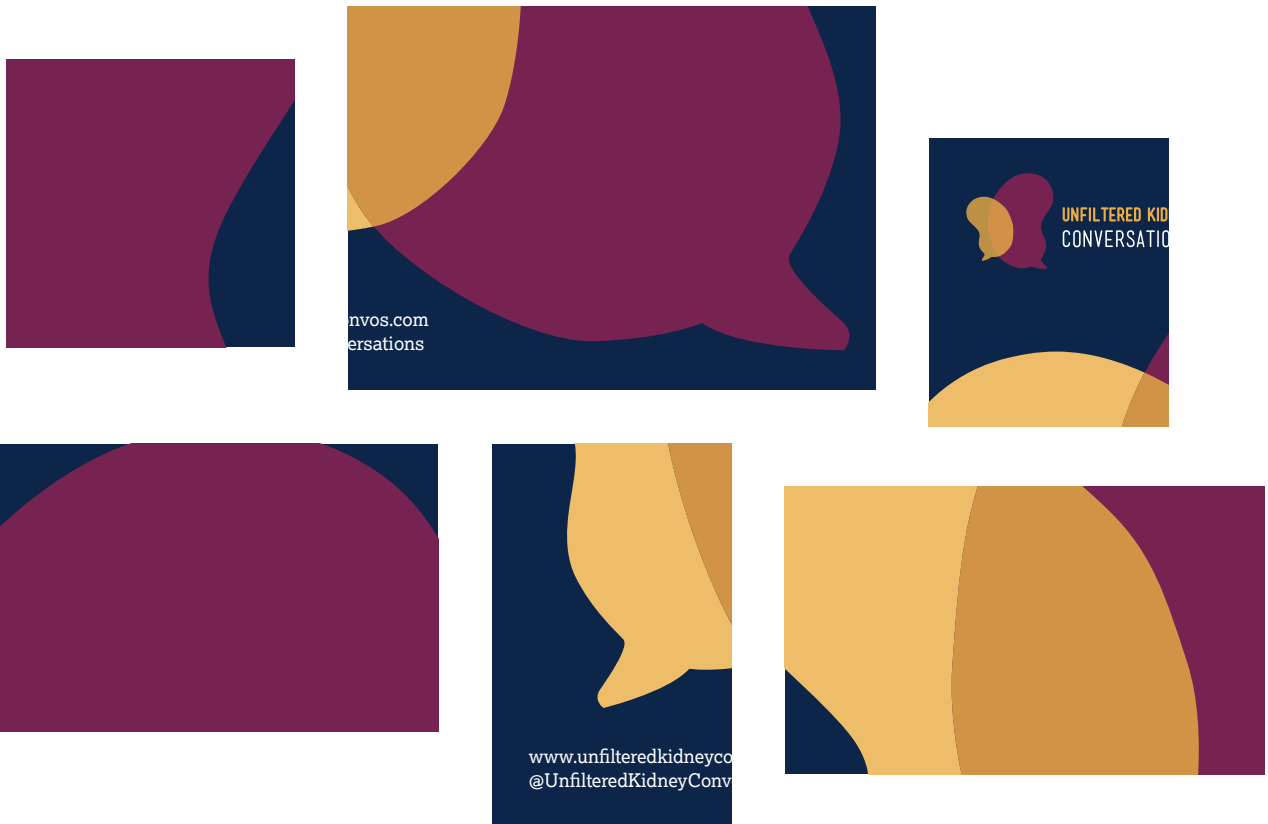
Hyperkalemia (HK), also known as high potassium, is when the blood has higher than normal potassium levels. People living with chronic kidney disease (CKD) face a higher risk of HK because their kidneys can't remove excess potassium in their blood. Even if your blood test results are 'normal,' continue to ask your doctor about your potassium levels and regular monitoring if you are at an increased risk of HK.

To help you ask the right questions at your next doctor visit, cut out the above questions about HK and take them with you!

Solve the Puzzle

Knowledge is power when it comes to living with chronic kidney disease (CKD) and hyperkalemia (HK). Finding a community of fellow CKD warriors can also provide inspiration and support.

Cut out the squares and connect the puzzle to find out where you can join a community that seeks to help inspire everyone affected by CKD and HK, whether you're living with it or supporting someone you love.



Join Unfiltered Kidney Conversations by visiting www.unfilteredkidneyconversations.com or scanning the QR code. You can also join our Facebook community @UnfilteredKidneyConversations

A DASH of CREATIVITY

2nd Place Winning Essay, 21st Annual Essay Contest
by Willi Fuller

Web ID 5081

For the fifth time that day, mired in hopelessness, I stood in front of my refrigerator and stared at its contents. I wanted my old life back, before chronic kidney disease and its challenging restrictions had shut me down.

Perhaps inside I would find a secret portal to a magical realm where I could savor my favorite dishes on command without consequences. In search of that mystical land, I opened and closed the fridge door so often my face should have suffered from freezer burn.

After the unexpected diagnosis, denial, anger, bargaining, depression, and acceptance were my constant companions. Elisabeth Kübler-

Ross's seven stages of death and dying were the go-to reactions to the reality of living with a chronic illness. My entire existence had changed at once, without warning or permission, and the self-pity I

experienced was overwhelming. I lingered at the angry stage for a year or more with little interest in learning to cope with the disease.

My pantry was now a tomb as I looked at the fully stocked shelves, convinced those foods would never grace my plate again. Each aisle

of my local market induced bouts of depression as I searched labels for acceptable levels of phosphorus and sodium. Monitoring my protein intake was easy because I had never

been a huge meat eater, but carbs? Oh, boy. Every piece of bread I ever encountered was the beginning of a passionate relationship. Any type, you name it—whole wheat, white, rye, ciabatta, croutons, or Panko crumbs used to batter shrimp. My spicy minestrone cried out for its usual partner, an enormous square of even spicier jalapeño cornbread or fluffy biscuits. So I, along with a few million others in 2021, learned to bake healthy loaves during the pandemic. They were delicious—moist, chewy, bursting with oatmeal, moderate amounts of salt, no sugar, and tinged with desperation.

My love affair with carbs started young. I grew up in a struggling African American home in the 1950s as the sixth child of seven. Carbohydrates were a staple of every meal. Dinner often consisted of chili packed with beans, spaghetti (sometimes combined with yesterday's chili), and endless pots of bean soup. The texture and smell of these dishes reminded me of a time of unimagined opportunities. Losing these specific foods was tragic and limiting as I continued to cycle between Kübler-Ross's five stages.

Several months passed before the deep melancholy squeezing me in its grip forced me to take action. I did what I had always done, which was to meet tough times head-on. I had refused to accept this health issue

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Willi Fuller is an almost-retired college English professor who writes fiction and non-fiction. She has an MFA in Creative Writing from Mills College and lives in Northern California with her spouse where

she has mastered the art of layering clothing to accommodate the always changing microclimates. She owes a debt to her first-grade teacher, Miss Wagner, who encouraged her to keep writing against all odds. Over the years, Willi has published several short pieces and is presently working on her debut novel.



“
EVERY PIECE OF
BREAD I EVER
ENCOUNTERED
WAS THE
BEGINNING OF
A PASSIONATE
RELATIONSHIP.”



MIND GAMES

3rd Place Winning Essay,
21st Annual Essay Contest
by Bill Naifeh

Web Id 5082

I am a baker. I usually work out of the left side of my brain. I am very methodical and list-oriented. I do everything with precise weights, measures, and temperatures. Occasionally, however, the creative right side of my brain takes command. This is what happened when I found out that I was in kidney failure. I had to be creative to tackle what was in front of me. In true “baker” fashion, I sat down and made myself a list:

- 1) I needed to cook with less salt.
- 2) I had a drinking problem.
- 3) I needed to exercise more.

I was using too much salt. The first thing I did was remove the salt shaker from my kitchen table. I figured if it was not there, I would not be tempted to use it. I started using over-the-counter salt-free seasoning. I rediscovered fresh herbs and spices.

I found that turmeric would kiss my food with an exotic flavor and a beautiful yellow tint. Fresh mint and basil would turn any dish into a cool summer evening with a bright whimsical flavor. I discovered that sage doesn't have to be used just once a year at Thanksgiving. It tastes great

**I had to learn to rely on
creative thinking to make
the dialysis experience
successful for me.**

in a fresh salad! I was really enjoying using the creative right side of my brain. It was like I was back in cooking school developing new recipes. However, I was really going to have to task my right brain if I was going to conquer my drinking problem.

You see, I was drinking over a gallon of water a day! I had a half gallon

thermos sitting on my counter and I filled it up at least twice a day with ice water. The first thing I did was get rid of the thermos. I purchased packages of sugar-free drink mix that I could put in a 16-ounce water bottle and refrigerate. Whenever I was thirsty, I'd take a small drink from my bottle of flavored water. When it was empty, I was done for the day. I also purchased fresh fruit, such as strawberries, grapes, peaches, and pineapple. I cut the fruit into bite-size pieces and froze them on a sheet pan. When I was thirsty, I would get a small bowl of frozen fruit. Another trick I use is to have a dish of sugar-free hard candy on the table. I found that sucking on the candy would quench my thirst. The frozen fruit and sugar-free candy have an additional benefit: my grandchildren love them.

I have never really liked to exercise. I worked long hours in the bakery and when I got home, I was tired. There was not much in me that wanted more physical exertion. I did know that the dietitian, nurses, and nephrologist thought exercising would help me with dialysis. That's when I discovered I could create my own playlist from a streaming service. I put fast-paced songs that I like to listen to on my playlist, and when I cue it up I just start moving. I listen when I am out walking on the street or lifting weights in the gym or just riding my stationary bike. That playlist helps me achieve something I didn't think was possible—looking forward to exercise!

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Bill Naifeh was born in Tulsa, OK. Bill's journey with dialysis began in 2014. Bill met and married the love of his life, Helen, in 1976. In 1980, they opened a bakery/ deli in Kingfisher, Oklahoma and operated it for 16 years. After that, Bill taught Family and Consumer Science and Culinary Arts, then switched to working in the healthcare industry as a chef and dietary manager.



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/home-hemodialysis-experience Web ID 2023HHD



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FLIP THE SCRIPT

4th Place Winning Essay,
21st Annual Essay Contest
by TeeJay Riedl

Web ID: 5083

Let's flip the script. My kidney disease supports my creativity. We must begin with the simplest fact: In my life, I have people who love me, and I have people who might dislike me to a degree. But I am unaware of anyone who hates me, or would wish ill, or kidney disease, on me. Thus, when my nephrologist bid me to begin dialysis, I was not left standing dazed and confused, wondering "Why me, God?" Instead, I soberly assessed the scenario, and considered what I was going to do during the fifteen hours a week that I would be in the chair. I have been in the chair for about a year now—when not here, I am working diligently to remain on the transplant list. The clinic has a nice deployment of individual TVs, but I don't watch them. My stance on TV would fill a separate essay.

I considered my blessings: I am, by nature, a fairly creative guy, and I enjoy my own company. One of my life's ambitions is to get better at playing guitar. At the dialysis clinic, that would not be possible; my playing would disrupt or annoy my

“THE PROCESS OF
CREATION IMMEASURABLY
HELPS MY SELF-ESTEEM
AND SENSE OF WORTH”

fellow patients. Worse, what if they hated "Free Bird"? I investigated silent guitars and headphones, and then realized that the tubes snaking

betwixt my stent and the Slurpee Machine would get in the way of my fretting hand. And even then, I reasoned that the plinking of silent strings would still annoy my dialysis brethren. So, my dialysis entertainment would need to be constrained to something that would not disrupt the clinic, and that could be supported while in the confinement of the chair.

But the answer came to me fairly quickly. I've always toyed with the idea of writing a science fiction book (and had actually started writing, pre-kidney disease), but had given up the idea when "real life" threw too many interruptions in my path. But now? Who was going to interrupt me while sitting in the chair? My work would require nothing but a laptop, and the occasional notebook close at hand. And, after I began dialysis, the effect was like night and day: my head simply "worked better" when all the toxins had been cleared from my blood. My thinking was faster and more acute.

I set-to with a jolly determination. To write a credible book would require (what turned out to be) some nontrivial research. I had almost limitless time to construct the details I'd need. The clinic's Wi-Fi helped me a lot as I collected data

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TeeJay has been on dialysis for one year, and is awaiting a donor kidney. Beyond his engineering day job, TeeJay is a musician, aspiring author, and dog lover. His first book—on home studio sciences and techniques—was followed by his first fiction work, written largely during his dialysis sessions. He is currently working on his second novel. TeeJay is the "provider pet" to two loving rescue dogs, and his supportive bride, Juli.



Birdhouse Blessings

President's Pick Winning Essay,
21st Annual Essay Contest by Cayla Kim

Web ID: 5084

In 2022, I got very sick, and my mom told me I almost died. I spent five months in the hospital at UCLA Mattel with several infections. My kidneys stopped working and I had to go on dialysis. Being on dialysis was so hard, and I got very sad. I already have many serious medical conditions affecting almost all of my organs, but I never had problems with my kidneys before.

After I got out of the hospital, my parents drove me three hours round-trip to the dialysis center and

hospital four times a week. I was very tired, and my stomach hurt so much. I could no longer walk, so even getting in the dialysis chair was

a big challenge. I also had a giant wound on my sacrum with a wound vacuum attached, and this also hurt when we drove. And my oxygen tanks were heavy. Life was hard but I found happiness in some of the other teens I met at the dialysis center, like Giovanna and a cute boy named Nikko. The nurses also made me laugh. For example, my nurse Mark dressed up like Elvis and sang

songs on the ukulele during Halloween. And my doctor, Dr. Salusky, dressed up like a platypus. Everyone was so nice.

Unfortunately, due to my wound and bleeding disorder, it got too hard to travel. Mom told me last January that she was going to learn to do

“I decided to create my own birdhouse business and share my talents with other people, while also funding my art habit!”

dialysis at home and we would not be coming to the center anymore.

I loved doing dialysis at home because I could watch TV in my PJs! But I got very lonely and bored. I tried to continue my schooling online via Zoom, but I would fall asleep. I do not have many friends, and my brother left home for college. Mom decided to buy me a lot of art supplies and I tried to think about what to make while I was on dialysis. One of the things I loved before I got so sick was to watch the birds in my backyard. We had many hummingbirds that would zip around, and even fight over food. They were so funny and colorful. I decided to make wooden birdhouses so they would have a place to sleep and hide from predators. We put them in a big oak tree, and they looked beautiful. I felt very proud, but my art supplies were very expensive. So, I decided to create my own birdhouse business and share my talents with other people, while also funding my art habit! First, I borrowed money from Mom to buy all my supplies. I went to Michaels and purchased the birdhouses too. Then, I decided to market my business by making flyers and letting family and teachers know about my business. I set up a new email account and it was fun to email all the people I knew. My houses are very colorful; I often use

Continued on page 22

Cayla Kim lives in Los Angeles County with her family. She loves to draw, write stories, engage in arts and crafts, and listen to all kinds of music. Cayla's favorite animal is the killer whale and she

hopes to one day travel to see them in the wild. Cayla also loves visiting all the delicious restaurants in her city. When she is feeling well, she sports a big smile and laughs a lot. Cayla hopes to become a night nurse someday.



Champions Of Kidney Care



The goal of RSN's Kidney Care Champions is to educate elected officials about the issues that have an impact on people living with kidney disease, are on dialysis or have a kidney transplant. That's where you come in. YOU can make a difference by getting involved and cultivating a relationship with your own representatives, sharing your experience and knowledge directly to those who are in a position to influence change. We'll give you all the information and tools you need.

Members of Congress (United States senators and representatives) make time for meetings with constituents as part of their duties as elected officials. Face-to-face meetings are one of the most powerful ways to advocate for kidney-related policies, as a meeting makes you and your issue more memorable to legislators. The good news is you can use Zoom!

It is important to know that the staff who work for members of Congress are very important, too. Whether you meet directly with your senator or representative or with their staff person, you are taking an important step by building a relationship with them. This makes them much more likely to pay attention when you call or email about a specific issue in the future. Sign up to get started today at rsnhope.org/advocacy.

Why Should You Advocate for 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

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

The Living Donor Protection Act will promote and protect living organ donation. This bill will prohibit discrimination of living organ donors by employers, life insurance providers, disability and long-term care insurance carriers.

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

Passing this Act will be a significant step toward improving care for people who have kidney disease. This bill will expand kidney disease awareness and education, incentivize innovation and secure ability to have access to Medigap insurance for all people who have ESRD.

Take action! Learn more about these bills, new legislation and regulatory opportunities and make your voice heard at 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

The Great Escape: How Creativity Reduces Stress

Continued from page 3

I love looking at Pinterest for creative ideas, and pin away. Creativity is endless. I belong to several creative Facebook groups and subscribe to several artists on YouTube channels. If you consistently follow a group, it facilitates the formation of social connections through opportunities to share experiences, learn from others, and receive support for your creative endeavors. It is important to note that creativity is not limited to certain individuals or professions. It is a skill which can be developed and nurtured through practice, curiosity, and open-mindedness.

I like to invite my friends over and we can play with a pile of creative supplies and munch on potluck snacks and chit chat for hours. It's the best therapy for my soul. I encourage you to do the same and engage in your creativity.

There are several places where you can find creative ideas:

1. **Pinterest:** Pinterest is a great platform for discovering and saving creative ideas. You can search for specific keywords or browse through various categories to find inspiration.
2. **YouTube:** YouTube offers a vast array of videos with creative content. You can subscribe to channels that focus on creativity or search for specific topics to gather ideas.
3. **Facebook Groups:** Joining Facebook groups centered around creative topics can connect you with like-minded individuals who share their ideas and projects. These groups often have engaged communities that provide valuable insights and inspiration.

Landscaping, Gardening and Flowers Everywhere

Continued from page 12

and shoveling massive quantities of ice for days and days. As I push the shovel and lean forward into the pile of rocks or dirt, my arms and back feel as smooth as yoga moves. Then I lift, using my fistula arm only to brace the handle of the shovel on my thigh. The burn on the bicep of my good arm sings. I feel alive for a moment like I used to, shadows of my healthy self dance in the sun.

I am planning on having a pond in by Christmas (I will wait for warm weather to fill it) and lay some patio/walkway slabs down. Then I will buy a firepit on legs with a screen and grill. I need to patch and paint some of the stucco walls where stucco was put over cinder block. I think some kind of turquoise or other bright color will work. Perhaps I will plant agave near one of the walls, along with autumn sage, which blooms in purple, pink, or violet colors all summer long, and more lavender. When I walk my dogs, I see a large amount of lavender in yards in this neighborhood of 1950s homes. There are so many creative folks in my neighborhood with colorful yards. My neighbors inspire me.

As my future becomes opaque, then clear, then cloudy, then dark, then stormy, and then sunshine, my shovel, wheelbarrow, and pueblo red dirt keep me from fluttering away from life, like a frenetic hummingbird dashing around. I arrange and rearrange and discover new patterns and colors I can use to create my refuge from the world and kidney disease. I am grateful, alive, and trying to live somewhere over the rainbow.

Renal Support Network's

25th Annual
PROM NIGHT

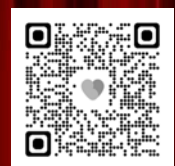


SUNDAY
JAN. 14, 2024
6:00 PM

At Stars On Brand
in Glendale, CA
with Virtual
Option available.

Dinner,
Dancing,
Entertainment

All young people who have kidney disease and one guest are invited at no charge.



Sign up to attend at
RSNhope.org/Prom.

A Dash of Creativity **Continued from page 15**

long enough. Negativity had drained my spirit, and now I sought ways to apply my creativity to my medical condition. I treated it like a project and read articles, attended online meetings, and purchased a gazillion recipe books geared toward people who suffer from CKD. I revisited the practice of yoga, which was important to me years ago. A regular meditation routine helped me release resentment and accept my health status. I explored other types of products that could be substituted for pasta. Some tasted good, but a few reminded me of the flour paste used for grade school projects.

Inspired by the need to devour pasta, the search for a tasty tomato-free sauce began. Bruschetta, which was made from artichoke hearts and roasted red peppers, emerged as the clear winner, and it delighted me. I had regained access to my favorite carb, which inspired me to perform more experimentation. The new methods and unusual spices I tried when cooking unfamiliar vegetables and fruits helped to renew my creative spirit as I continued to seek options to live a fuller life with kidney disease.

I began this journey devastated by my diagnosis, positive that anger and hunger would be lifelong companions. Now, I focus on adjusting my attitude and deciding which actions will allow me to be the best person for this journey. Each time I recreate a childhood dish using the techniques and tips I have learned since my diagnosis, I get excited. Thanks to my collection of vegan, vegetarian, and low-potassium cookbooks, home cooking is my new normal. I wake up each morning in anticipation of how to make this a better day for me and my family. Managing my kidney disease may never be easy, but with dashes of creativity, my life has become lighter, more manageable, and definitely tastier.

Mind Games **Continued from page 16**

When I first looked at that dialysis mountain, I didn't think there was any way I could get over it. It wasn't until I unleashed the right side of my brain and let it create new pathways for me to follow, that I was able to conquer it. By learning new ways of cooking with less salt, drinking less water, and exercising more, I am able to make my time in the dialysis chair much more pleasant and efficient.

In the fall, I will begin my tenth year of dialysis. This is something I am very proud of. Being a left-brained person, the process of dialysis was all very natural to me. But, I had to learn to rely on creative thinking to make the dialysis experience successful for me. I look forward to creatively meeting any further challenges that dialysis might bring my way.

Flip the Script **Continued from page 18**

and honed my plot. When I finally started drafting the manuscript, the heated chair became one of my preferred places to write, with my noise-cancelling headphones drowning out the beeping of the Slurpee Machines. A year later, I have a 120,000-word novel, which I am currently editing for publication. I began planning two sequels, plus I had an idea for a fourth book.

The above might make me seem like some creative fiend. Trust me, I am not. For those who would attempt to do the same, let me offer some advice: Be kind to yourself. There have been days at dialysis when I have just plopped myself in the chair and slept, or trolled Facebook, or read a book. I have never assigned myself a fixed goal or target, like all the "how to write a novel" books demand. When I feel like writing, I write. Sometimes that has been my

novel, sometimes song lyrics, and sometimes essays. I'm in the chair as I write this. In retrospect, my disease has afforded me the goal of realizing a life's ambition, and the process of creation immeasurably helps my self-esteem and sense of worth. God dealt me a rough hand; I'm playing it to the best of my ability.

And don't tell anyone, but I've dedicated the book to my nephrologist. If he hadn't sent me to dialysis, my toxin-dulled brain would never have been able to write it.

Birdhouse Blessings **Continued from page 19**

pinks, purples, and oranges. I also use iridescent colors because they remind me of hummingbird feathers.

Making birdhouses while I am doing dialysis, and having my own business using my creativity, makes me feel good. I am doing something productive, and I have made \$800! I can't go to school, but a lot of my old teachers have ordered birdhouses so I was even able to see them again. I am able to text or email people who are buying birdhouses from me. I am able to have social interactions with people outside of my family. I have a lot of pain in my stomach, butt, and in the bones of my feet, but concentrating on making beautiful birdhouses distracts me from that pain. Finally, people are always helping me. Making birdhouses allows me to do something for others. I can bless them with my birdhouses instead of being the one in need. People's faces light up when they receive my birdhouses. Without facing the trial of dialysis, I doubt I would ever have thought to launch "Cayla's Birdhouses." I'm so proud of using my creative talents to bless others, and to have a new job!



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, Google Play, and iHeart Radio by searching for "KidneyTalk."



Kristin Larson MSN, RN,
AGNP-BC, CNN *Web ID 3115*



Learn why itching often accompanies kidney disease.



Dr. Meredith Stensland
Web ID 3106



Learn the advantages of pet therapy in dialysis centers.



Patricia Kelmar
Web ID 3119



Learn steps you can take to protect yourself from unexpected medical bills.

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 at RSNhope.org. *Web ID SYS22*



KIDNEY TRANSPLANT DASHBOARD



This tool will help you see at a glance national and state statistics. 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*



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 that will guide you toward your destination: holding your first peer support group meeting. The training videos will guide you through each step of the process to make sure you feel prepared to host your first meeting.



**Sign Up Here to
Be Notified When
the Course is Live.
[RSNhope.org/
support-group-
masterclass](https://rsnhope.org/support-group-masterclass)**

COOKING FOR YOUR KIDNEY HEALTH



INTRODUCING RSN'S NEW ONLINE NUTRITION INFORMATION TOOL FOR THE KIDNEY DIET

Knowledge is power! RSN's Nutritional Information Database is a great resource for people who have chronic kidney disease, are on dialysis, or have a kidney transplant. This list is for people who like to prepare their own food from raw ingredients found at the grocery store. 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. This list does not include prepackaged or restaurant food. Prepackaged and restaurant food is always higher in sodium and phosphorus, which is a preservative. Always check with your renal dietitian before making any changes to your recommended diet.

rsnhope.org/nutrition-data-information-for-the-kidney-diet



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.



RELAX WITH AMBIENT SOUNDS

We know kidney disease is 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

SAVE THE DATE

**25th Annual Renal Teen Prom
Sunday, January 14, 2024**

*All youth who have
kidney disease ages 14-24
are cordially invited.*

See page 21 and RSNhope.org for details

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 Himber. Watch and share the videos to help raise awareness of the need for the gift of life!



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.

SUPPORT YOUR KIDNEY KIN COMMUNITY

The Renal Support Network relies on charitable contributions to fulfill our mission to make a lasting and positive difference in the lives of people who have kidney disease. Every penny you give will go directly to work in our numerous, life-enriching programs.



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.



Contribute to RSN Online or see our contact information on the back cover.

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

Renal Support Network's

You Make a Difference

Lapel Pin Gift Collection

Choose from any of our 19 designs. See the entire collection online.



Message Option 1:
Hummingbirds, like you, are seen as healers and bringers of love, hope and joy.

Message Option 2:
Hummingbirds, like you, are seen as healers and bringers of love, hope and joy. Keep up the great work.



Message Option 1:
You are my sunshine. You give me hope and make me feel at peace.

Message Option 2:
You shine as bright as a sunflower. You bring positivity and warmth into the workplace and your contributions stand out every day.



Message Option 1:
I'll never forget the amazing care, patience and hope you provided me.

Message Option 2:
I'll never forget your wisdom, empathy and leadership.



Message Option 1:
You are an extraordinary healthcare professional. Thank you for all you have done to help me get my sparkle back!

Message Option 2:
You possess the remarkable ability to listen, observe, and understand. Your dedication is the heartbeat of the team.

Our lapel pins are a meaningful gift to give to your favorite healthcare professional, caregiver, friend or coworker. Let them know how grateful you are for all the times they have provided you with loving care, support and hope.

Each lapel pin comes with two mini greeting cards each with "from a patient" or "from a healthcare coworker" messages. Donate \$15 at RSNhope.org/Pins or scan the QR code with your smartphone. Then choose your favorite design to make someone's day.



TREAT YOURSELF, A KIDNEY DONOR, OR A KIDNEY WARRIOR YOU LOVE



Kidney Warrior Collection

Send something special to a kidney warrior, a living kidney donor, or to a donor's family as a symbol that their selfless decision to give the gift of life will never be forgotten. All sales benefit the Renal Support Network's life-enriching programs. Web ID SHOP01



Pavé Kidney Jewelry Collection



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Service to those affected by chronic kidney disease

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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.

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9 AM-5 PM Pacific Time
Monday-Friday

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

