KidneyTalk
Fall/Winter 2022

IN THE NICK OF TIME

WHY YOU NEED THE RIGHT DIALYSIS ACCESS

MANAGING RESTLESS LEG SYNDROME

HIGH POTASSIUM AND YOUR KIDNEYS

SHPT HAPPENS SECONDARY HYPERPARATHYROIDISM

ANNOUNCING THE 20TH ANNUAL ESSAY CONTEST WINNERS!

1ST PLACE:
THIS IS WHAT BRINGS ME JOY
BY JOY ARAUJO

by Renal Support Network
Helping to educate and motivate people living with chronic kidney disease.
KidneyTalk Magazine 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.
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.

When you are told you need to have a dialysis access placed, it means your kidneys can no longer do their job. You will need regular dialysis treatment so that you may live.

Before you begin treatment, you will need surgery to place some type of access, whether you choose hemodialysis (HD) or peritoneal dialysis (PD). An HD access (fistula, graft, or catheter) enables blood to exit and re-enter the body continually to be cleaned by the dialysis machine. A PD access allows dialysate fluid to enter and exit your peritoneum and does not involve accessing your veins.

For hemodialysis, all experts in kidney care agree that a fistula is the preferred type of access, a graft is the second, and an HD catheter is LAST and should only be used temporarily.

Why do healthcare professionals recommend that you get either a graft or fistula, and not a catheter? Statistics show that when you have an HD catheter, you are at the highest risk for infection and even death.

The “permanent” HD catheter is tunneled under the skin and goes in the right atrium that leads to your heart. A temporary HD catheter is placed in your intrajugular vein that sends blood directly to your ticker. There is not a lot of room for error when you have either a temporary or a tunneled catheter.

I know it is confusing because what is called a “permanent” catheter is not meant to be permanent. Just a few stitches make it more permanent, but it is only a temporary solution until a fistula or graft is available to be accessed more safely with needles.

A peritoneal dialysis (PD) catheter is needed to allow you to have PD treatment. This catheter is placed in your abdomen. There are no needles in this treatment option. You still must take precautions to prevent infection. The risk of severe consequences is not as high as when you have a catheter sitting by your heart. I was on PD for nine years and had two catheters and one infection. There is still some risk of infection, so you need to heed all the precautions.

I’ve had all of the above treatment options, and none of them are pleasant. It can be so overwhelming. The fistula and graft can be scary as they require the use of needles to gain access to your blood. But the reality is that kidney disease is not for the faint of heart. I decided to do all I could to live a great life and not let my fear get in the way. I accepted dialysis. And I take it one day at a time. I know that having access to dialysis is a luxury not everyone is afforded in some areas around the world. Needles or not, I was going to do all I could to take care of myself.

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Artist Larry Green draws his fistula access during treatment.
Many people who are on dialysis report feeling an uncomfortable sensation in their legs during treatments and when trying to sleep. This sensation can range from mildly uncomfortable to disturbing to the point where it is difficult to sit still during dialysis and difficult to fall asleep.

This medical condition is called Restless Leg Syndrome (RLS), also known as Willis-Ekbom disease, an intense and irresistible urge to move your legs while resting, lying down, or even receiving dialysis treatments. People with RLS often describe it as a “tingling” or “creeping” sensation in the legs. RLS affects 5% to 10% of the general population, but the prevalence of this condition in patients with chronic kidney disease (CKD) ranges from 20% to 73%. The condition tends to worsen as people age.

So, why does this happen? Diabetes can be one contributing factor to RLS. Diabetes can cause damage to the nerves of the lower legs and feet, which leads to a condition called peripheral neuropathy, a nerve disorder. Another cause of RLS is iron deficiency, which people on dialysis often experience. Iron stores decrease in your body due to the loss of red blood cells during dialysis. Anemia, a condition in which one lacks enough healthy red blood cells to carry adequate oxygen to their body's tissues, is common in patients with CKD and almost universal in patients with end stage renal disease (ESRD). It is also a risk factor for RLS.

There are ways to effectively treat Restless Leg Syndrome and reduce its impact. For example, your doctor may advise you on ways to control your diabetes and recommend treatment for your neuropathy.

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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
The Scoop on Fistulas, Grafts, HD Catheters (Temporary and Permanent), and PD Catheters

**HD Catheters** are often used for temporary access to a vein until a fistula or graft can mature and be ready for use. They are not as convenient, and since they directly access your larger blood vessels you will need to take more precautions to keep from getting an infection. Ask your healthcare team for a list of what you should do to prevent complications.

**Grafts** are also surgically implanted and use a synthetic tube acting as a blood vessel to connect the artery to the vein. They are also used in patients with small veins that will not properly develop with a fistula.

Grafts heal more quickly and are ready to use much sooner than a fistula. However, they do have a higher percentage of complications (stenosis and thrombosis) because of the synthetic tube. If properly cared for, they also can last for several years.

**Fistulas** are surgically created in your arm (or in rare instances, in your leg). Fistulas use your own natural veins. This involves connecting an artery and vein, which causes more blood to flow into the vein. The vein then grows stronger and larger, enabling easier needle insertion and better blood flow to the dialysis machine.

In most cases, the surgery for implanting the fistula can be performed on an outpatient basis with a local anesthetic. After surgery, the fistula takes 6-8 weeks to mature for use. This kind of access has the lowest complication rate and tends to last many years, longer than other kinds of dialysis accesses.

**PD Catheters** With peritoneal dialysis, you need to be aware that peritonitis, or inflammation of the peritoneal cavity, is the most common cause of infection. You can help prevent such infections by cleaning the tubing exit site daily and always using sterile methods or techniques with each exchange.

Symptoms of peritonitis include abdominal pain, nausea, fever, chills, vomiting, diarrhea, or constipation. Another sign of peritonitis may be cloudy peritoneal fluid following an exchange. Keep the cloudy fluid for your nurse to examine. And always alert your doctor or nurse right away so the proper medication (probably an antibiotic) can be prescribed. This is very important since bacteria can quickly travel to other organs and cause a serious infection. I had peritonitis a couple of times and it is painful, but I received medication and recovered quickly.

Note: Always remember to check with your doctor or nurse before trying any course of treatment not previously prescribed.

Art by Larry W. Green
Now for the important part. As the patient, it is your responsibility to care for your own access between dialysis treatments. It is one of the most important things you can do as a participant in your care. If you have a question about anything pertaining to your access, do not be afraid to ask your care team. This is your lifeline. Protect it always!

Caring For Your Graft or Fistula

• After the surgery to implant your device, or at any other time for that matter, immediately call your vascular surgeon or nephrologist if you have fever, chills, or other signs of infection. These may include redness, swelling, drainage, or heat at the access site. Also, contact your doctor if you have painful, cold, or blue fingers.

• Always keep the access clean, and use antibacterial soap before each treatment. Make sure you practice good personal hygiene to reduce the bacterial count on your skin.

• At the end of each dialysis session, use a gloved hand or a clean gauze pad to apply pressure to the access site to stop the bleeding.

• If you have a fistula, regularly exercise your arm with a handgrip or ball to strengthen and enlarge your veins.

• Do not bump or cut the access, and do not scratch it. Fingernails are a source of infection.

• Make sure no one places a blood pressure cuff on the access arm or uses that arm for injections, blood withdrawal, or an IV line.

• Make sure your needles are not placed continually in the same location. This is called rotating your needles. Inform your dialysis technician where the previous needles were placed.

• Jewelry or tight clothing should not be worn over the access site.

• Never sleep with the access arm under the head or body.

• You should not lift heavy objects that may cause pressure to be placed on the access.

• The access pulse (often referred to as a vibration or thrill) should be checked daily. If there is no pulse, call your dialysis unit immediately. This could indicate a clotting episode.

• Avoid clamps whenever possible, especially on a fistula.

• Alert your doctor before any dental work (including a routine cleaning is performed) since an antibiotic may be necessary to prevent infection.

• If you can learn to cannulate yourself, it can preserve the life of your graft or fistula.

Caring For Your PD Catheter

• If the skin around the catheter is red or you feel soreness, contact your doctor immediately.

• Make sure the nurse checks the catheter for signs of infection.

• You can take showers when the exit site is fully healed.

• Different centers have different protocols about swimming, since it is not a good idea to keep your catheter submerged in water. (No tub baths or spas, for sure!)

• Learn how to change the dressing and keep it clean and dry.

• Always wear a mask when connecting and disconnecting from your PD treatment. Anyone assisting you should also wear a face shield and gloves.

• If the catheter is accidentally disconnected, or if the catheter is leaking, immediately clamp above the leak (pinch with fingers if necessary) and call your PD team.

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HEMODIALYSIS CATHETERS
The Good, The Bad and The Ugly

The Good
Immediate access to vascular system for lifesaving dialysis

The Bad
Risk of clotting, device dysfunction, and need of a new catheter
High risk of infection and hospitalization
Marginal dialysis due to recirculation of blood

The Ugly
Damage to central veins
Pulmonary or cardiac complications
Creates inflammation in the body and shortens life span
May cause delay in receiving a kidney transplant if listed as inactive due to higher risk of infection
Increased risk of death

Thoughts on Vascular Access Preference by People on Dialysis
"I am thankful I have had a fistula for decades. I have seen my peers on dialysis have one complication after another." – Larry G.

"I thought I could just keep the catheter and not have to deal with another surgery. I now am 'inactive' on the transplant list due an infection that is antibiotic resistant. I made a bad choice." – Kathy L.

"I was so afraid of getting an access and being stuck, but a nurse helped me learn how to cannulate myself and surprisingly I can do it." – Julie B.

Art by Larry W. Green

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Potassium is an essential nutrient that plays a crucial role in several important bodily functions including muscle movements in the digestive tract, skeletal muscles that enable mobility, and cardiovascular muscles that keep the heart beating and supplying blood throughout the body. Healthy kidneys work to filter out extra potassium and remove it from the body through urine. When kidneys do not function properly, they may not be able to remove enough potassium.

Hyperkalemia (HK), also known as high potassium, is a condition that occurs when the potassium level in the blood is too high (over 5.0 mmol/L), which can cause serious complications if not treated.

Hyperkalemia and its Symptoms

In 2014, an estimated 3.7 million adults in the US were diagnosed with HK, which can be associated with health conditions including chronic kidney disease (CKD). In fact, 40-50% of people living with CKD in the US are affected by HK. Even though many times there are no symptoms of HK, too much potassium in the blood can cause irregular heartbeats, muscle weakness, numbness, tingling, or even death. In sudden or severe cases of HK, you may have shortness of breath, heart irregularities, chest pain, nausea, or vomiting.

Understanding Potassium Levels

The only way to know if you have HK is through a blood test. Normal potassium levels are between 3.5 and 5.0 mmol/L. Any level above 5.0 mmol/L may be considered high and potentially dangerous. It’s important to remember your results only show the amount of potassium that was in your blood at the time you had the test. This is because your potassium level depends on:

- How well your kidneys are working
- How much of it you are getting in what you eat and drink each day
- If you are taking certain medicines that can affect your potassium level
- If you are taking certain medicines that lower potassium as prescribed by your doctor, such as potassium binders

For those who are on dialysis, which can help to lower potassium levels during treatment, it’s important to consult with a doctor to check potassium levels on a regular basis, as levels can increase between sessions.
IT’S TIME TO GET UNFILTERED ABOUT KIDNEY DISEASE

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. You can also join our Facebook community @UnfilteredKidneyConversations

Crystal, CKD Warrior
IN THE
Nick
OF TIME

To this couple, a donated kidney is worth its weight in diamonds.

By Mary Nesfield
Web ID: 4062
Leslie Carey was diagnosed with kidney disease in 1988, the year she turned 27. It was something with which she was familiar. Nine years earlier, her father was undergoing dialysis for polycystic kidney and liver disease. His doctor advised his daughters to be tested. Results showed that both Leslie and her older sister inherited the disease. Leslie’s lab numbers looked good, but her sister was not so lucky. In 2009, Leslie’s sister died following a liver resection surgery. Leslie went on with her life as a single woman hoping that healthy lifestyle choices might delay the inevitable. She had yet to meet Nick.

Nick Manzano was about to become an “empty nester.” His wife succumbed to breast cancer the same year Leslie’s sister died. Nick had not been on a date in more than 30 years. He set up an online dating profile and discovered Leslie’s profile. He contacted her to set up a first date. “We got each other almost instantly,” Nick said, and they grew closer as they shared their stories.

While on their fourth date, Leslie let Nick know she had chronic kidney disease. He asked questions and scoured the internet to learn more. One date led to another, and then, in 2016, Leslie began experiencing symptoms of a urinary tract infection. A blood test showed a high level of potassium. Two weeks later she was diagnosed with Stage 5 kidney disease. Doctors started her on peritoneal dialysis. Complications arose two years later, and she was admitted to the hospital for diverticulitis. The infection spread to her peritoneal cavity and she contracted sepsis. Her doctor switched her to hemodialysis.

Meanwhile, Nick’s father and mother both died, leaving him to go through their belongings. He found family rings and showed them to Leslie. She picked up Nick’s great grandmother’s ring and tried it on. Coincidently, it was a perfect fit. Was it a sign?

Leslie had been going to a center to dialyze. There she found the Renal Support Network’s (RSN) Kidney Talk Magazine. One day, in her final year of dialysis, Leslie learned about the RSN’s “Share Your Spare” campaign featuring Neff and Nuff, two animated characters that talk about kidney donation. Nick was learning more on the golf course about being a donor as well. While with a client, who happened to be a retired doctor, he shared Leslie’s situation. The client relayed the story of a man who, at age 60, donated one of his kidneys to his spouse. Coincidently, Nick had turned 60 that year. It got him thinking. When his wife was dying of cancer, there was nothing he could do to save her. But this time, with Leslie, he came to realize there was something he could do. He was tested as a donor and was a match for her. He volunteered to “share his spare.”

Surgery was on! While Nick was being wheeled away, he told the anesthesiologist he had a ring at home for Leslie, but said he had not yet proposed. The anesthesiologist asked him if he wanted to talk to Leslie. He said yes, and with that, he was wheeled over to Leslie’s bed, where he proposed. That was the last thing Nick remembered before surgery. Later, when he woke up, the nurse showed him the following words written on paper: October 8, 2020. Nick & Leslie. She says YES!

Nick’s gifts to Leslie included a new kidney and his great grandmother’s ring set with new diamonds.

When talking about his recovery, Nick said, “It was way easier than I thought it would be.” He believes that if people knew the process was not as bad as they may have expected, more might step up to donate.

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“I can’t tell if you are this happy all the time or if you’re just faking it.” Lost in the mix of busy college students shuffling in and out of classrooms, the words of my history instructor fell flat. I giggled awkwardly, a smile still plastered on my face, and did not respond. This was over a decade ago, but I still ponder possible retorts in my head. How should I have responded? Perhaps by saying, I have a lot to smile about! Maybe I could have dug a little deeper, letting her know, I’ve always had to look through rose-colored glasses to keep moving forward. Life has been so hard with kidney disease. What would she have said if I had replied, The trauma of losing kidney function and waiting for a transplant has caused great depression. Smiling is all I can do to keep from crying. However, nothing was said that day. This essay is my response.

I have a naturally cheerful disposition, but I am not always “happy.” Kidney disease has left me physically and emotionally scarred. There have been times, while lying in a hospital bed, enduring my 20th fistula poke, where I thought I would die because I couldn’t get my dialysis treatment done and was scared to get another perm cath. There were times when I was so weak that I hobbled into a restaurant but could not get the strength to stand up from the booth and walk back out. We all know coping with kidney disease is difficult, and we all have managed to cope in unique ways. While I carry many coping mechanisms in my pocket at any given time, I smile through my pain mostly due to deliberate positive thinking.

For a little over 1,500 days of waiting for a kidney transplant, many thoughts went through my head about the probability of actually getting a new kidney. Day after day, little thoughts seeped in about the prospect of living on dialysis for the rest of my life. I was scared, but not defeated. I consciously thought positive thoughts every day. Well, I would say to myself, if a kidney never comes, I will live my best life now. anyway. I signed up for personal training at a gym to get moving. I even signed up for a beauty contest halfway across the country, calling my dialysis-supplies manufacturer to deliver supplies directly to my hotel the weekend of the competition. I made new friends, volunteered with local organizations, and learned to cook yummy, low-phosphorus recipes. Every day, these positive thoughts turned into positive actions, which turned into positive habits, which made for a positive lifestyle. I thought this was as good as life could get, new kidney or not!

My positive thinking gave me hope. While most days I didn’t truly believe a kidney was coming, I had hope that life was going to keep blossoming into beautiful opportunities everywhere I turned. I wrote positive songs on my guitar as hope flowed through my fingertips. I wrote positive words, spinning them into poetry. I recited positive affirmations aloud, generously giving compliments to myself and strangers. Life was beautiful!

The morning I was set to leave for my long-awaited beauty contest, I lay in bed finishing up with dialysis when my phone rang. I answered groggily, wondering who would call so early. It was my local transplant center. A kidney had become available. I was to miss my contest but stand by for surgery. The next morning, I was transplanted. Just when I thought life had blossomed to be as beautiful as it could be, it got even more beautiful! I wasn’t expecting it but was simply coping through my kidney disease with positive thinking and hope.

Today, I am overjoyed with life! I have down days, of course. Everybody does. I still smile most of the time. I still think as positively as I can, acknowledging when I have darker emotions, feeling them, too, but remaining hopeful that life will always be beautiful for me. I’ve been given more opportunities recently to live beautifully by landing my dream job, meeting my kidney donor’s family, and making beautiful music. And I recently competed in a beauty contest.

To my instructor, whether her words were meant to be snarky or not, I think I’ve come up with a fulfilling response to her question, No, I am not happy all the time, but I choose to think positively and to smile because this is what brings me joy.

Joy Araujo is a Development Specialist at a local nonprofit in Indiana. She has had two kidney transplants and spends her time volunteering and writing music. Her future goals include coaching those with chronic illness to feel confident about themselves and their personal goals.
You have enough to deal with when it comes to managing your hemodialysis care and staying on schedule. The Lutonix™ 035 Drug Coated Balloon is a special medical tool that was shown to reduce the number of times a procedure was needed to fix your narrowed or blocked fistula compared to treatment with a standard balloon.

Ask your physician if a Lutonix™ 035 DCB could be right for you. For more information please visit www.lutonixdcb.com/patients

**Indications for Use:** The Lutonix™ Catheter is indicated for percutaneous transluminal angioplasty (PTA), after pre-dilatation, for treatment of stenotic lesions of dysfunctional native or prosthetic dialysis fistulas that are 4 mm to 12 mm in diameter and up to 80 mm in length.

Lutonix AV Clinic Trial data on file. N=285. At 6 months, treatment with Lutonix™ 035 DCB resulted in a primary patency rate of 71.4% versus 63.0% with PTA alone. Primary patency defined as ending with a clinically driven re-intervention of the target lesion or access thrombosis. The primary effectiveness analysis for superiority of DCB vs. PTA was not met with a one sided p-value of p = 0.0562. Number of interventions required to maintain TLP at 6 months were 44 in DCB arm versus 64 in the PTA arm. At 30 days, treatment with Lutonix™ 035 resulted in a freedom from primary safety event rate of 93.0% versus 95.8% with PTA alone. Primary safety defined as freedom from localized or systemic serious adverse events through 30 days that reasonably suggests the involvement of the AV access circuit. The primary safety endpoint for non-inferiority for DCB vs. PTA was met with one sided p-value of p = 0.0019. Percentages reported are derived from Kaplan-Meier analyses. The Lutonix™ 035 DCB should not be used: in patients with known hypersensitivity to paclitaxel or related compounds; in patients who cannot receive recommended anticoagulation therapy; in women who are breastfeeding; in men intending to father children; where the device cannot be completely inflated; or where the delivery system cannot be properly placed. Models for illustrative purposes only.

“Limiting the amount of procedures needed to fix my fistula allows me to spend more time helping others.”

Steven, Potter (Actor portrayal)
As he accepted The Mark Twain award, Jon Stewart said, “Comedy survives every moment.” It has been scientifically proven that laughter and smiling lowers stress levels, strengthens the immune system, reduces pain, and increases positivity. When I first found out that my kidneys were failing, I was stressed (which increased my high blood pressure). I laid in a hospital bed for three sleepless nights and days, listening to reality show reruns and intermittently crying over my new reality. It was as if I were in a long, dark tunnel and someone had just blown out the last candle.

For the next month, I could barely get out of bed most days, a side effect of all the meds I was on. It was countless daytime naps, then lying awake in the dark hours of night feeling scared and grieving the life I thought I was going to have. Hours bled into days, days into weeks, and weeks into months. The cycle kept repeating itself in between numerous doctor visits and prescription refills.

Then, I slowly started reading all I could about kidney disease and joined some online kidney disease and dialysis forums. During one of my many nights of scrolling, I came across an advertisement for the National Kidney Foundation’s “33 Miles in 30 Days” walk. I decided I could walk at least a mile a day for a month, promote kidney disease awareness, and fundraise for the organization. That was the literal first step of reigniting my light.

The next step was talking on the phone with one of my dearest friends. She asked, “How are you doing?” I replied, “I’m hanging in there, except my body is failing to thrive again. Now on top of everything else I’m sneezing every two-and-a-half minutes from allergies. I have been failing to thrive since I was born; when I was a baby, I had jaundice and almost had to go back to the hospital.

So, it's business as usual.”

My friend immediately started laughing hysterically. That in turn made me laugh so hard that my stitches, from a recent dialysis port surgery, hurt. Even through my pain, I felt lighter; the rest of my physical pain lessened and I even managed to smile. It was a special moment. We both realized the irony and hilarity of my situation; we laughed the kind of laughter that makes you wipe away tears. This was one of the first moments when I felt like I could begin to crawl up my new mountain of challenge.

My strategy to combat this horrible illness: to find something to laugh about every day. It might be the fact that I put my shirt on backwards, or that my dialysis machine is finicky like a newborn baby, or that I wore a winter coat for the entire spring season due to my anemia. I told my husband every lady in a winter coat during springtime was one of my friends. Then we would take walks and see how many “friends” we could count. It was something we could laugh about and make the best of a miserable situation. The laughter makes the unbearable moments bearable.

As I continue on in this kidney journey, it is my hope that I can bring light and laughter to the world. The joy I find in being able to make others laugh keeps my flame ignited in what can be a very dark and twisted tunnel. The relief of laughter makes me forget about the medical bills piling up and hip pain from catheter placement. Laughing through tears gives me the strength and hope to feel that life is worth fighting for. As Dolly Parton’s character in Steel Magnolias says, “Laughter through tears is my favorite emotion.”

Carrie George was born and raised in California. She graduated from Diablo Valley College with a degree in Liberal Arts. For over twenty years and in many states she was a proud early childhood educator. She started her kidney disease journey in 2019 and has been a PD dialysis patient since 2022. Carrie is an avid lover of all things coffee, instgramming kidney friendly meals, and travel. Carrie is an overly proud aunt to Abbigail, Jena, Claire, Jack, Ben, and Averi. She currently resides in Boise, Idaho with her bearded husband Zach.
I have kidney troubles.

At 3 years old, that was my declaration to my nephrologist as to why I had come to the clinic that day. Too young to remember how this condition entered my life as a byproduct of a congenital heart defect, all I knew was that kidney troubles meant I did not get to be like most preschoolers. It meant being bribed with quarters into taking medications. It meant that instead of climbing on the backyard playset, I had to go to the doctor and get tests done, none of which were pleasant. Yet rather than being upset, I was told by my mother that I learned to cope with my disease by taking charge of my medical appointments, and through that, my health.

Admittedly, the prospect of a 3-year-old taking charge of her own medical appointments sounds like risky business. However, my mom is a nurse, and she knew that early involvement was necessary to prepare me for the lifelong care that kidney disease requires, as well as gain a sense of power in an unpredictable disease. She started simple, teaching me to recite the names of the medications I had to take, along with their purposes (kidney troubles!). I also learned to identify the kidneys’ locations in my body and insisted that the ultrasound technicians turn the computer screen toward me so I could see the organs for myself. When mom pulled out the blue binders stuffed with lab results to review with the nephrologist, I watched their interactions to make sure everything was okay. These activities, though small, were important since they laid the foundation for me to be able to cope by giving me little things I could control. Little things that would only grow.

Around age 8, my mom let me slide into the driver’s seat and take greater charge of my appointments. When clinic days rolled around, I was the one who would lead the way in, ready to tackle the agenda my nephrologist and I had worked out. After going over the medication list, we would get to my favorite part: reviewing my lab results. With my nephrologist seated on a stool at the computer and me perched on a nearby chair, we would banter over various values that I had learned about: “The creatinine looks good.” “Urine protein is a little high.” Then, I would pull out the sheet of GFR equations while my nephrologist tapped the buttons on his wristwatch calculator to reveal the results. Both of us understood that I could cope with kidney disease if I could comprehend its effects and treatment implications for myself, so we viewed each other as equal partners. He spoke to me directly rather than to my mom, and allowed me to help make treatment decisions, even though he and my mom had the final say. Slowly, but surely, I was surviving kidney disease and building up to thriving.

In high school, when my kidney function took a sudden decline, it was a blindside that no one saw coming. We did our agenda as usual that day, and then it came time to decide on a treatment plan. In a mutual decision, my nephrologist and I agreed that we would discuss everything together, but I would have the final say in regard to anything related to my kidneys. Furthermore, my parents agreed to stand behind my decisions. Those agreements symbolized how the strategy I had used to cope with kidney disease had led to two important milestones. The first was that I had gained my nephrologist’s trust in my ability to cope well enough to be able to give that final call on medical decisions. The second was that I was ready to not only survive with kidney disease but take charge of it, and thrive.

I do not have to spend nearly as much time at doctor appointments as I did as a child, but taking charge of nephrology appointments is still a coping strategy I use today. It is one I would recommend to anyone experiencing kidney disease whether you’re recently diagnosed or have had kidney disease for years. The more you can show your healthcare team that you understand what is happening in your body, the better it is in the long run for your physical and mental well-being. Of course, this strategy does not happen overnight. But once it starts developing, it can be used among the arsenal of mechanisms that can help you cope with those “kidney troubles.”

Abigail Clary is a Northern California resident who was diagnosed with chronic kidney disease secondary to an acute kidney injury caused by coarctation of the aorta and premature birth. She received her BA in Liberal Studies and a teaching credential from Sonoma State University and now works as a special education teacher. In moments of free time, she enjoys reading, baking, and spending time with her twin sister.
Call Me GUMBY

By Ginger White

It’s not far-fetched to say things have been difficult recently. In fact, it’s hard to recall “how things used to be!” Coping strategies have become creative, hard-fought, tried on and discarded as non-workable solutions, sometimes all in the same day. Perhaps we circled back around, modified what was set aside before, and tried again, to find it is okay this time, and will fit successfully into our efforts.

For me, living roughly a two-hour drive each way from my nephrologist and dialysis center, coping methods have been achieved by trial and error. The best one? Be flexible.

Being flexible with time allows me to get where I need to go, because one just never knows. A snowstorm hit the night before my AV fistula was scheduled to be placed. I had to be at the hospital at 5:00 a.m. We drove up the night before and were able to grab a hotel room nearby, so we didn’t stress over not being able to get there. We had a lot of miles to cover, and there can be any number of delays, like traffic! I’d rather be there early and sit in a parking structure, than to be calling to report how I am stuck somewhere and will be late. That messes everyone’s schedule up!

On some days I feel I am on top of the world; some days I feel the world is on top of me. And some days it’s like I’m stuck in the middle. And you know what? It’s all okay.

Be flexible in your interactions with staff. On days I don’t feel good, they may not feel good either. Perhaps they had a less-than-positive experience before me. Smile! I get that smile to go all the way to my eyes, especially when wearing a mask! Speak in a friendly manner, even when feeling frazzled. Empathize as needed. Call people by name. Be polite, inject a bit of humor if you can, and always say thank you. They will remember you and try harder for you the next time the need arises. Trust me, I know!

Be flexible when getting feedback and suitable information. Rely on reputable websites, like teaching hospital sites, world-renowned medical facilities, and established organizations for in-depth data. Steer away from “Dr. Google.” Ask questions of support groups, whether face-to-face or online, and pay attention to the things that worked for other patients. We are an invaluable source of knowledge for each other, and we never know when a phrase we utter may be just the answer to someone else’s unspoken concern.

Be flexible in your treatment options. The old saying, "there is more than one way to skin a cat" presents a gross picture, but the meaning behind it is oh so true. Ask questions, listen, review, and make decisions with your medical team, as a team. You’re a part of that team too, you know. Be flexible with yourself. On some days I feel I am on top of the world; some days I feel the world is on top of me. And some days it’s like I’m stuck in the middle. And you know what? It’s all okay. Take a deep breath and begin again.

You may find that the flexible option you take today will give you the chance to try flexibility in other parts of your life!

Ginger White, has had kidney disease for over 15 years, recently started peritoneal dialysis to deal with an ultra-rare kidney disorder while also living with a blood cancer. Combining involvement with rsnhope.org, being a volunteer mentor for Mayo Clinic Connect and an advocate for Donate Life, she strives to educate and assist people in how to live each day to the fullest.
As I am led into the dialysis clinic, my temperature is taken and I begin breathing slowly in and out, counting to 10, and then shaping my breath into words: “The Lord is my shepherd, I shall not want.” Although I am not a Christian, I began to use this phrase in the early ’80s and ’90s while longlining for black cod and halibut in the Northern Pacific, the Gulf of Alaska, and the Bering Sea. After forty-some years of saying this phrase when I needed to get through moments when reality wants to eat me alive, the Lord, whatever that is, becomes breathing.

The door to the inner clinic opens, revealing all the dialyzers beeping and flashing beside patients hooked up to the machines: blood pink, clear plastic lines; one input, one output, stabbed or plugged into each patient in their lower arms, upper arms, or chests. All the machines voraciously pump blood for the cleansing of toxins and removal of fluids, the work the kidneys used to do. On the side of each machine are foot-long clear canisters, thinner in the middle and wider at the ends, about the size of small 8- to 10-pound exercise weights with fatter than normal middles.

I sit down in the brown faux leather easy chair and lay my elbow on the edge of the chair, preparing to stretch my arm out straight to give the tech a clear view of my arteriovenous, or AV, fistula that creates an artery out of a vein. I am in awe of this special vein. I often have trouble pronouncing multisyllabic medical words like “arteriovenous,” which I say quietly under my mask. My long, steady breaths begin to stutter while I wait to be meat-stabbed by the huge, yet finely sharpened dialysis needles that will pierce two large, red, scarred-up mounds on my fistula.

The tech, a mid-thirties, dark-haired, dark-eyed native lady named Caroline, who I know is as smooth as butter on the stab, places a commonly used medical towel-like sheet (one side blue; the other side a thick, absorbent white) on the armrest and a small metal table attached to the chair. I move the left arm to be as immobile as possible, as I can feel the needles on the sides of my super vein when I move it to adjust the computer, or use the urinal, which is quite a challenge.

I have to get my mind to fly high, and away from here. It brings to mind my mother’s love for the song, “Somewhere over the rainbow … Where troubles melt like lemon drops …” This song is in my soul too. I have not memorized all the words, but I work on remembering them to move me away from the immediacy of the four-hour plane ride to life.

After four hours that move slowly through cramping, like crucifixion spikes pounding into my lower legs, and the half-sleep dreams of places I may never see again, the tech pulls the needles out of my pouting vein. I hold the two bandages covering the two holes in my fistula for 10 minutes; then I stagger out, feeling like I’m walking on the deck of a boat on a breezy day, as the ground pitches and rolls. I steady myself in the moon-glow darkness. I’m careful with my fistula arm because I’ve had it start bleeding again if I work my arm too much. It’s a crisp winter night, the moon is rising above the mountains, dappling soft light on everything as troubles melt like lemon drops.

I drive the eight minutes home, then sit on the couch between my two dogs, Ari and Ollie, my arms stretched across the soft fur of each one, and around their faces, ears, and chests as they curl into donut shapes, with noses against my thighs. Ari is a seventy-pound black lab with a kind of pit bull head, a big, black teddy bear. Ollie is a mix of beagle, English foxhound, and basset hound; his ears are the softest fur, shiny and super snugly. When he wants something, he’ll look me straight in the eye with one paw up, with a face a gentle mixture of sadness and sweetness that is a dog’s way of saying please.

I close my eyes with my arms on each dog; my left arm is still throbbing, like a pounding headache from the four-hour pull. My body is drained. I close my eyes. I say a soft prayer. I’m thankful for another day.

**John Unger** is a former college English teacher (College ESL; Adult transitional literacy), Navy Veteran, and former deckhand on commercial fishing boats in the northern Pacific, Gulf of Alaska, and Bering Sea. He now lives in Albuquerque, New Mexico with his two dogs, Aristotle and Oliver. He’s published several poems and a couple of short stories that end with poems in the *Human Touch*, *Hippocampus Literary Magazine*, and *The Bangalore Review*. 
President's Pick, 20th Annual Essay Contest

Choosing HOPE

By Meredith Kelly

“Hope is the thing with feathers that perches in the soul, and sings the tune without words, and never stops at all.” - Emily Dickinson

I passed by this quote every day. It was on one of the walls at Houston Methodist Hospital where my husband was donating his kidney to a stranger to save my life. A few weeks later, another stranger donated her kidney to me, finally ending the toughest sixteen months of my life. Throughout my sickness, people often exclaimed “I don’t know how you did it.” To be honest, I had no choice. To keep living, I persevered, held on to hope, and learned to cope with kidney disease along the way.

I thought I was healthy. It was early 2021, and at 31 years old I was newly married. And with a major renovation underway at our first house together, my husband Brendan and I were focused on our careers and a timeline for starting a family. After intermittent symptoms of fatigue, Meredith Kelly grew up in Long Island, NY and now lives in The Woodlands, TX with her husband and cat. She is a Senior Engineering Manager at a tech company and in her spare time she enjoys reading, cooking, and listening to music. She is looking forward to going back to the gym and traveling once her doctors clear her post-transplant. Kidney disease was an unexpected detour, but she still strives to accomplish her goals and live her best life.

throbbing headaches, and vomiting, I ended up in the emergency room. What came next was a shocking diagnosis of end-stage renal disease, which meant my kidneys had failed.

I went through the stages of grief many times that week in the hospital. I was admitted Sunday night and started emergency hemodialysis through a port in my chest on Tuesday. My official diagnosis was IgA nephropathy. It is a rare autoimmune disease where my immune system overreacts and creates too many IgA proteins that build up in the kidneys, causing inflammation and eventually shutting them down.

Hope is the thing with feathers that perches in the soul, and sings the tune without words, and never stops at all.” - Emily Dickinson

My first coping strategy after I was finally home from the hospital (I was discharged on our first wedding anniversary) was “Learn & Share.” I am a researcher by nature and spent my days Googling everything I could about kidney disease: dialysis, renal diets, IgA nephropathy, and kidney transplants. I felt that the more knowledge I had, the more power I had to control my situation and make the best of it. I had no choice but to accept my new reality and try to cope with the changes. I tried to absorb every detail the doctors told me. And then I told my family, friends, and coworkers everything I had learned, felt, and experienced. Having a vast network of support is crucial to getting through hard times. I never felt like I was burdening anyone when I shared because if they cared about me, they would want to know. The response I received was overwhelmingly positive. I never felt so loved and supported during my time of need, which made me forever grateful. For the first time since my diagnosis I sensed a surge of hope radiating from within.

My second phase of coping was “Return to Normal.” After a month of hemodialysis, I switched to peritoneal dialysis, or PD. A catheter was placed in my stomach and instead of going to a dialysis center three times a week, I could dialyze from the comfort of my own home while I slept. I was hoping that PD would give me some semblance of my old life back. But this was harder. I did not adjust to PD quickly, or easily. I felt the hope fading as I wrestled with sleepless nights, weakness, and nausea. I finally felt better in my third month of PD. I was able to work full time, swim, go out to eat with friends and family, and even take a couple of trips with my husband. When I felt good physically, it helped me feel good mentally. And when I mentally felt good, my hope of a transplant felt inevitable.

In late 2021, I was evaluated and approved for a transplant. My immediate family members were ineligible to donate, but my incredible husband volunteered to be part of a paired swap. In this situation, the hospital cross matches pairs of donors and recipients to find matching kidneys. The call for my matching kidney came at the end of May, fourteen months after I started emergency dialysis. My husband donated his kidney on June 9th, and on July 12th, I received the most precious gift of all.

Even with a transplant, I will always have to cope with kidney disease. I feel the best I’ve felt in years, which makes everything easier to manage. I’m not sure if my IgA will return, or if there will be any complications with the transplant in the future, but I won’t dwell on fears. I will always choose hope.
Renal Support Network's
You Make a Difference
Lapel Pin Gift Collection

Say “Thank You” to your favorite healthcare professional, caregiver, or friend. Let them know how grateful you are for all the times that they’ve provided you with loving care, support and hope.

Each lapel pin comes with a mini greeting card and matching quote. Donate $15 at RSNhope.org/Pins or scan the QR code with your smartphone. Then choose your favorite design to make someone’s day.

SPEND SOME QUALITY TIME WITH YOUR KIDNEY KIN!

RSN’s series of topical Zoom meetings are informative and so much fun. Topics include kidney disease support groups, exercise, hobbies, diet tips, and more. Participants need not have a Zoom account. 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 or use the QR code on this page.
High Potassium & Your Kidneys
continued from page 8

Managing Hyperkalemia

Having access to resources is crucial to managing health complications and living a fuller, healthier life. As such, here are some ways you can take control of high potassium:

Assess your medications: If you are currently on medication to manage CKD, diabetes, or high blood pressure, ask your doctor about how these medications could be impacting your potassium levels. Your doctor may recommend options, such as taking medicine called a potassium binder and/or changing medicines that might contribute to hyperkalemia.

Implement a healthy diet: Make modifications to your eating habits that are consistent with your dietary requirements. It’s important to speak to your doctor or a dietician to make sure your diet is personalized for you.

Adhere to your dialysis prescription: It’s important not to miss a dialysis treatment as that is the only way for people who do not have kidney function to rid their bodies of toxins, extra potassium being one of them.

Engage with the CKD Community: It’s important to know you are not alone. Consider engaging with others walking in your shoes to help educate yourself on kidney health and receive integral support on your wellness journey.

Talk to your doctor about HK and treatment options that may be right for you. It can be hard to talk about living with chronic disease, but open communication with your doctor can help you take control of your potassium levels and not just live—but thrive.

Sue Hellie, MD, MBA is the Head of US Medical Affairs, Renal at AstraZeneca. She has worked in the pharmaceutical industry for over 20 years. She joined AZ in 2021 and is responsible for the development of medical strategy and tactical execution for Chronic Kidney Disease and Hyperkalemia. Sue is a senior business executive with broad commercial, medical affairs and pipeline development expertise. Her experience spans drug development, franchise strategy development, product pre-launch and launch, brand management, medical strategy, post marketing/RWE studies in multiple disease areas such as CNS, Oncology, Hepatology, Women’s Health, Virology, Nephrology, Rare Disease and Diabetes.

KIDNEY CARE ADVOCACY

Get involved and make a difference!

An important aspect of kidney disease is advocacy. Know who your elected officials are and educate them on current policies and regulations that impact care. It is not a difficult thing to do, and it does not take a lot of time. It is so critical to speak up to ensure kidney related polices are understood and acted upon by our representatives.

Our online advocacy portal provides information on current legislation that is on the table regarding kidney care and how to you can reach your elected officials. It only takes a few minutes and makes a world of difference. Learn more about RSN’s advocacy program and take action to support current legislation at RSNhope.org/Advocacy

In the Nick of Time
continued from page 11

Leslie says, “Staying positive and upbeat, and educating yourself, helps. Share what you’re going through. Network.” The support Leslie got made dealing with the challenges she faced less stressful. “I just wish I had known about the Renal Support Network earlier,” she says. Still, the message that Neff and Nuff relayed got through “in the nick of time.”

In June of 2022, the couple married. “We have everything we need,” Nick says. And that’s why in lieu of wedding gifts, the couple asked for donations to RSN. What makes their marriage a happy one? Nick says, “It’s listening, not giving up, and practicing random acts of love and kindness.” Leslie especially likes the random acts. No doubt, because one of those acts saved her life.

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.
Managing Restless Leg Syndrome, continued from page 4

Always discuss your symptoms with your care team for any help you need in terms of making it easier for you to sleep. Not everyone’s preferences or circumstances are the same, and we encourage you to work with your care team to find the best solution for you.

There are also self-administered home therapies to maximize your chances of getting a good night’s sleep.

Here are a few ways that may help you to get more sleep despite RLS:

• Go to sleep and wake up at the same time each day. Our bodies thrive off of routine, and following a dedicated sleep schedule can train your body to fall asleep quicker and stay asleep.
• Make changes to your sleep environment. Turn off your phone, television, computer, and any other blue light radiating device about an hour before you go to sleep. Blue light blocks something in our bodies called melatonin, which is a hormone that makes us sleepy. Blue light may make us less drowsy at night which means it takes longer to fall asleep.
• Do some exercise during the day. Spend some time outside each day or have periodic dance breaks - all you need to do is move your body. This will help settle your body down at the end of the day for sleep.

Your care team may also suggest warm baths, massages, cold or warm compresses, and relaxation techniques such as meditation to get your body ready for sleep. While there is no cure for Restless Leg Syndrome, you can effectively reduce its impact through medication and treatment and doing your best to get a good night’s sleep.
Listen in to these inspiring shows!

Lori and Lazaro Cherem, MD, discuss advanced testing options and how to ensure your place on a transplant list.

Lori and Kam Kalantar-Zadeh, MD, discuss the different stages of CKD and how to delay the progression of the illness.

Listen as Molly Reehl, CDN, tells her story of becoming a dialysis nurse while working full-time and raising a family.

Michael Kraus, MD, discusses kidney care from the viewpoint of a nephrologist.

Lori and kidney transplant recipient Cher Thomas talk about their strategies for avoiding yeast and urinary tract infections.

Listen in and learn how Lori and Caitlin Harris, RD, make cooking fun despite kidney disease!
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

**HOW IS SHPT TREATED?**
- Vitamin D, calcium supplements or Calcimimetics
- Surgery to remove parathyroid glands

**WHAT CAN YOU DO TO MINIMIZE RISK OF SHPT?**
- Take medication as prescribed
- Don’t miss a dialysis treatment
- Follow dietary phosphorus recommendations

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

RSN shines a light on kidney health and organ donation with a clever animated video series featuring Neff and Nuff. Watch all three videos in English or in Spanish. Web ID NN01

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. Web ID SYS22

The holidays are coming. Are you wondering what to give to a person dealing with kidney disease? Are you a patient being asked what you want or might like? Here are some great ideas. Web ID 8020

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

Shop All Kidney Theme Gifts and More at RSNhope.org
If you have a change of address, phone number, or email address, please contact us to update it.

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Sign up today at rsnhope.org/join-rsn

Save the Date for These Upcoming RSN Events!

Hope Week: Education and Lifestyle Meeting
October 18 - 22, 2022
(Presentations will be available online.)

24th Annual Renal Teen Prom
Sunday, January 15, 2023

March is National Kidney Awareness Month
March 8th is World Kidney Day
April is Organ Donor Awareness Month

21st Annual Essay Contest
To Be Announced May 2023

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.