

KidneyTalk[®]



Spring/Summer 2023

by Renal Support Network

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

SEEDS OF HOPE

HOW THE RENAL SUPPORT
NETWORK CAME TO FRUITION
30 YEARS AGO

ITCHING, ITCHING EVERYWHERE

FUN & DELISH

KIDNEY-FRIENDLY DISHES

21ST ANNUAL ESSAY CONTEST TELL YOUR STORY!

DESIGNING YOUR ROOM FOR HOME TREATMENT

ADVOCATE FOR MEDICARE KIDNEY CARE PROGRAM - REACH OUT TO YOUR ELECTED OFFICIALS

FOUR HIGH-PRIORITY MEDICARE ISSUES

MEDICARE ADVANTAGE PROS & CONS WHAT YOU NEED TO KNOW

SHPT HAPPENS SECONDARY HYPERPARATHYROIDISM

3 TIPS FOR PROTECTING YOUR KIDNEYS

RSN
Celebrates
30th
Anniversary!



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New RSN Community-Building Program!

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



Medicare Advantage Pros and Cons

What You Need to Know

By Lori Hartwell

Over the past 50 years, the Medicare payment system has evolved, and people who have chronic kidney disease have a real stake in understanding how it works!

In 1972, Congress enacted legislation allowing qualified individuals with End-Stage Renal Disease (ESRD) under the age of 65 to enroll in Medicare, the federal health care insurance program. This was the first

a referral before seeing a specialist, which can be time-consuming and inconvenient, and can lead to longer wait times.

MA plans—"managed care" or "value-based care"—are designed to control healthcare costs while improving the quality of care. In a managed care system, healthcare providers work together to manage and coordinate the patient's care, overall health, and

and Human Services, through the Centers for Medicare and Medicaid Services, finalized the rule to strengthen Medicare, expand access to behavioral health care, and crack down on "misleading" advertisements.

The managed care companies' goal is to be more proactive, with methods such as eliminating duplication of services and assigning case managers to help patients navigate their health care. MA plans promote an integrated approach to care. By sharing and centralizing patient health data, managed care companies emphasize preventive measures to help improve the health of patients in their care. Such as stopping smoking, healthy eating, immunizations, and regular health screenings.

MA companies advertise via social media, television, radio, online and print media and direct mail. These advertisements may highlight the benefits of managed care services, such as lower costs, access to a network of healthcare providers, and preventive care options. Some

Anyone who has dealt with chronic illness over the long-term will tell you that staying with the same care team that knows and understands your condition – is critical to survival.

time that people were allowed to enroll based on their specific medical condition rather than by their age.

As of 2021, people diagnosed with ESRD can choose either original Medicare or a Medicare Advantage (MA) plan for this coverage. Prior to that, patients were not allowed to enroll in MA plans because Congress believed these plans had inadequate provider networks. For example, if I needed a vascular surgeon for dialysis related care, but I had an MA plan with only a limited number of vascular surgeons that were in-network, but they had no immediate appointments, I would end up in the ER. In an MA plan you need to seek

utilization of resources. Medicare Advantage is not Medicare, though the name can be misleading. When enrolling in an MA plan, patients choose a private insurance company to manage their coverage. MA plans assume the risk of the patient's care for a fee from Medicare. The U.S. Department of Health

companies provide incentives such as discounted premiums or co-pays, rewards programs, and free health screenings to encourage enrollment. They market their services in several

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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 the author of popular book called *Chronically Happy*. She is a thought leader and speaker 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.





Seeds of HOPE

*How the Renal Support Network
came to fruition 30 years ago*

By Mary Nesfield



“Nothing matches the feeling of being able to use your own life experience to help others.”

Renal Support Network started as a seed that began to grow in the brain of a very ill little 2-year-old. Her name was Lori. Back in 1968 there was not much hope for people suffering with chronic kidney disease (CKD) because the science of treating the disease was still in its infancy. A Scribner shunt was placed in her 22-pound body, and the Kiil dialyzer saved her life.

People around Lori, including family members and medical professionals, had low expectations for her survival. The emotions Lori felt ran the gamut. Loneliness and hopelessness were mixed with bouts of pain and fear, but she continued to beat the odds. People saw her as a “miracle,” an “anomaly,” since others like her had not made it. Survival was her priority; almost everything else was an afterthought. She was not willing to accept other people’s lack of expectations for her.

Interspersed between 50-plus surgeries, 13 years of dialysis, and four kidney transplants came hard lessons—not the kind learned in school, but the ones learned from experience. Lori continually faced her own mortality.

“Fear stems from a lack of understanding,” she says. She learned to control her fear through knowledge. When she was young, she soaked up all the information she could gather from her hospital stays by befriending her caregivers, including doctors and nurses. She also built resilience when her young life was turned upside down due to the divorce of her parents. Homeschool was the only option for her because of her inability to attend classes at school due to continual health issues.



Lori Hartwell, at age 3 in 1969

“I was not grounded enough to love myself as I was yet, and often felt like a burden,” she says, “but the world opened up for me when I finally felt worthy and decided to pursue my dreams.”

In her early twenties job opportunities came, and her bosses believed in her capabilities. She decided to join Toastmasters to help her better tell her story. It paid off. She met and married her husband Dean Hartwell in 1997.

“I was giving a speech about the importance of organ donation at a competition,” Lori recalls. “Dean showed up and I could tell he liked me. I thought, ‘What is wrong with him?’ My inner voice was wreaking havoc and I had to quiet it. I had to deal with the feeling of being ‘damaged goods.’ I needed to switch to feeling worthy.”

Lori credits her first boss, Eric Ward, a marketing and packaging genius, for giving her the chance to take on other challenges. Lori listened when he told her that her work defines her, not her illness. He taught her how to use creativity to think outside the box, and that anything is possible when you imagine it.



"The world opened up for me when I finally felt worthy and decided to pursue my dreams."



Lori also knew that many of her peers were suffering from the same feelings of loneliness that she had felt. On April 28, 1992, while sitting in Los Angeles traffic, the seed in Lori's brain blossomed into the idea of the Renal Support Network. The following year Lori created a directory to help people connect with each other, and she invited them all to a support group lunch. She saw people laughing and sharing war stories and coined the phrase, "One friend can make a difference."

Lori entered the medical profession working for a home hemodialysis company. She then transferred to a technical sales specialist position with a diagnostic company. She became an advocate for blood volume monitoring, emphasizing the importance of fluid management in dialysis. Next came a position as the Western regional sales manager for a dialysis catheter company. In this position, she helped surgeons understand the importance of dialysis catheter placement and how it is the patient's lifeline prior to a permanent vascular access. Before long Lori had visited more than 500 dialysis centers.

"My profession was sales, but I actually became the product," Lori says. She was in demand because she could share her knowledge and understanding of all she had lived through due to her first-hand experience with kidney disease. As one with CKD, the experience solidified her belief in the importance of advocating for oneself. Lori's book, *"Chronically Happy: Joyful Living in Spite of Chronic Illness,"* was published, and she traveled the country on a book tour. She also produced the educational video called, "Communication Prescription for the Renal Care Professional," which gave continuing education units to healthcare team members. In it, she stressed the importance of the patient/health-care-provider relationship.

Her gift for storytelling was paying off. She was offered a job as the editor of both the medical journal *Contemporary Dialysis & Nephrology* and the journal *For Patients Only*. Heads of various medical associations and companies began asking her to share her inspiring story. She went on to speak in front of thousands at healthcare conferences around the world. In 1999, Lori hosted the first annual Renal Teen Prom in Southern California through RSN, in part because she did not want her peers to miss this coming-of-age event which gave them the chance to meet new friends. She and her volunteer team are currently planning RSN's 25th prom. This celebratory event will be held in January 2024 and all the prom alumni will be invited back. These proms give youth hope and combat their loneliness by helping them connect with teens in similar situations because, as she says, "One friend can make a difference."

Lori's story-telling skills continue with her position as editor-in-chief of *KidneyTalk® Magazine*, which has a readership of 45,000. Lori truly enjoys educating and empowering people. Her lively interviews with both patients and professionals on her *KidneyTalk® Podcast* share hope and wisdom with thousands of listeners. And her annual essay contest inspires people to write their own stories of hope to inspire their peers.

Lori has become a powerful patient advocate and thought leader who speaks out on legislative and regulatory issues affecting the kidney

community. She recognizes that if someone does not have access to innovation, insurance, healthcare professionals, and treatments, it is difficult to have hope. She has won many awards for her advocacy work and is the first patient to ever receive the American Society of Nephrology President's Award.

Lori says, "Running a nonprofit from the ground up has taught me so many lessons. I can't believe I've been able to keep this organization going for so long, and that it now has a nationwide reach. I've learned so much about nonprofit management over the years."

Knowing that balance is important, Lori likes to spend her time making jewelry and painting. She and her husband love animals and have four dogs and a beloved African grey parrot. Lori credits her dog, Pepi, whom she had from age 10 to 28, with giving her unconditional love and a reason for getting up in the morning.

Speaking of animals, Lori says, "I wanted to do more to help animals because I have such a deep love for them. That led my husband and me to create another nonprofit, the Paws Fur Hope pet rescue group. Rescuing a dog and finding it a wonderful home is our idea of a good time."

Although Lori believes in the science of medicine, she thinks the community should realize that people who have kidney disease need hope in order to take good care of themselves. "Hope is equally important," Lori emphasizes. "It's very easy for the patient to just do nothing about this illness when they are depressed. They begin to miss treatments and doctor appointments, and forget to take prescribed medications. Unfortunately, this is usually caused by a lack of hope, and can lead to dire consequences."

She also wants her peers to know that although they have kidney disease, they can still pursue their dreams. "An illness is too demanding when you don't have hope," she says.



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"One friend
can make a
difference."

FUN & DELISH KIDNEY-FRIENDLY DISHES



Cucumber Cups Stuffed with Buffalo Chicken Salad

Opposites attract! Hot and spicy Buffalo chicken meets the cool, refreshing flavor of cucumber in these delicious appetizer cups. Great for snacks or light meals, too.

Not Too Spicy for Your Mama Chipotle Wings

Tasty, yes, but not too spicy. Just what's in this sauce? Chipotle peppers in adobo sauce, honey, butter, black pepper and chives. Oooh, Mama!



Hawaiian-Style Slow-Cooked Pulled Pork

Say “aloha” to this Hawaiian-style pulled pork recipe. Smoky and succulent, it can be served over rice, added to soup, or used as a high-protein addition to scrambled eggs for breakfast. Contributed by: Lori Fijiura, Aiea, Hawaii.

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**FRESENIUS
KIDNEY CARE**



Live the life you love

Fresenius Kidney Care is here to help you take an active role in managing your kidney disease. Through support, education, and tips on eating well and staying active, we will be with you every step of the way.

Learn more today.

FreseniusKidneyCare.com



Thrive On

Recipes Continued from Page 8

Cucumber Cups Stuffed With Buffalo Chicken Salad

Ingredients

1/2 teaspoon black pepper
1 teaspoon smoked paprika
1/2 teaspoon Italian seasoning
1 teaspoon cayenne pepper
2 tablespoons hot sauce
1/2 cup Kraft® mayonnaise
1/4 cup blue cheese crumbs
2 tablespoons lemon juice
1 tablespoon fresh garlic, chopped
2 tablespoons fresh chives, chopped
3 cups chicken breast, diced or shredded
2 large seedless cucumbers sliced into 1-inch pieces, with half of their centers scooped out (15-20 slices) (Tip: Cucumbers can run a little small or big, so be sure to get one at least 15 inches long or 2 smaller ones.)
1/4 cup fresh parsley, chopped, for garnish

Directions

Combine all ingredients except the chicken and cucumbers in a medium sized bowl.

Stir in chicken and mix until well coated. Set aside in refrigerator for about 30 minutes.

Remove from refrigerator and spoon equal amounts (about 1-2 teaspoons) into each cucumber slice. Garnish with chopped parsley.

Calories: 155
Total Fat: 13g
Saturated Fat: 3g
Trans Fat: 0g
Cholesterol: 53g
Sodium: 252g
Carbohydrates: 4g
Protein: 18g
Phosphorus: 159g
Potassium: 283
Dietary Fiber: .6g
Calcium: 47g

Not Too Spicy for Your Mama Chipotle Wings

Ingredients

1 pound fresh jumbo chicken wings cut in pieces or 20 individual pieces
Oil for greasing baking sheet tray
1 1/2 tablespoons diced chipotle peppers in adobo sauce*
1/4 cup honey
1/4 cup unsalted butter, slightly melted
1 teaspoon black pepper
1 tablespoon chopped chives

*Chipotle peppers in adobo sauce are available in cans in the Latino/Mexican/ethnic food aisle of most grocery stores.

Directions

Preheat oven to 400° F.

Place the precut wings on a large greased nonstick baking sheet tray. Bake for 18–20 minutes, turning halfway through the cooking time or until crispy on the outside and reaching an internal temperature of 165° F on an instant-read thermometer.

Add the remaining ingredients to a large bowl and combine with a rubber spatula, until well mixed.

Remove the wings from the oven and toss in the sauce until evenly coated. Transfer to a large platter and serve.

Calories: 384
Total Fat: 26g
Saturated Fat: 12g
Trans Fat: 1g
Cholesterol: 15 mg
Sodium: 99mg
Carbohydrates: 18g
Protein: 20g
Phosphorus: 146mg
Potassium: 266mg
Dietary Fiber: 0g
Calcium: 21mg

Hawaiian-Style Slow-Cooked Pulled Pork

Ingredients

4 pounds pork roast
1/2 teaspoon ground black pepper
1/2 teaspoon paprika
1 teaspoon onion powder
1/2 teaspoon garlic powder
2 tablespoons liquid smoke
Optional garnish: (pickled red onions or radishes) 1 red onion or 4 radishes, 1/3 cup white vinegar and 1/4 teaspoon of sugar

Directions

Combine black pepper, paprika, and onion and garlic powder in a small bowl.

Rub the seasoning blend on all sides of the pork. Place pork into a slow cooker or a crock-pot. Sprinkle with liquid smoke.

Add enough water to the slow cooker or crock-pot to measure 1/4–1/2" deep. Cook on high for 4–5 hours. Remove pork from cooking liquid and shred meat using two forks. Optional: Garnish with sliced pickled red onions or radishes.

Tip: For quick pickled red onions or radishes, marinate one sliced red onion or 4 sliced radishes in a 1/3 cup of white vinegar and a 1/4 teaspoon of sugar for 1 hour. Drain and use as a garnish.

Note: Shredded or pulled pork can be used in a variety of ways. Serve it over rice, add it to soup, or create a high-protein breakfast by adding it to scrambled eggs.

Calories 285
Total Fat: 21g
Saturated Fat: 7g
Trans Fat: 0g
Cholesterol: 83mg
Sodium: 54mg
Carbohydrates: 1g
Protein: 20g
Phosphorus: 230mg
Potassium: 380mg
Dietary Fiber: 0g
Calcium: 9mg



ENTER RSN'S 21ST ANNUAL ESSAY CONTEST TELL YOUR STORY!

HOW DO YOU USE YOUR
CREATIVITY TO HELP COPE
WITH KIDNEY DISEASE?



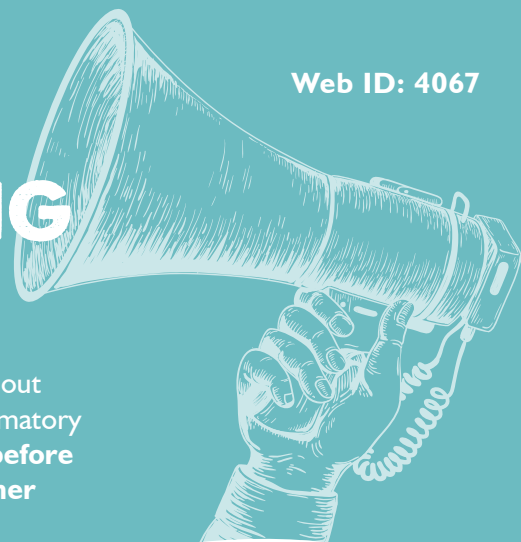
For this year's theme, we ask that you share a story about how your creativity helps you cope with the challenges of living with kidney disease.

Submissions are open to anyone in the U.S. who has kidney disease. Essays are due by August 10, 2023. Cash prizes awarded to 1st, 2nd, and 3rd place winners.

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



3 DULL YET ESSENTIAL TIPS FOR PROTECTING YOUR KIDNEYS



If you have been diagnosed with kidney disease, it is important for you to know about the risks and complications associated with contrast dyes, nonsteroidal anti-inflammatory drugs, and antimicrobial medications. **Always consult with your nephrologist before any of the following are administered or taken even if prescribed by another physician. Your nephrologist may recommend alternative treatments.**

1 IODINATED CONTRAST DYE

Contrast dye is a substance which is used to enhance the visibility of certain organs or tissues during medical imaging tests such as CT scans, MRIs, or X-rays. There are two types of dye: Iodinated and gadolinium. While contrast dye is generally considered safe, it can cause complications in people who have kidney disease.

The reason for this is that contrast dye is eliminated from the body through the kidneys. For those with kidney disease, the kidneys may not be able to filter the dye effectively, leading to a build-up of the substance in the body. This can cause a condition called contrast-induced nephropathy (CIN), which can damage the kidneys and even lead to kidney failure. While CIN is a rare occurrence, it is better to proceed with caution.


In addition, it is important that you stay well-hydrated before and after the imaging test. Your nephrologist may require intravenous fluids before and after the test.

2 NONSTEROIDAL ANTI-INFLAMMATORY DRUGS

Nonsteroidal anti-inflammatory drugs (NSAIDs) are medicines which are used to relieve pain, reduce inflammation, and bring down a high temperature. NSAIDs such as aspirin, ibuprofen, or naproxen can have negative effects on the kidneys, especially for those who have had a kidney transplant. Excessive use of NSAIDs can also cause acute kidney injury. Acute kidney injury is a rapid fall in glomerular filtration rate (GFR) over hours to days.

3 ANTI-MICROBIAL MEDICATIONS

Anti-microbial medications, including some anti-bacterial, anti-fungal, and anti-viral medications, can be hard on the kidneys because they are cleared from the body via the kidneys. When these medications are taken in high doses or for extended periods of time, they can cause damage to the kidneys and impair their function. These medications are nephrotoxic, and for people who have a kidney transplant or chronic kidney disease, it is essential to monitor renal function while taking them.



**“Itching, itching everywhere,
I scratch and scratch, but it's still there.
My nose, my ears, my feet, my head,
I wish this itch would go to bed.**

**I try to ignore it, but it won't quit,
It's like a never-ending, ticklish fit.
I even try to distract my brain,
But the itch has me going insane.”**

**To alleviate itching of the skin, the first
step is to determine the underlying cause.**

IS IT DRY SKIN?

Try topical creams and oils, and use warm water for showers. After showering, blot dry and use moisturizer.

IS IT AN ALLERGIC REACTION?

Try antihistamines, steroid tablets, and steroid creams.

IS IT AN UNDERLYING MEDICAL CONDITION?

Chronic pruritus is a condition which affects people who have advanced chronic kidney disease. It is caused by toxin build up, inflammation, abnormal nerve conduction, or opioid receptor activity imbalance.

TALK TO YOUR DOCTOR IF ITCHING IS KEEPING YOU UP AT NIGHT.

If you are interested in learning more about a clinical trial for the treatment of moderate to severe pruritus associated with chronic kidney disease by Cara Therapeutics, please visit theKICKstudies.com



SECONDARY HYPERPARATHYROIDISM (SHPT)

SHPT HAPPENS

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

WHY DOES SHPT OCCUR IN PEOPLE WITH KIDNEY DISEASE?

High blood phosphorus levels
Kidneys cannot make active vitamin D that the body needs to absorb calcium
Low blood calcium levels

WHAT ARE THE SYMPTOMS OF SHPT?

Weak, broken bones or joint pain
Feeling nauseated, loss of appetite, tired and weak
Kidney Stones
Itching

WHAT CAN YOU DO TO MINIMIZE RISK OF SHPT?

Take medication as prescribed
Don't miss a dialysis treatment
Follow dietary phosphorus recommendations

WHAT TESTS DETERMINE IF YOU HAVE SHPT?

Parathyroid hormone (PTH)
Calcium (Ca)
Phosphorus (P)
Calcium-phosphorus product (Ca x P)

HOW IS SHPT TREATED?

Vitamin D, calcium supplements or Calcimimetics
Surgery to remove parathyroid glands

WHAT HAPPENS IF SHPT IS LEFT UNTREATED?

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

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

Calcium build-up leading to weak and brittle bones



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If you are on dialysis, you can do your treatment in the comfort of your own home.

Peritoneal dialysis (PD) is a treatment for kidney failure which 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 PD 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.

Home hemodialysis (HD) is a treatment for kidney failure. Hemo is a process in which your blood is filtered outside your body through a dialyzer or "artificial kidney" to remove unwanted waste, toxins, and excess fluids. The cleaned blood is then returned to your bloodstream. This treatment

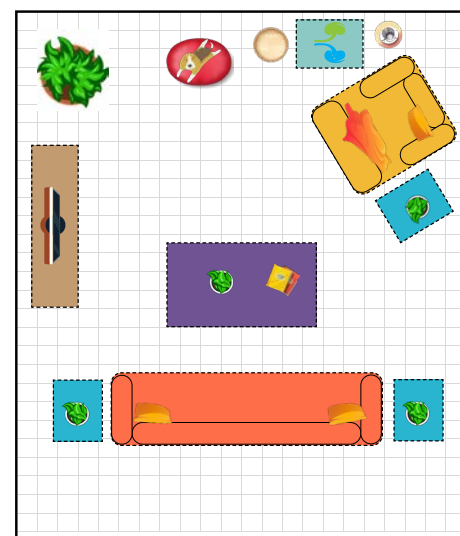
option can be done in-center or in the comfort of your own home. We often hear, "How big is the machine? Can I move it easily to another room? How much room do I need to store supplies? What does a typical home dialysis treatment set up look like?"

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

To use the tool just print out the grid and all of the furniture pages. Draw a line to fit your room size and cut out the dialysis machine and furniture that fits your dimensions. Then you can use the cut-out pieces to decide where everything will go in your

space BEFORE having to move heavy furniture around to see if it works.

Here is a sample room layout:



You can access the Home Dialysis Room Design Kit at RSNhope.org/DialysisRoom

IT'S TIME TO GET UNFILTERED ABOUT KIDNEY DISEASE



James, CKD Warrior

Unfiltered Kidney Conversations is a community that seeks to help and inspire everyone affected by chronic kidney disease (CKD), whether you're living with it or supporting someone you love. Join the community to connect and discover information about CKD and hyperkalemia, because knowledge is power when it comes to your CKD journey.



Join us by visiting www.unfilteredkidneyconvos.com or scanning the QR code below. You can also join our Facebook community @UnfilteredKidneyConversations



UNFILTERED KIDNEY
CONVERSATIONS

Advocate for Medicare Kidney Care Program Reach Out to Your Elected Officials

Web ID: 4070

Renal Support Network (RSN) is dedicated to giving patients a voice on issues which are vital to their longevity and quality of life, so that legislators and regulators can make informed decisions on these issues.

RSN is committed to advocating for people who are living with chronic kidney disease, are on dialysis, or have a transplant. We believe it is essential to ensure that patient needs are addressed through thoughtful legislation and regulations. We believe that supportive public policies form the essential foundation for excellence in patient care and positive patient outcomes.



Legislative Branch:

This branch includes the United States Congress, which is responsible for creating laws and overseeing the Medicare program. Within Congress, there are committees and subcommittees dedicated to healthcare and Medicare specifically, such as:

House Committee on Ways and Means: This committee plays a critical role in shaping health policy and oversees Medicare and other programs.

House Committee on Energy and Commerce: This committee has jurisdiction over public health and some Medicare issues. Its Health Subcommittee oversees Medicare and Medicaid and is responsible for proposing legislation to improve the program.

Senate Committee on Finance: This committee also oversees the Medicare program and some other health policies, with responsibilities such as reviewing Medicare-related bills and nominations for key health positions.



Executive Branch:

Various departments within the executive branch have roles in advocating for improvements to Medicare:

Department of Health and Human Services (HHS): HHS is the primary federal agency responsible for health policy, including Medicare. The Centers for Medicare and Medicaid Services (CMS), an agency within HHS, directly administers the Medicare program and develops policies aimed at improving healthcare for Medicare beneficiaries. HHS also includes the Health Resources and Services Administration (HRSA), which oversees federal organ transplant policies and programs.

Office of Management and Budget (OMB): OMB plays a role in reviewing and approving Medicare policies and proposals, as they are responsible for coordinating and overseeing the administration's fiscal and health policy decisions. OMB is part of the White House oversight of agency activities.

The White House: The President and the White House staff can shape Medicare policy through executive orders, budget proposals, and by advocating for specific healthcare priorities. The President may also appoint and work with the HHS Secretary and CMS Administrator to shape and improve Medicare policies.

Renal Support Network is dedicated to giving people who have kidney disease a voice on issues which are vital to their longevity and quality of life, so that legislators and regulators can make informed decisions on these issues.

These are the main government branches and organizations involved in advocating for Medicare. Healthcare professionals, patients, family members, and many other stakeholders such as patient advocacy groups, healthcare providers, and private industry also play a role in shaping Medicare policies and improvements.

Find out who your representatives are and learn on which committees they serve.

See link and QR code on page 20.

FOUR HIGH PRIORITY MEDICARE ISSUES

Web ID: 4071

Here are some policies that either the legislative or executive branch can help resolve. It's important to let all decision-makers understand the inequities of the Medicare system.

Guaranteed access to Medigap policies

People with ESRD face limitations in accessing Medigap policies. These supplemental insurance policies help cover costs not covered by Medicare. There is currently no “all-inclusive” provision for access to Medigap or

supplemental insurance for ESRD patients under the age of 65. Only 31 of the 50 states offer Medigap coverage. Because the ESRD program provides Medicare to people affected by and receiving treatment for renal failure, this leaves people under the age of 65 choosing either to pay potentially huge out-of-pocket costs or to compromise their treatment by picking and choosing what they can afford. This obstacle can financially cripple people living with kidney disease.

ASK A federal law requirement that all ESRD Medicare recipients have access to Medigap coverage in every state would guarantee that the full range of services required to maintain their health is available to them. Provide guidance to insurance companies so they do not charge higher premiums for supplemental coverage. High premiums are cost prohibitive for people who have ESRD, who are then left without supplemental coverage.

Kidney Healthcare Professional Shortage

We know there is a critical healthcare shortage which has been greatly exacerbated by the demands of the pandemic. Sadly, the number of medical graduates entering the nephrology specialty has declined by nearly 50 percent. Similarly, the number

of nurses trained in nephrology care is decreasing. Since quality kidney care largely depends on quality staff, it is imperative we look for both short- and long-term solutions. Moreover, the pandemic has led many health care professionals to leave their jobs. Providers find it difficult to find nurses and technicians to staff their facilities, especially when Medicare rates have not increased to reflect the increasing cost of hiring workers.

ASK We request The Center for Medicare and Medicaid Services (CMS) to use any authority they have and help ensure payment is sufficient, so dialysis facilities can compete with other healthcare fields which do not have the financial limitations of a dialysis bundled payment program. We also need to review our immigration policies and support employment and job-training programs to encourage people to choose the healthcare field.

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FOUR HIGH PRIORITY MEDICARE ISSUES

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Innovation is important

means to incentivize and improve kidney care. The bundled per treatment payment includes medications, laboratory services, supplies, staff, and capital-related costs related to furnishing maintenance dialysis.

Improved devices and technology are currently not reimbursed at the rate or percentage for kidney disease as they are for other chronic illnesses. There is no incentive for companies to develop new products or treatments. Currently, there is only a two-year promise of reimbursement to encourage innovation. This is insufficient and sends the signal that people on dialysis are not as important as those with other chronic diseases. We need a reimbursement pathway which allows people who have kidney disease to have access to innovative treatments.

The Transitional Drug Add-on Payment Adjustment (TDAPA) and the Transitional Add-on Payment Adjustment for New and Innovative Equipment and Supplies (TPNIES) provide reimbursement for new products in traditional Medicare (not required in Medicare Advantage).

ASK Payment drives practice. The ESRD payment system must provide long-term payment mechanisms which adjust the bundle when new products become available. To force innovation to be reliant on this two-year window is unrealistic and a hindrance to an increase in new innovative therapies and technology to improve care.

The current End-Stage Renal Disease (ESRD) bundled payment program has no sustainable

Oral Drugs (Phosphate Binders)

supposed to be taken within 5 to 10 minutes before or immediately after meals and snacks. Phosphorus is found in high amounts in protein foods, so patients who are trying to increase their albumin may need to take an additional binder. Phosphorus content is not required on FDA food labels.

ASK Leave phosphate binders out of the bundle system. It is important that doctors be able to prescribe the most effective treatment for their patients. There are hundreds of combinations of medications to affect bone mineral metabolism and they are given at a very high volume. Therefore, they cannot be effectively managed and stocked with efficiency in a dialysis facility or nursing home.

Also, there are no approved quality measures which can protect the patient from receiving the cheapest medication instead of the most effective one. Medicare Advantage plans can use a formulary to start a patient on the cheapest form of a medication regardless of what is prescribed by a physician.

These critical distinctions lead us to ask that phosphate binders not be included in the bundle. We believe that doctors should have the freedom to prescribe the best binder for each patient's specific situation, and that patients can pick up the medication from their pharmacy so they have the opportunity to speak with a pharmacist.

Although dialysis removes phosphorus, it usually does not remove enough, and many people with kidney failure require phosphorus-binding drugs. Phosphate binders are

Join us in raising our voices for kidney care. Learn more at RSNhope.org/advocacy.



GOVERNMENT PLANS ON OVERHAULING ORGAN TRANSPLANT SYSTEM

By law, the Organ Procurement and Transplantation Network (OPTN) is operated under contract between Health and Human Services (HHS) and United Network for Organ Sharing (UNOS). UNOS manages the national transplant waiting list, matching donors to recipients according to policies developed by the community and approved by the OPTN Board of Directors. UNOS is the only contractor to ever hold, or bid for, the OPTN contract.

Reps. Bucshon and Kelly introduced a bipartisan bill H.R. 2544 to make organ procurement and transplantation more effective and efficient. This legislation will allow the contracts to be open to other entities with the goal in mind of improving technology, data transparency, governance, operations, quality, and innovation.



The goal of the legislation is to open the process up for bid. RSN would like to see many changes including:

- Update the OPTN system that is used to match and track transplants.
- Improve tracking of organs through a GPS system to prevent loss or delay.
- Create a transparent system to know if someone is active on the list or not.

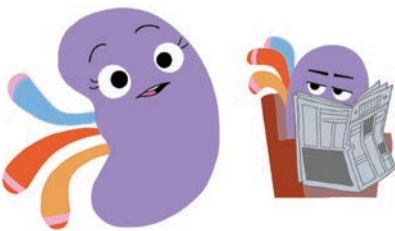
Get Involved, see link and QR code on page 20.

Active vs. Not Active on the Kidney Transplant Wait List

If you are listed on the kidney transplant wait list, do you know if you are active? Over **40 percent** of people are **not active** on the kidney transplant list. “Not Active” means your name is on the list, but a box is checked which prevents you from being matched in the system.

You may be checked as “not active” if you are waiting to get some type of medical testing completed or experiencing a health issue which needs to be resolved. If you are unsure what your status is, ask your transplant team to confirm whether you are active on the list.

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



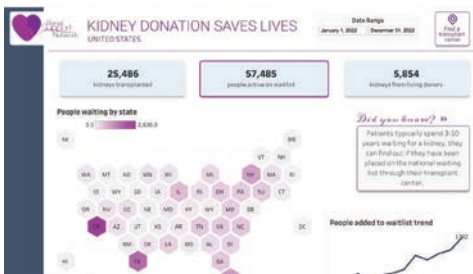
SHARE YOUR SPARE KIDNEY DONATION CONVERSATION KIT



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



COMING THIS JULY, 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)**

Medicare Advantage Pros and Cons: What You Need to Know Continued from Page 3

different ways to get patients to sign up. If what they are saying sounds too good to be true, buyer beware! Do your due diligence.

Managed care companies work to reduce healthcare costs by negotiating rates with healthcare service providers. They renegotiate contracts every year with providers and vice versa. Some providers may not want to work at their negotiated rate. But here is the catch for patients: when contracts are not renewed, and providers switch in and out, patients may have to change their doctor, dialysis facility, or transplant center.

Something managed care does not always offer is continuity of care, which is very important in my mind. Anyone who has dealt with chronic illness over the long-term will tell you that staying with the same care team who knows and understands your condition is critical to survival.

Kidney disease is unlike any other illness. It is not just a hip replacement, a one-time procedure with no need for follow-up. We need continuous care, and relationships with our providers and facilities are vital to managing our health. In addition, some people have found that MA plans limit access to certain treatment options or procedures in order to control expenses, resulting in fewer treatment options.

To wrap up, MA plans can offer several benefits such as lower cost, but will limit you to a network of healthcare service providers they contract with that may not include your doctor, dialysis or transplant facility. Eligible individuals should weigh the pros and cons of managed care and consider what is best for their specific needs and circumstances.

Seeds of Hope, How the Renal Support Network Came to Fruition 30 Years Ago Continued from Page 7

She also wants her peers to know they too can enjoy their lives and go after their dreams and goals. Emotions play an important role. "If those who have an illness don't learn to understand their emotions, they will have a more difficult time navigating the illness. I know my peers often feel 'stuck' in time," she says, "and think that what they are going through at the moment will last forever. It makes them feel out of control, which can lead to depression and anxiety."

"Nothing matches the feeling of being able to use your own life experience to help others," Lori says. If she had not realized that true happiness comes from helping others, RSN may never have come to fruition. She is living proof that you can enjoy a happy life despite a chronic illness, because when you give of yourself to others you are rewarded with appreciation. "That's the secret to happiness," she says.

Photo credits: Page 6, top to bottom, Lori Hartwell speaking series "Communication Prescription," Lori and Dean Hartwell at their wedding, Dean Hartwell and the Hartwell pups—Missy, Sammy, Parker and Eleven. Page 7, top to bottom, Bruce Molitaris, 2013 President of ASN with Lori Hartwell, the first patient recipient of the President's Award, Lori Hartwell's Toastmaster magazine cover, Wendy Rodgers and Lori Hartwell at RSN's Patient Education Meeting, Lori Hartwell and prom attendees, Lori Hartwell and her pediatric nephrologist, Dr. Fine.

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.





Calling all Crafters, Knitters, and People Who Like to Organize a Volunteer Activity!

RSN's **Warm Hands, Hopeful Hearts** project is all about engaging with the community by making a gift for someone on dialysis. If you have ever been on hemodialysis, you know that your hands get cold along with your entire body.

Fingerless gloves are a practical solution for people on dialysis who need to keep their hands warm while still being able to use their fingers for various tasks, such as typing or texting. We ask you to reach out to your community and get them involved.

There are patterns and tutorials available on the website. Learn more about this campaign at RSNhope.org/Warmhands





KIDNEYTalk®

24/7 Podcast Radio Show

Hosted by Lori Hartwell

Listen in to these inspiring shows!

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



Dawn Edwards
Web ID 3108



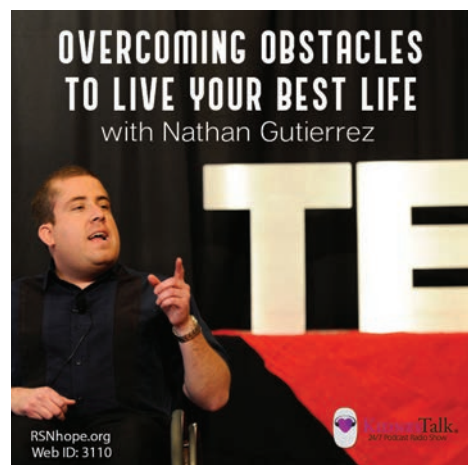
Dawn Edwards speaks about kidney care and how to cope and thrive in spite of the disease.



Anyssa Dang
Web ID 3107



Anyssa Dang, author of the book, Kidneys for Kids, talks about children and kidney disease.



Nathan Gutierrez
Web ID 3110



Nathan Gutierrez, confined to a wheelchair since birth, shares how his challenges do not define him.



HOPE WEEK

RSN's 5-Day Online Patient Education & Lifestyle Meeting for People Who Have Kidney Disease

October 18-22, 2023

Hope Week is a five-day national, virtual event. Each day will focus on a specific disease or treatment for kidney disease. Speakers include healthcare professionals, caregivers and people who have learned to live and thrive in spite of having kidney disease. Sign up for reminders at RSNhope.org/join.

I enjoyed attending Hope Week. It reconfirmed what I already knew but had slipped from the forefront of awareness, provided new information, and a variety of perspectives. It was time well spent. –Robin S.

When the Hope Week attendance package arrived, I was in a hard place. I can't tell you how it lifted my spirits. I am so glad that I found the Renal Support Network and I am looking forward to future events. –Margaret S.



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.*

Stay tuned 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: Hummingbirds, like you, are seen as healers and bringers of love, hope and joy.



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



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



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



Message: I am grateful to you for helping me find my wings and giving me hope for a better tomorrow.



Message: Listening requires the use of our hearts as well as our ears. Thank you for hearing me, you're a stellar healthcare professional.

Say "Thank You" to your favorite healthcare professional, caregiver, or friend. 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 a mini greeting card and matching quote. Donate \$15 at RSNHhope.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



Shop All Kidney Theme Gifts and More at RSNHhope.org



Service to those affected by chronic kidney disease

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Sign up today at
rsnhope.org/join-rsn

HOPEline

Peer Support Hotline

Call (800) 579-1970
Monday - Friday

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

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

About RSN

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

CONTACT INFORMATION

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or other information,
please contact us.

