KidneyTalk®

Spring/Summer 2021

by Renal Support Network

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

REDEFINING YOURSELF AFTER A KIDNEY TRANSPLANT

And Choosing Happiness!

YOU HAVE KIDNEY DISEASE, SO NOW WHAT?

EAT THIS, NOT THAT

EXER-WHAT???

Life Before and After RSN's Exercise Program

TUNE IN TO ME, PLEASE

CHOOSING COLORS FOR CARE

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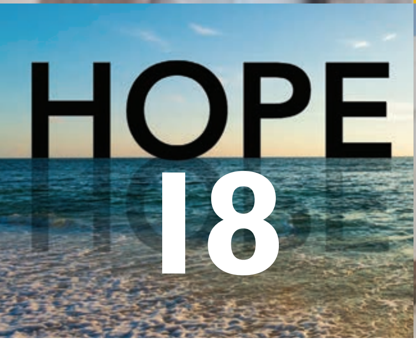

KidneyTalk® Magazine (formerly Live&Give) is a program of Renal Support Network (RSN). The magazine's articles are written by people who have kidney disease and by healthcare professionals. Those with kidney disease share their knowledge and experiences about living a full life in spite of their disease. KidneyTalk™ Magazine subscriptions are offered at no charge to people who have kidney disease and their families. Join RSN at RSNhope.org to subscribe.

Renal Support Network
RSNhope.org

Web ID: 4038

Tune In to Me, Please!

By Lori Hartwell

When I meet a new healthcare provider, I put them in one of two categories.

One category is for the providers who have a set list of questions that suit their own needs. They go with their own tune. When I ask a question, disagree, or want to discuss a different treatment option the healthcare provider is not aware of, the provider reacts with surprise or shock. These providers may sing the song of health care, but they don't know my melody.

The other category is the health care provider that is interested in my specific melody. What is important to me? Studies show over and over again that empowered patients live longer. This type of healthcare professional recognizes the importance of patient engagement and values my input by using open-ended questions to gather information. These healthcare providers try to get in tune with me so we can harmonize.

I have lived with kidney disease since the age of two. I have learned the best ways to support my inner instincts and needs, and I respect the lifelong knowledge I have gained of my body and the melody that keeps it thriving. What beat makes me dance?

Take, for example, the home nurse and nurse-in-training who came to help with an infusion of my IV antibiotic. As they bumbled a bit with supplies, I carefully watched every move they made to be sure they observed infection precautions.

I mentioned I needed to call the doctor about a medication missing from my list to ensure it was not a mistake. When they looked at my discharge papers and said the medication was not listed, I told them that did not mean the list was correct. I reminded them that medical errors happen all the time, which is why I check everything and wanted them to verify the list with the doctor. I mentioned I have prevented serious harm to myself on many occasions by catching mistakes.

The nurse asked me if they transplanted my left kidney or the right one. I replied that both of my kidneys were removed when I was 13, and my latest kidney is right smack dab in the middle of my body. She went on to ask why I was not on Medicare since I had a kidney transplant. I explained how Medicare health coverage applies only during the first 36 months after a transplant after which I had to apply for private health insurance.

As the nurse began to prime the lines for my IV, saline sprayed all over my iPad. Luckily, I had paper towels

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Lori Hartwell is the Founder and President of Renal Support Network (RSN) and the host of KidneyTalk™ Podcast Radio. Lori was diagnosed with kidney disease at the age of two. In 1993 she founded RSN to instill "health, happiness and hope" into the lives of those affected by chronic kidney disease. Lori is also the author of the inspirational book Chronically Happy: Joyful Living in Spite of Chronic Illness *and is a four-time kidney transplant recipient.*

YOU HAVE KIDNEY DISEASE, SO NOW WHAT?

kidney disease treatment options

A Q&A with Michael Kraus, MD, Associate Chief Medical Officer at Fresenius Kidney Care

You have kidney disease, so now what? More than 37 million people are living with Chronic Kidney Disease in the United States, but what does that mean? When do you need treatment? What does treatment entail? Michael Kraus, M.D. and Associate Chief Medical Officer at Fresenius Kidney Care, breaks down the basics on kidney disease treatment.

Q: What is kidney disease, and when does someone need kidney care treatment?

MK: Chronic kidney disease (CKD) occurs when your kidneys don't work as well as they should to filter waste, toxins, and excess fluids from your body. Kidney disease progresses in five stages and may lead to end stage renal disease (ESRD) or kidney failure. When you are approaching kidney failure and have not had a preemptive kidney transplant, it is time to look into dialysis options for treating kidney disease. Your doctor will help you navigate this process.

Q: What are options for a patient when they first require kidney care?

MK: First, let me say that for many patients, receiving a working kidney through transplantation is the preferred treatment. The best option, if it is possible in your situation, is to receive a transplant before ever needing dialysis. This is called a preemptive transplant. Discuss with your dialysis team and doctor what steps to take to be eligible for a transplant.

Dialysis essentially takes the place of kidney function, filtering the blood and ridding the body of unwanted toxins, waste products, and excess fluids. Most dialysis centers offer the option of receiving dialysis treatments either in-center or in your own home.

Q: What is in-center hemodialysis and how does it work?

MK: Hemodialysis (HD) is a treatment for kidney failure that occurs when a patient reaches ESRD. During the dialysis process of HD, some of your blood exits your body and is filtered through a dialyzer or "artificial kidney" to remove unwanted waste, toxins, and excess fluids. The filtered blood is then returned to your bloodstream. In-center dialysis treatment takes place in a kidney dialysis center, under the close supervision of a care team.

More than 37 million people are living with Chronic Kidney Disease in the United States, but what does that mean? When do you need treatment? What does treatment entail?

In-center dialysis is a safe and well-delivered therapy that allows people to receive care on a set schedule. With in-center dialysis, you'll typically go to a kidney dialysis center three times per week for about 3-5 hours each visit, depending on your prescription. You'll be connected to the dialysis machine via your hemodialysis access. Members of your care team will supervise your entire treatment and look after you throughout your appointment.

Q: What is home dialysis?

MK: Home dialysis allows you to perform your dialysis treatments by yourself or with the support of a care partner in the comfort of your own home, rather than at a center. It is an increasingly popular option for many people with kidney failure. It allows for more flexibility and other benefits which can improve quality of life, including treatments at night or more frequent treatments, consistent with your physician's dialysis prescription. The two options for home dialysis are peritoneal dialysis (PD) and home hemodialysis (HHD), both of which allow you to perform dialysis in your own home.

Q: What is peritoneal dialysis (PD) and what are the benefits?

MK: PD is a treatment for kidney failure that uses blood vessels in the lining of your abdomen—the peritoneum—to naturally filter waste from your blood. During PD, a cleansing solution called dialysate is sent through a catheter to your peritoneal (abdominal) cavity, where it absorbs waste and toxins from blood vessels in the peritoneum and is then drained back out and discarded.

PD is typically done at home or in any other clean, enclosed environment. PD treatments are done more frequently, so waste and toxins in your blood don't have a chance to build up as much between treatments.

There are two types of peritoneal dialysis—continuous ambulatory peritoneal dialysis (CAPD) and automated peritoneal dialysis (APD), also known as continuous cycling peritoneal dialysis (CCPD). CAPD is done manually, which can be a benefit when faced with an emergency like a natural disaster or power outage. APD, or CCPD, uses a machine to perform each exchange.

Q: What is home hemodialysis?

MK: Home hemodialysis (HHD) is the same as in-center hemodialysis, except it is performed in your home by yourself, or with the support of a care partner, and uses simpler devices. Depending on your prescription, you can dialyze approximately 2.5 to 3 hours each day and perform more frequent treatments. You can also do HHD for 6-7 hours while sleeping, referred to as nocturnal hemodialysis.

Q: What are the benefits to home dialysis?

MK: Home dialysis allows for a flexible schedule and gives you the freedom to travel. Many people report feeling better, since when dialysis is done more frequently than three times a week, it more closely mimics the normally continuous function of your kidney. Dialyzing at home can also eliminate the transportation challenges of receiving treatments on a set schedule. You may experience more leniency in your diet since you are removing wastes and toxins from your body more often.

Michael Kraus, MD, is Associate Chief Medical Officer at Fresenius Kidney Care focusing on home therapies. He held a similar role with NxStage Medical Inc. before Fresenius Medical Care completed the acquisition of the company in 2019. He is the former Service Line Chief for IU Health Physicians Kidney Diseases and Clinical Chief of Nephrology at Indiana University School of Medicine.

Renal Support Network's

HOPEline

Peer Support Hotline

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.

Call (800)579-1970

Web ID: 4040

KIDNEY DONOR OPTIONS

By Rafael Villicana, MD

Once you and your doctor decide that a kidney transplant is the best treatment choice for you, several options are available. Kidneys used for transplant come from two general sources: living donors and deceased donors. To help you make an informed decision about the most appropriate option for you, the transplant team will evaluate your needs and medical history. They will also evaluate the potential living kidney donor or place your name on the deceased donor list.

Things to Consider

It is important to consider the health risks of long-term dialysis while you are waiting for a kidney transplant. Some people spend years waiting for a kidney to become available. Studies have shown that a kidney transplant is the best option for long term survival.

Ideally, a kidney from a living donor has the best outcome. If a living donor is not available, a kidney from a deceased donor may be an option. There can be a greater risk involved in receiving a deceased donor kidney than in receiving a living donor kidney. However, for many patients, a transplant improves their health even when they receive a less-than-ideal kidney. Except in rare cases, a transplant is superior to remaining on dialysis since dialysis can never fully replace all the functions of a working kidney.

Living Donor Transplants

If you know someone who wishes to donate a kidney to you, donor compatibility could be an issue, especially if you have a different blood type. Even if you have the same blood type, the kidney could still be incompatible due to many other factors. Paired kidney exchange can be arranged to overcome this barrier.
In general, it's best to accept a kidney from the most compatible living donor. If the donor has a better immune match it can lead to longer term kidney transplant success. If an exchange is not possible, treatment options exist that can decrease the risk of rejection of a donated kidney. For instance, desensitization is a treatment that removes antibodies from the blood, decreasing the risk of immediate rejection of the donor kidney.

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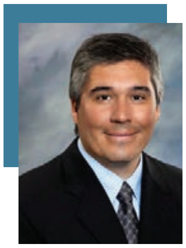

Rafeal Villicana, MD *is a transplant nephrologist and the medical director of the kidney transplant program at Loma Linda University (LLU) Transplantation Institute. His interests include kidney and pancreas transplantation, living kidney donation, and ABO /HLA incompatible kidney transplantation.*

Web ID: 4041

EAT THIS NOT THAT

By Lubna Akbany, RD

As someone who has chronic kidney disease (CKD) and is also a renal dietitian, I know that choosing foods that are good for me is critical. Every day we are bombarded with yummy commercials and temptations galore. But when you have kidney disease you have to be very careful about what you put into your body and make the right choices for your kidney health.

The kidney diet is very diverse. Protein, for example, is a very important element for our bodies. However, different stages of kidney disease have specific protein intake requirements. People in early stages might need to reduce protein to help maintain kidney function. People on dialysis may need more protein.

People on dialysis also must restrict their fluid intake. Those who have a kidney transplant must watch out for foods that counteract anti-rejection medication. Some people may need to increase potassium while others must restrict potassium, and possibly take potassium binders.

Steps to Eating Right

Step 1: Choose and prepare foods with less salt and sodium.

Why? To help control blood pressure.

According to the American Heart Association, the ideal amount of sodium should be no more than 1,500 mg per day for most adults, especially for those with high blood pressure. Cooking from scratch and avoiding prepackaged food will help you manage your daily sodium intake as will using spices and herbs instead of salt. Read the ingredient labels carefully as salt substitutes can be high in potassium.

Step 2: Eat the right amount and the right types of protein.

Why? To reduce stress on the kidneys and preserve kidney function.

As your body absorbs protein it is converted to waste, which your kidney must filter out of your system. In people who have CKD, the kidneys are not able to remove all of the excess waste. To avoid this problem, eat small portions of protein foods. Your dietitian will work with you to help you choose the correct amount and the type of protein you need in your diet.

Animal-protein foods include chicken, fish, beef, pork, eggs, and dairy. A cooked portion of chicken, fish, beef, or pork is about 2 to 3 ounces or about the size of a deck of cards. A portion of dairy foods is ½ cup of milk or yogurt, or one slice of cheese.

Plant-protein foods include beans, nuts, and grains. A portion of cooked beans is about ½ cup, and a portion of nuts is ¼ cup. A portion of bread is a single slice, and a portion of cooked rice or cooked noodles is ½ cup.

Step 3: Choose foods that are healthy for your heart.

Why? To minimize blockages from forming in your blood vessels, heart, and kidneys.

To limit saturated and trans fats, avoid deep frying and cooking in butter. Check labels for "trans fats" or "partially hydrogenated oils" to be sure you are choosing the best oils for cooking.

Step 4: Choose foods and drinks with less phosphorus.

Why? To maintain cardiovascular and bone health.

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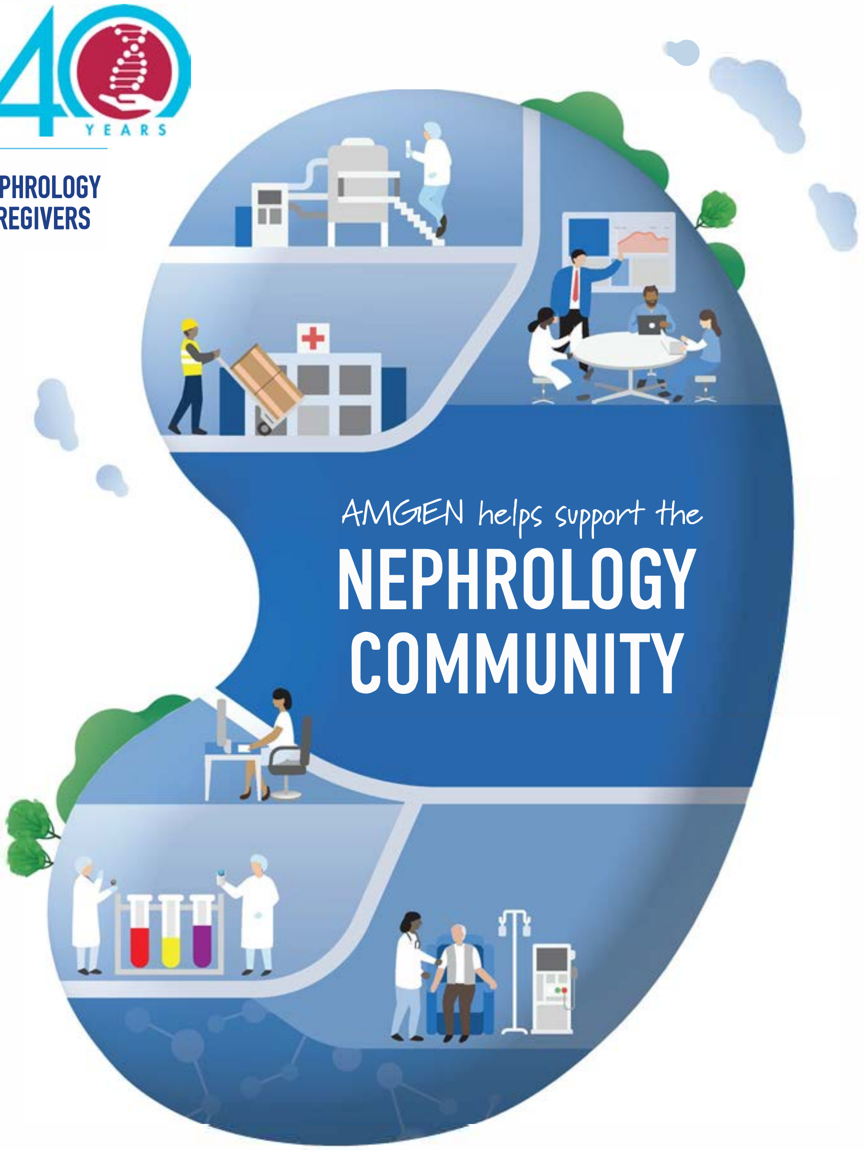
***Lubna Akbany, RD, CSR,** is a registered dietitian nutritionist and certified specialist in renal nutrition with over 20 years' experience. She specializes in chronic kidney disease (CKD) management and diabetes with a focus on CKD nutrition. She is a mom, a patient, and an effective nutrition communicator who loves cooking and eating delicious food with friends and family.*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LIFE / WORK CHOICES

To work or not to work? Is that the question?

By Mary Beth Callahan, LCSW

Chronic kidney disease (CKD) and end-stage renal disease (ESRD) bring lots of peaks and valleys into one's life. Fortunately, the Family Medical Leave Act (FMLA) not only protects family members. It also can protect your job when and if you must keep multiple doctor appointments or need to take off portions of a workday for dialysis. It also applies to if you need to take weeks off from work after a surgery, which might include a transplant.

An important step is to get short-term disability insurance if it is available through your employer. Sometimes short-term disability insurance is included in your benefit package, or sometimes it will be an added cost. Check to see if you can get it. Some people obtain it from a third party provider.

An illness could cause you to need more than just a few weeks off from work. Short-term disability usually lasts only three to six months. However, if you are not able to return to work by the end of the coverage period, you may qualify for Social Security Disability Insurance (SSDI) coverage based on not having earned income for five months since this five-month gap often sends people into bankruptcy. Medical evidence based on Social Security Administration (SSA) policy is still needed in order to claim any benefits.

Gaining employment and remaining employed have many good benefits. These include employer group health plans (EGHP), networking with peers, socialization, and keeping your mind and body active. Having a job to go to can also help fight against anxiety, depression, and sleeplessness. It also helps chronic illness seem like a smaller portion of your life since you have other things to occupy your mind. And earning extra money over time increases what the Social Security Administration (SSA) will pay if you eventually need SSDI.

The SSA also provides work incentives to those who have started receiving SSDI or Supplemental Security Income (SSI). It not only requires a medical disability; eligibility takes into account other household income and assets. SSDI does not. Therefore, SSA work incentives are different. Additional information can be found in the Red Book on the SSA website (www.ssa.gov).

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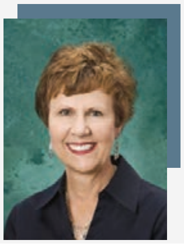

Mary Beth Callahan, ACSW, LCSW, APHSW-C *works with patients in all stages of chronic kidney disease (CKD). She has authored numerous articles and presented on a multitude of topics. She currently serves on the Board of the Society for Transplant Social Workers and is the past chair of the Council of Nephrology Social Workers. In 2015, she was the recipient of the NKF Council of Nephrology Social Workers Robert W. Whitlock Lifetime Achievement Award. Mary Beth continues to be an active contributor, member, and leader of numerous healthcare groups and committees related to the care of patients with CKD.*

What science can do

Chronic kidney disease
Chronic kidney disease is a progressive disease with no cure. At AstraZeneca, we are investigating ways to effectively manage life-threatening complications of chronic kidney disease, and ways to modify the progression of the disease itself.

Web ID: 4043

Exer–what???

Life Before and After RSN's Exercise Program

By Cheryl Moormann

"Eight, nine, ten… two more! Straighten that back, Ms. Cheryl!" These are the words of encouragement I hear Mondays through Thursdays each week through my computer speakers. In April of 2020, or just about the time the world shut down, I made a great discovery. And, day by day, it is changing me and improving my health.

Having fallen into a routine of baking and eating to fill my time and quiet my COVID-worried mind, I gained many pounds too quickly. I needed a new outlet. In scrolling through the programs offered by the Renal Support Network (RSN), I was intrigued by the 30-minute Zoom fitness classes with personal trainer Edina Tanacs. I signed up for the virtual exercise class and actually showed up for the first one! I have been a regular exercise 'Zoomer' ever since!

In 2018, after my second kidney transplant, I was finding it difficult to manage my weight. Because of my gratitude for my gift of life, I wanted to maintain my health by living a healthy lifestyle. I am blessed with normal kidney function for the second time because of my living kidney donor. She is a loving friend and a personal trainer. At the time of my transplant, I vowed to live "like she was watching."

In my mind, this meant eating healthy and exercising. Unfortunately, my good intentions left me feeling nothing but guilt because I wasn't taking action to keep my promise. I tried community exercise classes but lacked motivation. I didn't attend consistently.

Sugar and carbs had a hold on me, especially at night. I felt bad about what I was putting into my body. I felt bad about my lack of exercise too, but I had no hope for change. The healthy lifestyle I needed just wasn't in me.

But then, everything changed with my first RSN exercise class. I found others with kidney disease who wanted to add fitness to their daily routines. I was surprised to find participants from so many states across various time zones. We quickly found camaraderie and an unspoken knowing of shared experiences. Edina, the instructor (or "The Terminator" as we like to call her), makes the classes challenging yet

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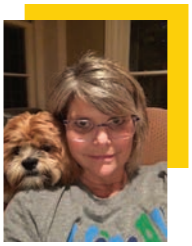
Cheryl Moormann is a retired kindergarten teacher and two-time living kidney transplant recipient. Cheryl is gratefully living a healthy, active life with her husband, daughter, and dog, Jordy, in Leawood, Kansas.



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Search NCT04195906

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InfoCUAtrial@Sanifit.com

REDEFINING YOURSELF

after a kidney disease diagnosis... and choosing happiness

By Mary Nesfield

Web ID:4044

Gemma Lafontant was approaching her 13th birthday when she first heard her kidney disease diagnosis. "Can we have pizza tonight?"

The phrase "low sodium diet" didn't exactly fit the bill, so her mom, Charlene, stepped up by preparing low-salt recipes. The entire family rose to the occasion by jumping onto the low-sodium bandwagon. "Even dad," Gemma boasts.

Gemma's other relatives wanted to help too, and the testing process for a donor soon began, with friends and family from across the country volunteering.

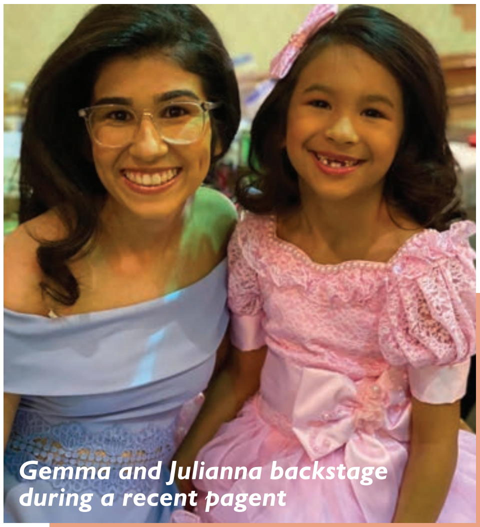
Before her diagnosis, there was concern when she wasn't keeping pace with the growth spurts other girls her age experienced. She was referred to an endocrinologist. "I had to take growth hormone shots," she says. She endured 365 shots in one year and her parents promised a family pet as a reward for being so brave.

"Even though the growth hormone barely added two inches to my height," she stated, "I met my furry soulmate, and it was worth every single needle." Her new best friend was a one-pound puppy named Skippy, who became Gemma's protector, often warning others to keep their distance from Gemma with a tiny but mighty little growl with no malicious intent.

One day, at a regular check-up, Gemma's blood pressure was extremely high for her slight 63-pound frame and this is when doctors discovered her need for a new kidney. To avoid eventual dialysis, Gemma's doctors and her family were striving for a preemptive kidney transplant.

Her mom could not be a donor; she had only one kidney after one had been removed previously. Gemma's dad was not a match either, but Gemma's cousin Claire was! In fact, Charlene recounts, according to the team at Children's Hospital Los Angeles, it was the best match they had seen in years. It was all set, that is until just a few days before surgery when Claire developed kidney stones. Having to cancel the procedure was disappointing.

Then an angel named Floris, the wife of another cousin, tested and was also a match. The 26-year-old was in graduate school in Minnesota at the time, and she flew to California to become Gemma's hero. The surgery took place in February 2017, and it was a success! Gemma was glad she could avoid dialysis! While recovering



Gemma and Julianna backstage during a recent pagent

in the hospital, she took to drawing Disney characters, giving one to each member of her medical team.

Something Gemma found difficult during her recovery was swallowing pills. Initially, she needed to take about 20 pills each morning and 20 more each night! Fortunately, her caregivers taught her to swallow them with Jell-O.

An active crafter, seamstress, and artist, Gemma enjoyed virtual painting classes during the Covid-19 pandemic and has kept busy with online school and other creative projects. She draws inspiration from Pinterest and YouTube videos. She's even led her own painting class at Renal Support Network's (RSN's) Studio Hope.

Gemma and Floris, her living kidney donor

Before her surgery, Gemma found something interesting on TV. It was a beauty pageant. After much preparation and practice, she entered her first pageant just days before her transplant.

Prior to the transplant, Gemma had been active in gymnastics and cheerleading. But when her post-transplant medication caused vertigo (and other health complications), those activities were no longer possible for her.

To satisfy her need to compete, Gemma continued along the pageant route. Her coach helps her develop stage presence and public speaking skills. Gemma sees it this way, "If it weren't for pageants, I would still have severe stage fright, I would not know how to deal with defeat, and I would not have met the people who have helped to shape me into the person I am today."

Gemma finds it fun to travel for competitions. She looks forward to reuniting with people of all ages, but forming relationships with younger competitors is what she enjoys most. One child Gemma looks forward to seeing is Julianna; she is inspired by Gemma, and the two have become friends.

"Gemma is modest about being a role model, but there are several younger girls on her pageant team who connect with and look up to her," her mom says. "It makes my heart happy to see who she has become in spite of her health challenges."

And although Gemma still feels nervous participating in judged interviews at pageants, it's what inspires her to tell her story. "I bring awareness about kidney disease and transplantation," she says.

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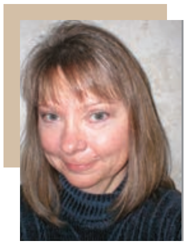

***Mary Nesfield** has enjoyed a long career in magazine publishing. She is a freelance writer and editor for Renal Support Network and works from her home in Columbia, South Carolina.*

“Choosing Colors for CARE”

By Suzette Maffi

Web ID: 4045

When you have a serious health issue such as kidney disease, an environment that has colors to support your mood can make you feel better. Color palettes (combinations of different colors) are designed to make you feel a certain way. Research shows that color can drive your mood and sway your thinking. It can also change your actions and cause reactions. Color can irritate or soothe your eyes, raise your blood pressure, or enhance or suppress your appetite. For example, some fast-food restaurant owners know they can boost their profits if they decorate with colors that are known to make people hungry.

This principle is known as “color psychology.” You can use it to make your home environment a soothing one, and you don’t need a college degree to do it.

Some colors are good for relaxation, and some have the opposite effect. People with kidney disease often say they have trouble sleeping at night. If you have this problem, try decorating your bedroom in muted cool tones like soft blues, pastel purples, or greens, which are often described as calming. Green signifies growth and rebirth. Purple symbolizes magic, creativity, and dignity. If you have a craft room, you may want to use it there.

It is said that blue has more complex and contradictory meanings than any other color. Some research shows that the color blue can result in a lower heart rates and slower metabolism. Most blues convey a sense of trust, loyalty, cleanliness, and understanding. Blue can also signify hope and good health. It can do double duty in your bedroom if that’s where you also do dialysis.

Too often, when you enter a healthcare setting you see bright colors. These colors foster alertness, which is not conducive to rest and relaxation. Think about the bright, intense colors, such as red, golden yellow, and magenta, used often at parties and festivals. These are considered “warm” colors,

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***Suzette Maffi** is a marketing professional, a graphic designer and a home décor enthusiast. When she's not busy manning RSN’s marketing and communications desk she can be found working on home DIY projects and rescuing homeless dogs and cats. Suzette lives in Austin, TX with her husband, four dogs, three cats and a regular rotation of foster pets.*

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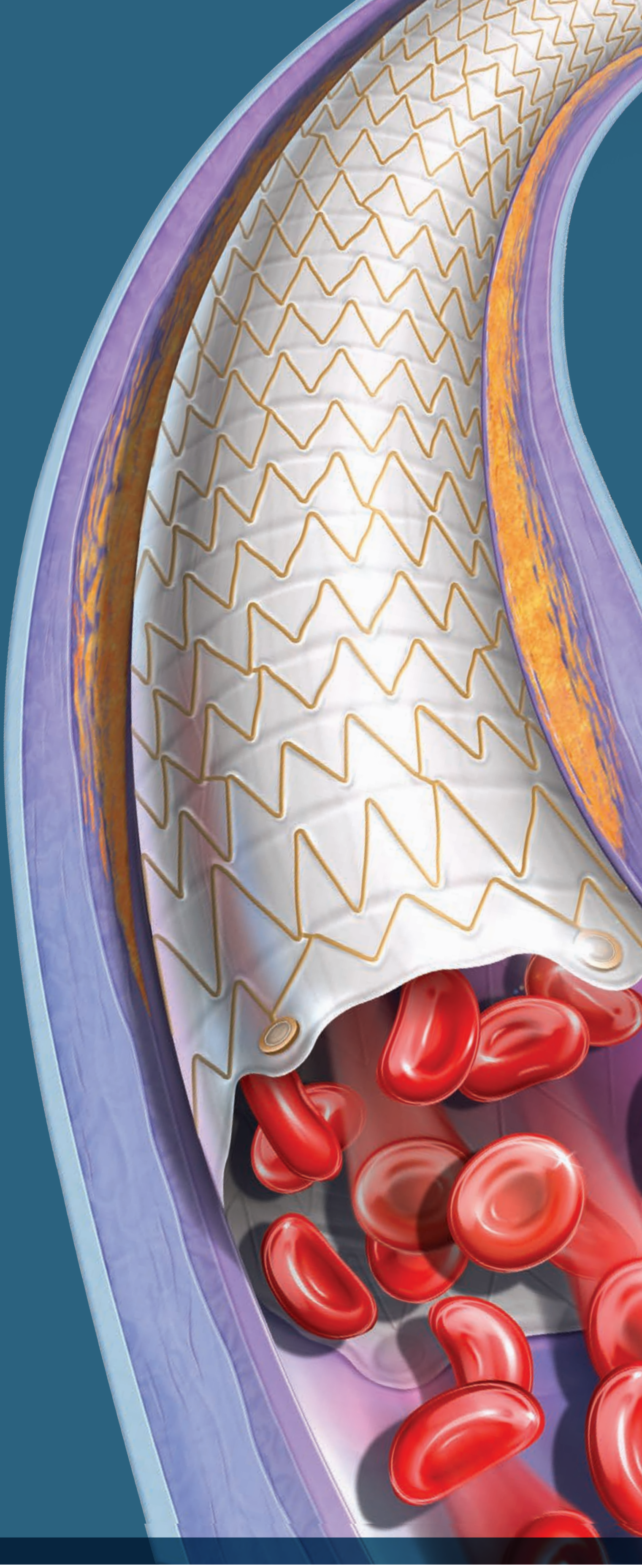

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Tune in to Me Please

Continued from page 3

nearby. As the nurse continued to work, I educated her and her colleague on kidney disease and treatment options, and summoned my husband to bring them a stack of kidney education materials.

Since I was experienced in doing home dialysis for over a decade, I told them I would feel more comfortable if I did the infusions myself. I only needed a few supplies, including small gloves. Without responding, the nurse said someone would call me the next day to set up my infusions. I guess they were satisfied now because the boxes had been checked off for their patient visit.

If you have been in the hospital lately, you know there are doctors or specialists for every body part. And in most cases the person in charge is a hospitalist who doesn't know your beat, or what tune makes your heart sing.

Whenever I am in the hospital for an unrelated kidney issue where the doctors do not know me, it is always refreshing to have them come and talk to me about my needs. It goes without saying that my primary need is to get better, but in addition to the medical care, the two other things I need are to have my pain managed and to get some sleep.

An important question healthcare professionals should ask is if you have a high tolerance for pain medication. It is about how they can make you more comfortable so you can get the sleep you need. I realize there is concern about opioid abuse and addiction, but when I have Level 8 pain I do not really care. I care about getting my pain under control so I can sleep. Then I can get out of bed with the energy to get better and go live the life I was meant to live.

Most of the time I've been lucky, and my healthcare providers do beat to the rhythm of what I need. But on occasion, I have been left to suffer alone in a hospital room without anyone taking the time to really listen to me and understand what I need. These are some of the darkest hospital memories of my life.

I write this with the hope that if you have also felt this way, you will no longer feel you have suffered alone.

The healthcare field is supposed to work for and with us. Standardized healthcare checklists are helpful. However, I would add a few more questions so that healthcare providers better know how to find the melody of the patient and tune in to that individual person's needs.

- How long have you been caring for yourself with this illness?
- What is most important to you while receiving care from me?
- Do you have any fears or challenges concerning your care we can work on together?
- What are you looking forward to when you get better or are released from treatment?
- We are going to do our best to help you feel better and address your medical needs. Okay?
- And finally, validate the patient's own ability to manage and survive with an illness.

Patients don't care how much you know until they know how much you care.

I think the next time I am in the hospital (hopefully never, but I'm a realist), I'm going to have a one-page sheet of paper to give my healthcare team. On it will be a head shot of me to remind them I am a real person, along with a few sentences about me so they can learn my tune. Who knows? We may even enjoy the same music.

For 27 years RSN has presented the Annual Patient Education meeting at no charge to people who have kidney disease and their families. This year RSN introduced a national, virtual five-day event. Each day has a series of presentations that focuses on a specific disease or treatment for kidney disease including an entire day dedicated to pediatric kidney disease. Speakers include healthcare professionals and people who have learned to live and thrive in spite of having kidney disease. **Watch the 2020 presentations at RSNhope.org.**

Eat This, Not That

Continued from page 8

People who have CKD can experience a buildup of phosphorus in their blood. As your kidney function decreases, your lab values may indicate that you need to reduce phosphorus in your diet. Excess phosphorus extracts calcium from bones which leads to joint pain and brittle bones, resulting in a higher risk for breaks. Processed food such as prepackaged meals, deli meat, and some fresh meat and poultry have phosphorus added to prolong shelf life. If you see words that start with "pho" on the ingredient label then there is added phosphorus in the product.

Ask your health care provider about prescribing a phosphate binder you can take with meals to lower the amount of phosphorus in your blood.

Step 5: Choose foods with the right amount of potassium.

Why? To protect the nervous system and to help your muscles function well.

Both high and low potassium levels can cause damage. Being aware of the amount of potassium in your food choices can help you manage your potassium levels.

Foods that are lower in potassium include apples, peaches, carrots, green beans, white bread and pasta, white rice, rice milk (not enriched), wheat cereals, grits, apple juice, grape juice, or cranberry juice.

Foods that are higher in potassium include oranges and orange juice, bananas, potatoes, tomatoes, brown and wild rice, bran cereals, dairy foods, whole-wheat bread and pasta, dry beans, and nuts. (Potatoes, sweet potatoes, and yams can be boiled in order to reduce their potassium content.) You may be able to include some of these foods in small amounts if you are very strict in monitoring your potassium intake. Also be aware that sports drinks, electrolyte water, and salt substitutes usually contain high amounts of potassium.

Deciding which foods to eat is very dependent on your own unique lab values. It's important to review your labs with a renal dietitian before making any changes to your diet to be sure that you are making the best choices for your own body.

KIDNEY CARE ADVOCACY

Get involved and make a difference!

According to the latest U.S. Renal Data System Report, more than 660,000 Americans are being treated for kidney failure, also called end-stage renal disease (ESRD). Of these, 468,000 are on dialysis and more than 193,000 have a functioning kidney transplant. Each year 100,000 people are newly diagnosed with stage 5 chronic kidney disease (CKD) which is the same as ESRD. About 30 million U.S. adults are estimated to have CKD and most are undiagnosed. Over 103,000 people in the U.S. are waiting for a kidney transplant.

Renal Support Network's online advocacy portal provides information on current legislation that is on the table regarding kidney care and how to add your voice to help get bills passed.

Learn more about RSN's advocacy program and take action to support current legislation at RSNhope.org/Advocacy.

Kidney Donor Options
Continued from page 6

Deceased Donor Transplants

Kidneys from deceased donors are not all the same. There are a few types of deceased donors: standard criteria donors, donors who rate high on the kidney donor profile index (KDPI), and donors whose behaviors increase their own risk of infectious disease (Public Health Service or PHS donors), though kidneys from PHS donors are considered low risk for the recipient.

Another newer source of deceased donors is the hepatitis C donor. The treatment for hepatitis C in the last few years has revolutionized the field of organ transplantation and has allowed for more deceased donor organs to be utilized. The main benefit is a shorter wait time to transplant although there is a risk that you may have side effects to the treatment, you may not be as responsive to therapy, or your insurance may not cover some expenses.

The selection process requires good judgement by the transplant team along with consent and input from you, the intended recipient. The deceased donor's kidneys are tested carefully, and the donor's medical records are also reviewed.

There are benefits and drawbacks to each deceased donor option. If you choose to limit your choice to standard criteria donors, you will usually receive a better quality kidney but may wait considerably longer (sometimes 3-4 years longer than other options in many regions). If you would like to receive a kidney sooner to avoid prolonged dialysis, you may choose to accept a high KDPI or PHS donor kidney. Less time on dialysis is almost always associated with better outcomes, even when the donor kidney is in one of these categories.

Take time to consider your options before the organ is offered to you. This allows you to think over risks and benefits and make the choice that is best for you ahead of time. Your clinic visit is a good time to discuss all the different options with the transplant team. You don't want to be caught trying to make a difficult decision about your options when a kidney suddenly becomes available in the middle of the night. Communication early in the transplant process is vital.

How Do I Make a Decision?

What are your feelings? Do you prefer to wait it out in hopes that a "better" kidney comes along, or do you go with what is available to you at the time you need it? Remember, a transplant is almost always superior to remaining on dialysis.

You can always decide to refuse a kidney that is offered to you regardless of what you said to the transplant team or what forms you signed. There is no penalty for saying no to an organ if you are not feeling confident about it. Even when you receive the call that a kidney is available for you, you can still feel free to ask questions so that you can make the best decision, such as:

- What was the cause of death?
- What is the age of the donor?
- Is there any health history that may impact the kidney?

Currently, nine out of ten deceased donor kidneys will function for more than one year. About 50 percent of transplanted kidneys will still be working in 10 years.

Be prepared. The choice is yours.

Save the Date for RSN's Virtual Fundraising Event

CELEBRITY CHARITY BINGO

AUG. 8, 2021

GAME PLAY
•
PRIZES
•
SILENT AUCTION

Contact us via our website at RSNhope.org to donate a silent auction item.

Learn more at RSNhope.org/events

Redefining Yourself
Continued from page 15

Once she takes the stage, Gemma confidently wows everyone with her magic routine, the one she developed by carefully observing other magicians. She has garnered myriad awards, and recently won the coveted top title, "Mega Ultimate Grand Supreme," at a West Coast pageant!

Gemma will graduate high school in June of 2021. She plans to continue on to college and study early childhood development to live her dream of becoming an elementary school teacher.

"Gemma loves working with children," says Charlene. "She has a calming way about her." There is no doubt the kids will love her—and that will bring Gemma joy throughout her life. Oh yes, and she's also very happy now that she's down to swallowing only 10 pills a day!

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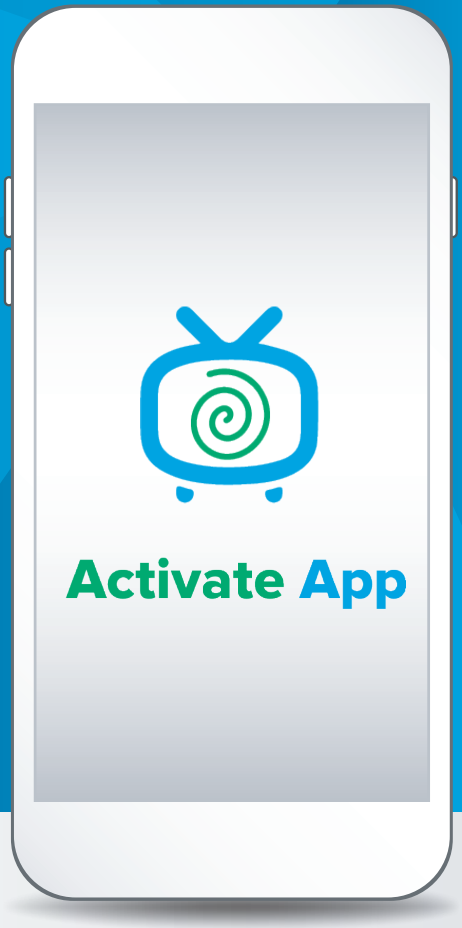

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Donate Life Hollywood (DLH) is a project of the OneLegacy Foundation supported by national DLH Partners, including the Renal Support Network

LEARN MORE AT ACCESSDLH.ORG

Exer-What???

Continued from page 12

doable for those of us just getting back into fitness. Her goal is to keep us coming back. She knows we are not going to show up again if we find the classes too hard or too strenuous. I've discovered exercise classes can work when you attend them!

I remember the first chair plank I tried under Edina's watchful eye, supervising me for correct form and safety. I rediscovered abdominal muscles I didn't know were still a part of me! Today I have willingly started a 30-day "plank challenge," holding planks for longer than I ever have! I give my kidney donor progress updates and it feels good knowing I am living as though she is watching. I feel proud I am now making healthy choices for my body, my kidney health, and my longevity.

Cheryl and her living kidney donor

I credit the RSN exercise program with helping me. It has made a tremendous difference in my life. Edina helps me learn how to do exercises correctly and work safely with light weights. She honors her participants, helping each one to progress at their own rate. Because of her knowledge, along with her care and concern, I've made great strides. She motivates me to maintain a healthy lifestyle.

To date, I have lost 25 pounds, and I now do some type of exercise daily. I feel stronger, and I have much better balance. I experience less back pain and I walk with faster, lighter, happier steps. I've made connections with others through the Zoom class too, and we learn from each other in the spirit of fellowship.

It's great to have consistency in exercising. And most importantly, I know I'm missed when I don't show up. A little connection goes a long way! I know I will continue to participate in the RSN exercise program.

Want to join me? I hope to see you soon!

Life Workforce Options

Continued from page 10

The SSA considers transplants "potentially disabling for 12 months." Following the time period of 12 months post-transplant, the SSA will evaluate your records. If you have no other disabilities, you will no longer be considered disabled based on a transplant or due to ESRD. Medicare can continue benefits under ESRD for the remainder of three years, but Medicare premiums must be paid by the person receiving Medicare.

SSA Work Incentives for SSDI recipients are:

Trial Work Period (TWP)

The TWP allows you to test your ability to work for at least 9 months. During this time you will receive full SSDI benefits regardless of how high your earnings might be, as long as you report your work activity to SSA, and you still have a disabling impairment.

When does the TWP start? It starts when you begin working and performing "services." In 2021, SSA considers a "service month" to be if your gross earnings are more than $940 a month, or if you work more than 80 hours in self-employment in a month.

How long does the TWP last? The TWP continues until you accumulate 9 TWP service months (not necessarily consecutive) within a rolling 60-month period if this begins before SSA reviews your case.

Continuation of Medicare Coverage

Most people with disabilities who work continue to receive at least 93 consecutive months (9 years, 7 months) of Hospital Insurance (Part A); Supplemental Medical Insurance (Part B), if enrolled; and Prescription Drug coverage (Part D), if enrolled, after the 9-month Trial Work Period. You do not pay a premium for Part A. Although SSDI cash benefits may cease due to work, you have the assurance of continued health insurance. The 93 months start the month after the last month of your TWP.

Substantial Gainful Employment

To be eligible for disability benefits, a person must be unable to engage in substantial gainful activity (SGA). A person who is earning more than a certain monthly amount (net of impairment-related work expenses) is ordinarily considered to be engaging in SGA. (SGA applies to people who might remain on dialysis or have another disease process.)

Amounts (2021):
$1,310 Non-Blind
$2,190 Blind

Bumps in the road are expected. Try to remain "work-ready," which means exercising, volunteering, remembering your value, and advocating on your own behalf.

Resources

Social Security Website:
Home Dialysis Central Website

Announcing RSN's 19th Annual Essay Contest!

Who is Your Healthcare Hero?

This year the theme is all about the champions on your healthcare team. Tell a story about a healthcare professional who went the extra mile and improved your experience of care.

1st, 2nd and 3rd place winners receive cash prizes! Winning essays will be published online and in RSN's KidneyTalk™ Magazine. First Prize: $500, Second Prize: $300, Third Prize: $100. Submissions are now open through August 10, 2021.

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

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With Troy Zimmerman

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With Stacy Hoblitzell

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Choosing Colors for Care

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and they can keep you dancing long into the wee hours of the night! Avoid using these colors in your bedroom if you have trouble falling asleep.

When using color in other rooms in your home, always think about your own likes and dislikes. Before designing any room, it can be fun to start with a piece of artwork you really love to design the room around. You also will have something pleasant to look at while you rest.

If you don't know what colors to choose start with Pinterest or Houzz. It is always fun to add a pop of color with paint to one wall. It can change the entire feel and look of a room.

If you are setting up an area separate from your bedroom, design with colors that make you feel your best. Many people choose yellow. It's the color of happiness and creativity, sunshine and spring. If you do home dialysis, brighten the room where you spend time on the dialysis machine with a cheerful, sunny yellow, which can help make you feel optimistic, or choose a light orange, which can leave you feeling healthy and cheerful. Colors like peach, light pink, or lilac can also lift your mood.

Lighting is also very important. You can dim the lights in a brightly colored room if you want to get some rest during treatment. Or turn all the lights on to be able to safely set up your dialysis machine.

Aside from color, another tip for relaxation is to remove as much clutter from your relaxation or sleep space as possible. Too much clutter and disorganization can be distracting, and in some people it can cause anxiety. Do you have boxes of supplies that you need to keep around the house? Hide them behind a room divider or screen. You can also create a bench style stack of your supply boxes and cover them with a throw blanket in an appropriate color.

Don't be afraid to experiment! Always try to remember to design a room to fit the specific purpose of that room. You may even have fun doing it!

Energizing Color Palette

Soothing Color Palette

DONATE & CONNECT

RenalSupportNetwork relies on charitable contributions to provide hope to people with kidney disease. We appreciate your help!

Use this form to make a donation to RSN and/or sign up to receive KidneyTalk® in the mail or the RenAlert E-Newsletter, or both!

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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.

KidneyTalk

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

EDITORIAL TEAM

EDITOR-IN-CHIEF	Lori Hartwell
CREATIVE DIRECTION	Suzette Maffi
COPY EDITOR	Shari Gilford

CONTACT INFORMATION

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

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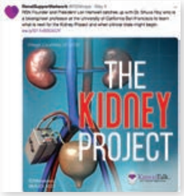

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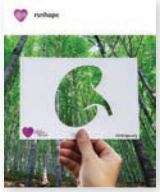

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