

KidneyTalk®

Fall/Winter 2021

by Renal Support Network

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

**DAVID TRUJILLO:
LIVING PROOF
THAT “CAN’T”
IS NOT A WORD**

**ENJOY LIFE,
BUT DON’T PLAY
AROUND WITH THE
CORONAVIRUS**

**19TH ANNUAL ESSAY CONTEST
WINNING ESSAYS**

ITCHING TO KNOW WHY

**FINDING THE COURAGE
TO SELF-CANNULATE**

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



Enjoy Life, but Don't Play Around With the CORONAVIRUS

By Lori Hartwell

I have been living in a makeshift bubble for over a year and a half to protect myself from getting COVID-19.

The previous 18 months have been a whirlwind of emotions as I try to grasp the real-time day-to-day decisions of living through a worldwide pandemic.

I have been on an emotional roller coaster as people I care about have contracted long-term side effects from this virus; some have even died. Knowing that I am at risk of getting any virus, my professional healthcare friends frequently tell me to stay safe, as this virus doesn't play around.

Over the years I have had many bouts with viruses such as bad colds, cytomegalovirus (CMV), and hepatitis. Some of my friends have suffered from the BK virus. COVID-19 is a new virus linked to the same family of viruses as severe acute respiratory syndrome (SARS) and some types of the common cold. I am thankful for the treatment options now available to help ward off some of these viruses.

I recently got a third vaccine as a booster shot and I am careful not to let my guard down. I will continue to wear a mask when inside a public place and I will not attend large gatherings, especially if they are indoors. I heard about a rapid COVID home test now available to the public, and to have an extra level of comfort I keep a few on hand for people who come to visit.

We all know immunocompromised people are more at risk of getting ill. I have learned to adapt to this new world and to cope with the stress and anxiety that I am feeling. Here are a few of my strategies:

Take news breaks I limit my exposure to television news and social media feeds about COVID-19.

Instead, I get the news from my digital newspaper and only read reports that come from peer-reviewed sources. Doing this helps with my stress level.

I take care of my body I stay current on doctor visits. It has been convenient having online visits that allow me to avoid traffic to get my results. I try to get enough sleep, eat properly, and exercise because it is essential to good health. RSN has several online "get moving" classes, and they are completely free to attend.

Connect with others If one good thing came out of COVID-19, I would say it is the ability for the majority of us to connect via online platforms like Zoom. It doesn't match being in the same room with someone, but it has provided so many opportunities for us. We used to say "There's an app for that." Now we're saying, "There's a Zoom meeting for that." If you want to learn something, I imagine you can probably find an online group to attend! RSN has joined in this digital learning movement. We have Zoom support groups, educational meetings, bingo games, and a "get creative" meeting. These are just a few of the many opportunities to connect with others.

Make time for fun I am big believer in arts and crafts and expressing creativity as a key to dealing with pain and difficult emotions. I have taken a deep dive into painting and

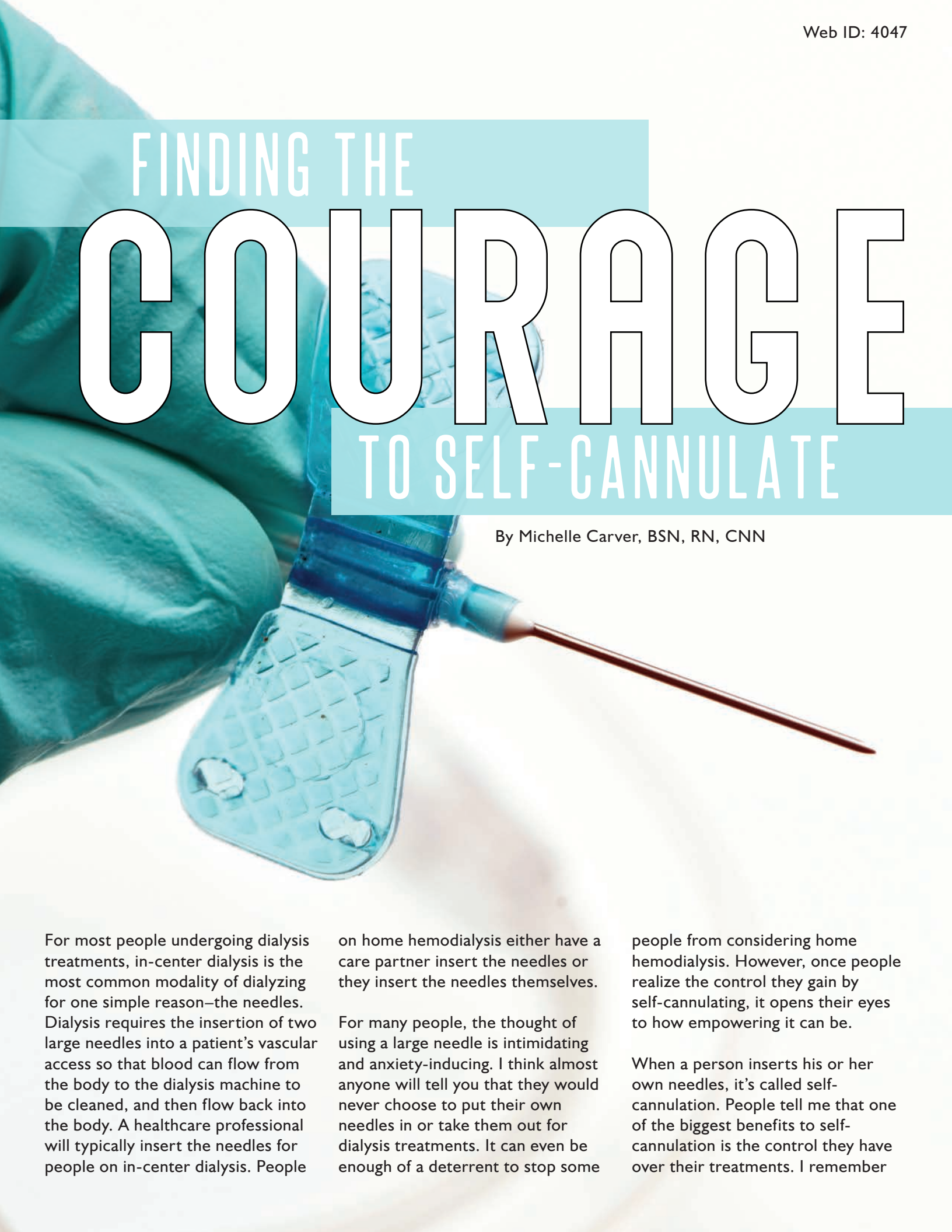
learning different styles and mediums. YouTube is one of the best resources for learning something. Pinterest is a source of inspiration for whatever hobby you enjoy. And now there are Facebook groups dedicated to specific crafts where you can connect and learn from others.

Plan activities For me, it is important to have things to look forward to. I like to cook, so sometimes I try a new recipe and share the dish with my neighbors. We also have enjoyable get-togethers in the back yard. My husband and I love animals. We have three dogs, a cat and an African grey parrot. We also take pleasure in helping rescue animals. We are currently fostering an abandoned dog to give him time to find a forever loving home. We also look forward to watching shows such as "Big Little Lies," "Ozarks," "Game of Thrones," "Glow," "Marvelous Miss Maisel," "The Kominsky Method," "Queens Gambit," and "Never Have I Ever," and we absolutely love "Ted Lasso."

It is my hope that you can stay safe and adapt to this new world we all must live in, but it is also important that you enjoy life. Take a look at the Zoom activities that RSN offers. You may enjoy them, and you might just make some new friends too!

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.





FINDING THE COURAGE TO SELF-CANNULATE

By Michelle Carver, BSN, RN, CNN

For most people undergoing dialysis treatments, in-center dialysis is the most common modality of dialyzing for one simple reason—the needles. Dialysis requires the insertion of two large needles into a patient’s vascular access so that blood can flow from the body to the dialysis machine to be cleaned, and then flow back into the body. A healthcare professional will typically insert the needles for people on in-center dialysis. People

on home hemodialysis either have a care partner insert the needles or they insert the needles themselves.

For many people, the thought of using a large needle is intimidating and anxiety-inducing. I think almost anyone will tell you that they would never choose to put their own needles in or take them out for dialysis treatments. It can even be enough of a deterrent to stop some

people from considering home hemodialysis. However, once people realize the control they gain by self-cannulating, it opens their eyes to how empowering it can be.

When a person inserts his or her own needles, it’s called self-cannulation. People tell me that one of the biggest benefits to self-cannulation is the control they have over their treatments. I remember

one person was very resistant to putting his own needles in, but after self-cannulating for the first time, said that he would never let anyone else do it again. He compared it to putting a cotton swab in your ear—would you rather do it yourself or have someone else do it?

You are the only one that experiences how the needle feels once it's in your body. So, when you cannulate your own vascular access, it is less painful. Needle placement is typically better when you place the needle yourself rather than having someone else do it. When you self-cannulate, you are in control of where the needle goes and how it feels once it's in. Self-cannulation gives you control over your dialysis treatment.

In addition to being less painful, many people's accesses last longer when they learn how to self-cannulate. Your vascular access is your lifeline, and you are the expert for your own access. You notice slight changes or issues much earlier than someone else would and can advocate for yourself. When you self-cannulate, you can typically experience fewer infiltrations and complications.

Self-cannulation also opens the door for people to transition to home dialysis. Home dialysis allows for more flexibility in your treatments, including the ability to do your dialysis treatments in the comfort of your own home. Many people choose to dialyze more frequently on home dialysis because it more closely mimics the normal continuous function of your kidneys. You may also have more flexibility in your diet with more frequent treatments. Finally, one of the biggest benefits of home dialysis is that people can travel more easily than when they do their treatments in-center. Many people also say that they feel better and have more energy on home dialysis.

So, you've decided you want to learn self-cannulation, but where should you start?

Start at the end and work your way toward the beginning. Removing your needles is less intimidating than inserting your needles, so I'd recommend starting there and gradually taking on more of the process yourself as you gain confidence and feel more comfortable. We have lots of practice tools that we use when training people to self-cannulate so that they can get a sense for how much pressure they need to apply when inserting the needle, what positioning is most comfortable, and other parts of the process.

When you are in training, your care team is also a great resource. Ask to be a passive participant in inserting your needles with your care team—hold your hand over his or her hand when inserting the needle—and then switch roles during a later treatment. You may also want to consider reading glasses, a headlamp, or other tools which people have said help them feel more comfortable when self-cannulating.

If you're interested in learning self-cannulation and taking control of your treatments, talk with your care team and learn about your options.

Michelle Carver, BSN, RN, CNN, is the Vice President of Clinical Services Initiatives at Fresenius Kidney Care. In this role, she develops programs to improve the quality of care and clinical outcomes for individuals on dialysis. Michelle has more than 25 years' experience in nephrology and is passionate about




empowering patients to self-manage their renal disease. She lives in Nebraska and enjoys biking, hiking, and spending time with her family.

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Whether you purchase an item with hopeful messaging, fun jewelry, or just support RSN via your online shopping, you are making a difference. All sales benefit the Renal Support Network's life-enriching programs. Look for these pressed Czech Glass Button earrings and more at the shop at [RSNhope.org](https://www.RSNhope.org)





Tina's Gift

1st Place, RSN 19th Annual Essay Contest

By Abigail Clary

The pediatric lab services station at University of California, San Francisco Medical Center (UCSF) did not always have its own home. Sometimes it was in borrowed lab space, other times, just a hallway cubicle. Despite the lack of permanency, there was something about that lab that never changed no matter where it was: the photographs. Dozens of overlapping photographs graced one wall of the lab, each featuring a child smiling or grimacing after a blood draw. My photo was on that wall, too—a snapshot of me around age 7, grinning alongside the one who had requested it, a phlebotomist named Tina.

Phlebotomy refers to the art of puncturing veins to extract blood for testing, and this practice was one I knew well. As a child, I required routine bloodwork to assess my kidney function, which had been damaged by a severe heart condition in infancy. Unfortunately, my veins were notoriously small and difficult to stick, leading to a strong distrust of anyone holding a needle and an equally intense dislike of the multiple pokes that followed. After one especially disastrous attempt as a toddler, my

mother was told by the phlebotomist, “Take her to Tina. She can get it on one try every time.”

That was Tina’s gift. Black curls bobbing above her white lab coat and brown eyes taking in my shrieks and flailing body at our first meeting, Tina was quick to promise that she could indeed get my blood on one try. Then, as my parents restrained my arm, she methodically scanned the veins that had tricked previous phlebotomists before smoothly sticking one vein and drawing the necessary blood. My screams were instantly quelled, and there was a strong sense of relief among all of us that the ordeal was over. It seems like such a small gesture, but by drawing my blood on the first stick, Tina successfully fulfilled her promise and began to build my trust in healthcare providers.

From then on, my parents would make the 70-mile drive to UCSF every time I needed a blood draw just so Tina could do it. If Tina was not at the lab upon arrival, I would stiffen my body and refuse to go in until she was there because no one else could get it on one attempt. Tina was gifted in knowing just the right vein to stick. It was a skill that brought less fear and a deeper bond between Tina and all her patients—a bond that enabled her to create her famous photo wall. It was her special way of remembering us, as well as providing something positive to see during each visit. Though I would argue that seeing Tina herself was better than seeing the photos.

As the years passed and blood draws caused less distress, I started going to local labs to get bloodwork. However, I would still make it a priority to visit Tina anytime I was at UCSF just to say hello and laugh about old times. I was counting on her to draw my blood for a kidney transplant evaluation in high school, but it sadly was not to be. A large void in my heart opened that day when I learned that Tina had unexpectedly passed away a couple of months earlier, shortly after our last visit.

It has been several years since her death, but the legacy of Tina’s gift lives on. It lives on at UCSF, where her photos have been replaced with a plaque dedicating the now-permanent lab station to her and the care she gave her patients. Her gift lives on in the phlebotomists I see for routine bloodwork when they listen to my draw preferences and can stick the vein without too much trouble. Her gift resides in the phlebotomists who, during the COVID-19 pandemic, serve as one of the points of contact and care for patients stricken with the disease. Yes, care can come with a poke.

Above all, the legacy of Tina’s gift lives on in each of us. We are not all skilled in phlebotomy, but we all have a gift or character trait that can be used to bring reassurance and kindness to someone else. Tina used her gift to help a scared young girl learn to trust her, and eventually the rest of her healthcare team. She was and always will be my healthcare hero.

Abigail Clary is a California resident who was diagnosed with CKD secondary to an acute kidney injury caused by Coarctation of the Aorta and premature birth. She received her BA in Liberal Studies and 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.





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Ode to NURSE MARY THE PIRATE

2nd Place, RSN 19th Annual Essay Contest

By Mike Gothard

When my kids were little, in a different place and time, we watched Veggie Tales every day. These days my kids have marooned me on a deserted island so I watch Veggie Tales by myself. But that's okay, I still love it.

My all-time favorite Veggie Tales song is "The Pirates Who Don't Do Anything." They sing, "Well, I've never plucked a rooster and I'm not too good at ping-pong, and I've never thrown my mashed potatoes up against the wall, and I've never kissed a chipmunk and I've never gotten head lice, and I've never been to Boston in the fall." If I had a nickel for every time I sang that song to my kids my treasure would rival Edward Teach's chests of gold.

These days I live in an area of the world that is saturated with pirates—pirate tales, pirate festivals, pirate museums, pirate ships, and pirate history. You can't blink your patch-covered eye without seeing something pirate related. Most days and nights while editing photos, I listen to Jimmy Buffett croon about a pirate looking at 40; though in my case it's 57.

Mike Gothard has had PKD for 39 years and has been on peritoneal dialysis for the past four years. He



is a photographer and owns/operates Beaufort Photography Co. on the Crystal Coast of NC. He plays Magic the Gathering, restores vintage fountain pens, and collects James Bond related autographs.

A couple miles from my apartment, Blackbeard's infamous ship, The Queen Anne's Revenge, lies sunk in 25 feet of salty water, having run aground on June 10, 1718, near Beaufort Inlet. One can visit the Maritime Museum on Front Street in downtown Beaufort and walk among actual artifacts from The Queen Anne's Revenge—cannons, utensils, guns, coins, and actual timbers. Every August, pirates literally invade our small coastal town for an entire weekend of pirate festivities—blacksmithing, dancing, storytelling, drinking, and real live battles between pirates aboard pirate ships in Taylor Creek. Living here is truly a pirate's life for me.

Thus, it's no surprise that my healthcare hero is none other than Mary, a gun-toting, rum-drinking pirate nurse who also happens to live in my pirate town of Beaufort, NC. Mary has surely joined the ranks of such women pirates as Anne Bonny, Mary Read, Mary Farley, and Mary Crickett (with a name like "Mary" she fits right in!).

I've been on peritoneal home dialysis for four years now, and Mary, the gun-toting, rum-drinking pirate nurse of Beaufort, has been with me every step of the way. Though I'm convinced she has tried to dispose of me several times by using syringes the size of swords, more often than not she works hard to keep me alive. And while she will occasionally threaten me with walking the plank, half the time I probably deserve it.

Why is Mary, the gun-toting, rum-drinking pirate nurse of Beaufort my healthcare hero? I'm convinced that in another day and time Mary would undoubtedly have been the pirate nurse aboard a Sloop, Galleon, or Man O' War, quite possibly even Blackbeard's own Queen Anne's Revenge! As such, even before my kidneys decided to "jump ship," I'm sure I would have crossed paths with pirate Mary, for I would have undoubtedly sailed on one of those pirate ships back in the day.

Mary checks up on me regularly, draws my blood once a month like clockwork, ensures I go easy on the grog, keeps my med list current, and swears one day I'll finally receive a kidney transplant (though sometimes I wonder if she's just spinning a tall tale). She also listens to my bellyaching, corny jokes, and countless semi-true stories. In short, she makes sure I walk the line; or plank, in my case.

So join me in hoisting a chalice of rum, I mean water, to Mary, the gun-toting, rum-drinking pirate nurse of Beaufort, my healthcare hero!

Ode to Nurse Mary the Pirate

*There once was a nurse named Mary.
Giving shots she was quite contrary.
Though she used a small syringe
After coming off a binge,
Gun-toting, rum-drinking Nurse Mary.*

*Nurse Mary had once been a pirate.
Her Glock you couldn't help but
admire it.
Drawing blood she'd yell, "Aargh!"
"You're headed straight for the morgue!"
"If you don't obey Mary the nurse pirate!"*

*If you want to stay alive and be well
Three hours your fluid must dwell.
Drink lots of strong rum
Pee full a 50-gallon drum,
Bewitched by Nurse Mary's dialysis spell.*

*Grateful for Mary my healthcare hero
Who keeps me from becoming a
dead zero.
Though she's a wench who drinks rum
And carries a sword and a gun,
She manages to keep me on the straight
and the narrow.*



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Tap, tap, tap! The doctor kept tapping on my forehead.

"Is it over yet?" I asked as he kept tapping.

"Don't think about it," he stated calmly, a slightly different tone in his voice than two hours earlier when I had nervously exclaimed, "You know, I'm going to need Valium for this!" He had retorted back, a slightly irritated, simple, "No." After all, this was just a kidney biopsy. I had had my brand-new kidney transplant a week or so before, but as the doctor predicted, I was experiencing rejection because of my high antibodies.

"Just focus on the tapping." I held really still, trying to focus on my forehead, not the giant apparatus taking a piece of my new kidney out. I had had biopsies before, my last being particularly traumatizing, performed by a student and accompanied by severe pain and copious amounts of blood in my urine for two days. I was *petrified* this biopsy would be the same. However, my surgeon, Dr. Goggins, kept tapping on my forehead to distract me and soon, it was all over. I didn't feel a thing.

"Thank you, Dr. Goggins," I stated casually, like it was no big deal. Truthfully, it was a big deal. Not only had the surgeon come with me to a mere biopsy appointment, he had

taken the time to listen to me, taken my fears seriously, and stayed by my side. You see, Dr. Goggins is not just a transplant surgeon. He's "24K Magic." Not only did he perform a successful kidney transplant for me, he anticipated all that would happen afterwards due to the antibodies in my blood and was prepared to treat the kidney *and* me as a person.

Fast forward a few days and I remember shaking my head, staring down at my Bruno Mars concert tickets that my sister had gotten me for Christmas the previous year. She had stayed on the phone line for hours trying to secure them for me. The concert was in two days, and I was sitting in the outpatient transplant center taking high doses of steroids and calming down after a biopsy. I wasn't going to the concert. I asked anyway, and Dr. Goggins looked at me like I was crazy (of course) and I laid back down on my hospital bed.

The day after the concert I laid there sulking. I watched as Dr. Goggins made his way around the room seeing patients, and I felt slightly irritated that I would never get to hear the live crooning of Bruno Mars on stage. When Dr. Goggins got to my bed, he whipped out his phone.

"I've got a video to show you," he said, scrolling away. He handed me the phone. It was a video of Bruno. "I

thought you might want to see this. He was really good last night!" he enthused. I almost cried. Not because I missed the show, not because this surgeon had secured what appeared to be the best tickets in all of the United States, but *because he had heard me*. He knew I had waited months to see Bruno and could not go, and he had taken the time to bring a little "24K Magic" to me.

I have worked with numerous healthcare workers throughout my near lifelong kidney disease journey. I have loved so many of them. It was difficult to even write this piece, because without nurse Suzie, Dr. Leiser, Dr. Schrader, and Dr. Taber, my kidney journey would have been impossible. Dr. Goggins represents the culmination of all my experiences with these awesome healthcare workers.

Suzie and Dr. Leiser took me through my pediatric experiences and gave me the strength to hold on until I was able to get my first transplant. Dr. Schrader believed in my tenacity to fight through dialysis when that transplant failed. Dr. Taber took me all the way through the evaluation for my second transplant and after-transplant care with a huge sense of humor.

The pinnacle of these experiences was there on a biopsy table, finger tapping on my forehead, calming me down and distracting me.

It was in the outpatient transplant center listening to Bruno sing his hit song "24K Magic" on a little phone screen.

It was on the ride home from the outpatient center with a bag of new medicines and a heart full of excitement and hope for the future.

For this, my healthcare heroes are Dr. Goggins and all those who brought me to him.

Joy Araujo is a Development Specialist at a non-profit 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.



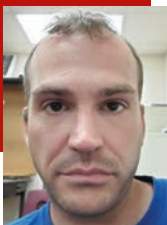
DIALYSIS WONDER WOMAN

3rd Place (tie), RSN 19th Annual Essay Contest

By Phillip Minnich

I am not a perfect patient. When I first began dialysis, I missed treatments, and not always accidentally. As I progressed in my journey through end-stage renal disease (ESRD) and became more educated, I realized the importance of not only attending every treatment but taking a more active role in my treatments. Twelve years later, while I consider myself to be a more educated and compliant patient, I still struggle at times. That struggle is different for every patient, but what we all have in common is that it is very real. Whether we do traditional in-center hemodialysis, nocturnal in-center hemodialysis, at-home hemodialysis with NxStage, or at-home peritoneal dialysis, there are times when we wonder, "Just how much longer can I keep this up?" Inevitably we mess up and may even want to just give up the fight altogether.

Phillip Minnich is 33 years old, and has been on dialysis for 12 years. He has experienced every dialysis modality, as well as one living donor kidney transplant. When he isn't working as a music teacher, he enjoys speaking with his fellow patients and caregivers about dialysis, transplant, and ESRD.



Fortunately for me, Judy has been there through it all.

I first began in-center hemodialysis on June 3, 2009. I was 21 and had just completed a rather tumultuous third year as an undergraduate music major. Tumultuous because throughout that entire academic year my health was deteriorating, and I felt like I was spending as much time in the hospital as I was on my studies. Even though I knew that dialysis was on the horizon, I did not want to accept it. That is probably why I ended up in the hospital with a tunneled catheter needing emergency hemodialysis instead of having a fistula inserted in my arm months prior, like my nephrologist had recommended.

Like I said: I was not a perfect patient, especially back then.

On May 29, 2013, I received a transplant from an incredible friend. I had hoped to have that transplant for at least 10 years; I got 16 months. Losing the transplant was the impetus for me to finally check out home dialysis. It was in September 2014 that I first properly met Judy. She had always worked at my clinic, but I did not know her prior to looking into home dialysis. What struck me was how kind she was, and how incredibly knowledgeable and experienced she

was about all things related to home dialysis. She taught me about the differences between peritoneal dialysis and NxStage. My first choice was peritoneal. I thought to myself, "No needles? No problem!" Well, not quite.

Fortunately, Judy knew better.

More than once, I called her with a problem. More than once, I had to run to the clinic for an emergency infusion of antibiotics into my peritoneum, and Judy was always the one to help me. It seemed that no matter the hour, she did not mind helping me. She seemed to have a trick up her sleeve for everything, and always had the answer.

I had to stop peritoneal dialysis in 2017 because of an unrelated infection, but I always knew that I wanted to return to home dialysis. I hated in-center, even though I loved the floor staff. I loved controlling my own treatments, I loved the feeling of autonomy that home dialysis provides, and I loved not having to leave home. It was just a matter of deciding to go back to peritoneal or trying this new-fangled NxStage. After discussing it with a friend who does NxStage, I decided to give it a try.

After all, I had done literally every other form of dialysis by then.

It was in February 2020, right as COVID-19 hit, that my NxStage training began. At that time, I had just begun a new job which threatened to interfere with my training schedule. Fortunately, Judy was willing to come in literally at 5 a.m. to do my NxStage training before I had to go to my new job. Thanks to her, I was able to do my NxStage training and my new job training simultaneously. It is not every day that someone is willing to go into their job before sunrise in the middle of winter specifically to help you. It really drove home to me how fortunate I am to have Judy as my home care nurse.

I am not a perfect patient. I do not know if I ever will be. But whatever struggles I face, I know Judy will be there to help guide me through them, even if it is at 5 a.m. in the middle of winter. After all, she is the Dialysis Wonder Woman.



Tabitha Taught me to LIVE, Not Just *Survive*

President's Pick, RSN 19th Annual Essay Contest

By Georgene Sims

Web ID: 5040

In March 2019, a door slammed shut. I found myself in the intensive care unit of my local hospital, dazed, in pain, and begging for relief. A parade of white coats streamed in and out, mirroring my consciousness. The stern faces of those with whom I was familiar should have alarmed me; but I was beyond that. I was ready to die and welcomed it. The pain in my legs was so great that the combinations of narcotics administered proved useless. The white coats were blunt: "We are not sure why you are failing here but we are bringing in specialists to look at you."

Three weeks later, I left the hospital with a permacath dangling from my chest, several rounds of hemodialysis behind me, going home to an uncertain future. A dizzying array of tests and treatments had been administered and the diagnosis was end-stage renal disease (ESRD) with a side of sepsis. I had heard of sepsis and that word echoed ominously in my brain. There were other frightening words too, like "transfusion" (apparently, I'd had two), and yet I was *alive*, and now that the pain was gone, I was actually excited.

My first visit to the dialysis clinic was a shock. There were all these chairs situated in a circular fashion around a nurses' station, and several patients looked curiously up at me as I reluctantly joined the club. This was quite different from my hospital experience where I was often the only patient in the room. The hum of the hemodialysis machines, the alarms, the scurrying of the professionals who attended to the alarms, the smell of disinfectant—all of this induced sensory overload. It was cold. I never did get used to the cold. That clinic was my new home, my tether to life itself. I would learn how this works and be the most compliant patient they'd ever met. I would learn to embrace the four hours a day, three days a week I'd be trapped in a chair and be grateful. After all, I wanted to live. Right?

One day, a few months into this routine, the clinical director stopped by my chair, and with her arms crossed and head cocked to the side, she muttered, "You really don't belong in here, you're so young. Have you ever considered PD?" I had never heard of "PD," so she scuttled off to summon a "PD nurse." I learned

that PD, or peritoneal dialysis, was a type of dialysis that would free me from that chair, allowing me to do treatments at home even while I slept. No needles, no blood coursing through tubes, just a catheter surgically placed in my abdomen that, through some medical magic, would introduce a solution into my body cavity and then remove toxins and excess fluid.

It is at this point that my healthcare hero enters my story. She is my PD nurse, Tabitha. This tiny, energetic, kind, patient person was going to train me, monitor me, and become my new lifeline. Training meant an intimidating book of material to cover and procedures to practice, but I tackled each lesson with enthusiasm, determined to do everything perfectly. My lab results would be stellar; I'd show the team that their faith in me was warranted.

Over two years later, as I reflect on this journey, I believe that the most important lesson Tabitha taught me was to live, not just survive. She encouraged me to have fun, lighten up, and expect the best. As I am a rather pessimistic person, she was exactly what I needed to find balance in my life. This new normal would not be a slow-moving death sentence, littered with A+ lab reports. There was still a lot of life to live! Tabitha encouraged me to get out of the house, dine out (while gently reminding me to take my binders), travel, and find new adventures. She taught me to be meticulous in my procedures, but she modeled how to find humor in my new way of life.

I have been extremely fortunate to have an amazing healthcare team, including a primary care doctor and nephrologist who collaborated to save my life. It was, however, during one of the darkest periods of my life that Tabitha brought kindness and light, offering hope. She is always a phone call away and knowing that, I can get through the challenges of ESRD and thrive.

Georgene Sims is a retired educator, whose hobbies include writing, gardening and community cat rescue. She holds a BA in political science and a Master of Arts in Teaching. She lives in NW Indiana with her husband, Jason, and daughter, Meghan.



**Together, let's
work towards a
treatment option
for wounds
in patients
on dialysis**

**Help us research
an investigational
drug that might
help patients
with calciphylaxis**

The CALCIPHYX Study is researching an investigational drug to find out if it can help improve calciphylaxis wound healing and reduce wound pain.

You may be able to join the CALCIPHYX Study if you:

- have at least 1 painful calciphylaxis wound
- have not received bisphosphonates (medications that help prevent or slow down bone thinning) in the past 3 months
- are not expected to have a kidney transplant within the next 6 months
- adhere to your dialysis treatments.

The investigational drug is:

- not approved for use outside of this clinical research study
- given in addition to standard treatment for calciphylaxis wounds and pain
- administered during your usual dialysis sessions.

If you are interested in learning more about the CALCIPHYX Study, you can also contact:

Want to know more?



**Visit [ClinicalTrials.gov](https://clinicaltrials.gov)
Search NCT04195906**

or



**Visit the CALCIPHYX Website
<https://calciphylxstudy.com/>**

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David Trujillo: **LIVING PROOF THAT “CAN’T” IS NOT A WORD**

By Mary Nesfield



Photography by Michael Hermogeno IG: @8x10proofs

“When You Wish Upon a Star” —Jiminy Cricket, from Disney Productions “Pinocchio”

Imagine being the parent of a very sick one-month-old infant. You take him to the emergency room looking for help and are told your child has renal dysplasia. Now imagine what it’s like to only hear three dreadful words from the ER doctor: “Call your pastor.” Those are the words Danny and Maria Trujillo heard when their precious baby boy was turned away by a doctor who offered them no hope.

Fast forward to today. We now see a different picture. David survived. And these days, David wears his big smile like a badge of courage. When his friends ask him why, he replies, “I have so much to be grateful for.”

He is a man of faith who believes things happen for a reason.

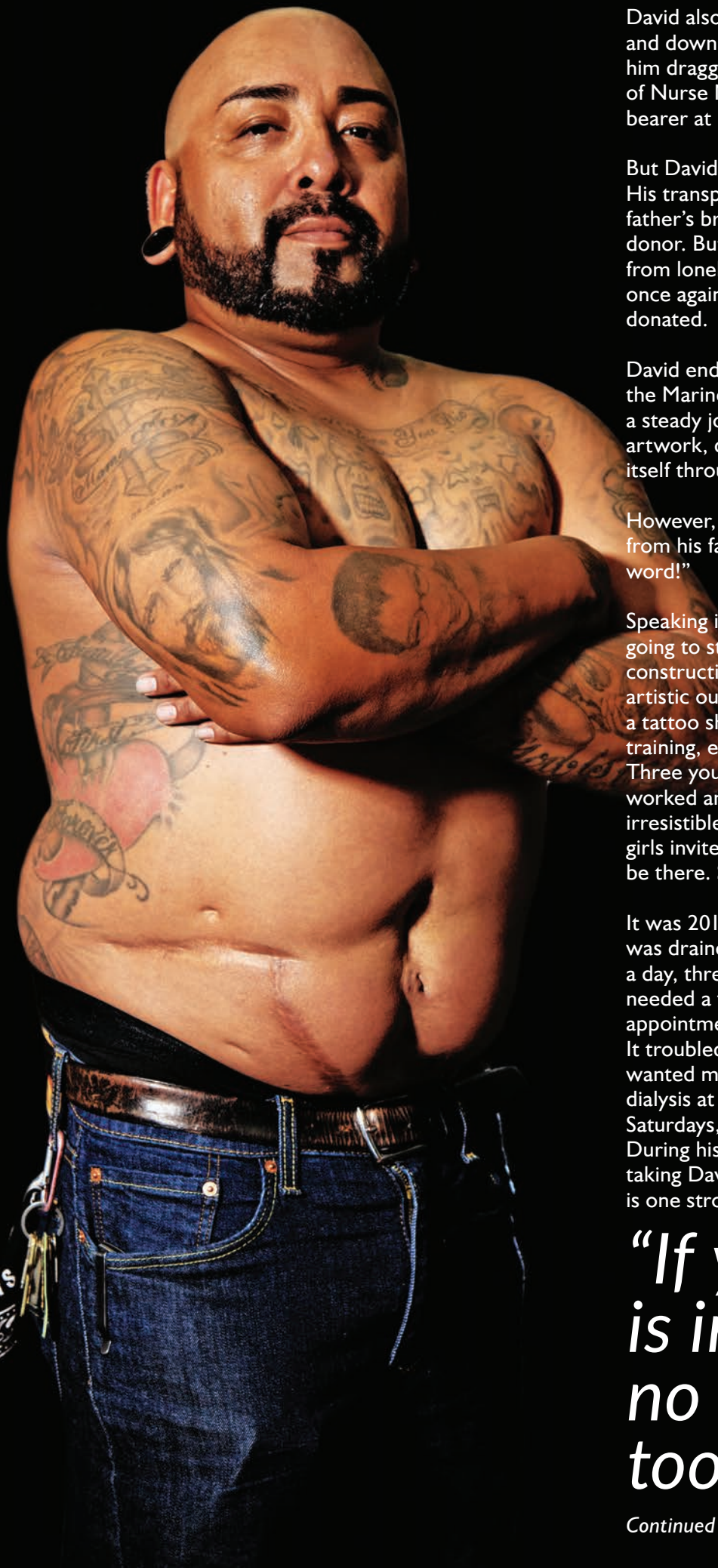
One reason for his gratitude is tied to that ER room almost forty years ago when a different doctor overheard the heartbreaking words delivered to David’s parents. Instead of remaining silent, this doctor referred them to UCLA where David was placed in a crib and hooked up to a dialysis machine in the new pediatric nephrology division. He was too young for a kidney transplant. Nightly dialysis kept him alive. Needles, needles, and more needles caused tears to run down his face. David’s mother stayed by his side, ready to do whatever it took to give him a chance. The doctors helped her master the peritoneal dialysis procedure that allowed her to take her baby home and treat him herself.

“She is the most wonderful mother I could ask for,” David says. “She is the epitome of love and selflessness.” Finally, when David was three, old enough for a transplant, his father was tested and matched as a donor. However, due to the continual medical trauma, David eventually told his father he didn’t want to live.

I asked David what he remembers about those painful early years. Looking back, he still gets emotional, but not over the pain he suffered. It’s that gratitude again that he feels. “The nurses were like moms to me,” he says. But it wasn’t just the nurses.

“They were all beautiful people,” he assures me. He chuckles as he recalls the big brown chair that he sat in watching “The Wizard of Oz” and “Pinocchio” movies at the hospital each night. When he talks about UCLA’s “

Star Room” where kids like him went to play, a sense of wonder and joy comes through in his voice as he says, “The room would be darkened so that we could watch stars as they were projected onto the ceiling.” David also enjoyed drawing. Sitting in his hospital room, he’d illustrate cards for other kids, his brother and sister included.



David also has special memories of participating in races up and down the hospital halls, with his dad running alongside him dragging his IV pole. And he proudly shares memories of Nurse Mary, and the day he walked down the aisle as ring bearer at her wedding.

But David's life was to be a series of sucker punches. His transplanted kidney lasted until he was 12. Art, his father's brother, stepped up to become David's second donor. But David was missing a lot of school and suffering from loneliness. More disappointment came in 2003, but once again family came through. His uncle's wife, Yolanda, donated.

David endured more "punches." His scarred body caused the Marine Corps to reject him, and his ability to hold down a steady job was hindered. But all along, he kept up with his artwork, dabbling in charcoal and acrylics. His pain revealed itself through the angry faces he painted on canvas.

However, the one critical lesson David took to heart came from his father who many years ago said, "'Can't' is not a word!"

Speaking in a powerful tone, David assures, "Nothing was going to stop me from pursuing my dreams." He landed a construction job that started at 3 a.m. He felt he needed an artistic outlet to keep it together, so after work he'd head to a tattoo shop where he was an apprentice. He needed job training, even if it meant working without pay. And it paid off. Three young ladies came into the tattoo shop where David worked and asked for tattoos. David found one of them irresistible. "It was love at first sight," he recalls. One of the girls invited him to a party. He went, hoping Brittany would be there. She was. The two began dating.

It was 2012 when David's third kidney began to fail. David was drained, having to undergo dialysis treatments four hours a day, three or four days a week. He lost 40 pounds. He needed a fourth transplant. Brittany began driving him to his appointments and reminding him about his daily medications. It troubled David to think that she'd become his caregiver. He wanted more than that. But Brittany persevered. He'd go to dialysis at 5 a.m. Mondays, Wednesdays, Fridays, and some Saturdays, and then to work at noon seven days a week. During his treatments Brittany slept in the car outside. After taking David home, she'd begin her day as a hairdresser. "She is one strong woman," he adds.

*"If your heart
is in your dream,
no request is
too extreme."*

Continued on page 16



David's brother, Dustin, tested to be a donor but was told he'd be a better match for a young girl named Aimee. And, via the kidney exchange program, David would receive a kidney from Stanley, Aimee's father-in-law. David's extended family—including Aimee, Stanley, and the doctors, nurses, and others who cared for him—was expanding. For that he was grateful. "I'll hold them all in my heart forever," he adds. But there was still one thing he wished for, and that was a family of his own.

David's fourth transplant, and recovery, was made all the more difficult because of the scar tissue that was left behind from previous surgeries. Brittany thought David could use a new friend to help him get through his recovery. She introduced him to Frank, the beloved dog that the couple still dotes on today. "I was becoming more and more confident that she loved me for me, not for my disease." Their engagement came six years after they first met.

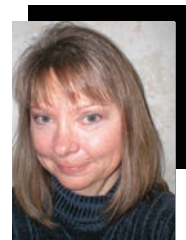


David and his brother are currently engineers at their father's construction company. Having a physically demanding job is tough for anyone but David takes care to drink lots of water and he reenergizes by taking plenty of breaks from commandeering heavy equipment. And he and Brittany have yet another family member to dote on. After doctors told David he could never father a child, Zion was born. She's now seven years old. And when he can, David gives back by volunteering at the Renal Support Network.

Still another punch to the gut was to test David's faith. It came in 2020. He was back in the hospital struggling to breathe for a week after contracting COVID-19. He lay in bed not able to sing, but he promised God he would, because after all, "can't" is not a word. Now he starts every day by singing the song, "Give Me Faith." Faith mixed with gratitude keeps that big, beautiful smile on David's face. "It's because I have so much to be grateful for," he emphasizes again. No more angry faces painted on empty canvas because he is not who he once was.

What words of advice does David have for others in similar situations? "Remember, 'can't' is not a word! There's definitely hope for everyone." —To quote the words of Jiminy Cricket, "If your heart is in your dream, no request is too extreme."

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.



An Attractive Non-Surgical AV Fistula Creation Option

The WavelinQ™ EndoAVF System uses two thin, flexible, magnetic catheters and a burst of RF energy to create an AV fistula without open surgery. This non-surgical approach helps to reduce surgical scarring and can minimize arm disfigurement often associated with traditional AV fistula surgery.

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The WavelinQ™ EndoAVF System is indicated for the creation of an arteriovenous fistula (AVF) using concomitant ulnar artery and ulnar vein or concomitant radial artery and radial vein in patients with minimum artery and vein diameters of 2.0 mm at the fistula creation site who have chronic kidney disease and need hemodialysis.

Please consult product labels and instructions for use for indications, contraindications, hazards, warnings and precautions.

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Itching TO KNOW WHY....

By Mandy Trolinger, MS, RD, PA-C

As someone who has been on dialysis, I know that there are a variety of symptoms all of us experience. As a former dialysis patient and physician assistant (PA) who treats people with kidney failure, I have met several people who do well with dialysis, but I have met some that deal with a very annoying symptom ... ITCHING!

Itching can be minor, or it can be so extreme that it interferes with sleeping or being able to focus on daily activities, resulting in a decreased quality of life. People with kidney disease, researchers, and providers have tried to fully understand why some people experience itching and how it occurs. Overall, it appears to be caused by an immune system dysfunction, a high level of toxins, poorly controlled labs, or an imbalance of receptors that regulate pain in the body. Several studies have found that itching occurs more often in people who are either not receiving adequate dialysis; have uncontrolled phosphorus, calcium, and/or parathyroid levels; have dry skin; or have high magnesium or aluminum levels.

Itching can occur at any time. Some people experience it more during dialysis, and some when they are not on dialysis. Some have found that heat triggers the itching as well. Itching tends to occur less in children that have kidney disease as compared to adults. One dialysis type does not appear to cause itching more than any other, unless one is under-dialyzed. A change in dialysis modalities can improve this.

Several hypotheses exist as to why itching occurs in the kidney population. Is it an overall inflammatory condition rather than a “skin disorder,” or is it due to imbalances in different receptors in the body that control itching?

When discussing itching with your provider it is important to rule out other causes not related to dialysis that might easily be treated. If no other cause can be found, the following are some treatment methods to try that may alleviate or resolve itching:

- 1) Keep your labs controlled. Some things that can cause itching if not controlled include dialysis adequacy (Kt/V), and phosphorus, calcium, and parathyroid levels.
- 2) Topical treatments. Emollients can be helpful if you have very dry skin. There are three main groups of emollients: lotions, creams, and ointments. Ointments tend to be “messy” and do not absorb quickly into the skin. If this is bothersome, you can try a cream during the day and apply an emollient (e.g., Aquaphor or Eucerin—look for the ones in a jar) before you go to bed. It is best to apply them after bathing to keep the moisture in your skin. It can take up to six weeks to notice a decrease in symptoms.
- 3) Oral medications. Over the counter medications like Diphenhydramine and Hydroxyzine can help, but they can be sedating. Loratadine is another option that is less sedating. Prescription medications that might help include Gabapentin or Pregabalin, but these can be sedating and must be dosed according to amount of renal function. Please check with your medical provider before taking any oral medications. Antidepressants have also been researched, but studies are limited.
- 4) Other therapies. In severe cases, UVB therapy might be an option, but this is associated with an increased risk of cancer and should not be used in people with weakened immune systems. Research is continuing to explore if Montelukast or Omega 3 fatty acids help. Recently, the injectable medication Dikelocephalid was approved for itching in adult hemodialysis patients. It works by targeting certain receptors in the body. However, this medication can have side effects such as dizziness, nausea, tiredness, and mental status changes as well.

Itching can be devastating for some people with kidney disease. Make sure you keep your labs within target range and work with your healthcare provider to find the best treatment so you can not only relieve symptoms, but also improve your quality of life.

SHARE YOUR SPARE

RSN's "Share Your Spare" campaign 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.



RSN's organ donation conversation kits are available for a donation of \$50!

Learn more at
RSNhope.org/ShareYourSpare

Mandy Trolinger, MS, RD, PA-C, is a dietitian and physician assistant who works at Rocky Mountain Kidney Care in Denver, CO. She is also a two-time kidney transplant recipient and former dialysis patient.



Learn how to slow the progression of CKD using a low protein diet supplemented with a Keto-analogue.



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KIDNEY CARE ADVOCACY

Get involved and make a difference!



According to the latest U.S. Renal Data System Report, more than 661,000 Americans are being treated for kidney failure, also called End-Stage Renal Disease (ESRD). Of these, 468,000 are on dialysis and more than 193,000 have a functioning kidney transplant. Each year 100,000 people are newly diagnosed with stage 5 chronic kidney disease (CKD) which is the same as ESRD. About 30 million U.S. adults are estimated to have CKD and most are undiagnosed. Over 97,000 people in the U.S. are waiting for a kidney transplant.

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

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

5

Kidney-Friendly Breakfast in a Mug Recipes

By Katherine Schury

Breakfast is ready, come and get it! Just eggs, a few pantry staples, and a microwave oven are all that is needed for five quick and easy kidney-friendly breakfasts. Make ahead for an even faster route to your tummy the next day.



Italian Roots

1 mug = 1 serving

Ingredients

2 large whole raw eggs
 ½ tablespoon shredded parmesan cheese
 ½ teaspoon ground basil (or one fresh basil leaf)
 ½ teaspoon oregano (fresh or dried)
 ¼ teaspoon garlic (fresh or dried)

Directions

Grease a microwave-safe coffee mug with a nonstick oil spray.
 Crack both of the eggs into the mug.
 Add the parmesan cheese, basil, oregano, and garlic.
 Mix all of the ingredients together with a spoon or fork.
 Place the mug in the microwave and cook on the highest power (usually around 1200 watts) for 1-2 minutes or until done. Eat directly from mug or unmold onto a plate.



Mediterranean Style


1 mug = 1 serving

Ingredients

2 large whole raw eggs
 1 tablespoon crumbled feta cheese
 2 raw spinach leaves
 2 fresh chives

Directions

Grease a microwave-safe coffee mug with nonstick oil spray.
 Crack both eggs into the mug.
 Add the feta cheese and spinach.
 Mix all of the ingredients together with a spoon or fork.
 Place the mug in the microwave and cook on the highest power (usually around 1200 watts) for 1-2 minutes or until done. Eat directly from mug or unmold onto a plate.



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

Steven, Potter (Actor portrayal)

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

Lutonix™ 035

Drug Coated Balloon PTA Catheter

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

Lutonix AV Clinical 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 95.0% 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 blood thinning 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.

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Egg Mug Recipes

Continued from page 20



Dessert for Breakfast

1 mug = 1 serving

Ingredients

¼ cup quick-cooking plain oatmeal, dry
1 large whole raw egg
½ teaspoon brown sugar
1 tablespoon any type of berry (fresh, dried, frozen, or jam)
2 fresh mint leaves

Directions

Grease a microwave-safe coffee mug with nonstick oil spray.

Add the oatmeal, and crack the egg in the mug.

Stir the two together.

Sprinkle in the brown sugar.

Place the mug in the microwave and cook on the highest power (usually around 1200 watts) for 1-2 minutes or until done. Top with the berries or jam, and mint leaves.



The Taste of Country Time

1 mug = 1 serving

Ingredients

1 large whole raw egg
½ cup unsweetened applesauce
1 teaspoon ground cinnamon
1 fresh mint leaf

Directions

Grease a microwave-safe coffee mug with nonstick oil spray.

Add unsweetened applesauce to the mug.

Crack the egg into the mug.

Stir both ingredients.

Add the cinnamon.

Place the mug in the microwave and cook on the highest power (usually around 1200 watts) for 1-2 minutes or until done. Eat directly from mug or unmold onto a plate.



Eccentric Taste

1 mug = 1 serving

Ingredients

2 large whole raw eggs
½ teaspoon chili powder
½ teaspoon grated parmesan cheese
½ sprig of fresh rosemary (or dried)

Directions

Grease a microwave-safe coffee mug with nonstick oil spray.

Crack the eggs into the mug.

Add the chili powder, parmesan cheese, and rosemary.

Mix the ingredients together.

Place the mug in the microwave and cook on the highest power (usually around 1200 watts) for 1-2 minutes or until done. Eat directly from mug or unmold onto a plate.



Katherine Schury is a Clinical Regulatory Coordinator in clinical trials at Loyola University Chicago. She is also the social media chair of the renal practice group through the Academy of Nutrition and Dietetics.

Recipe/single serving	Calories	Protein (g)	Fat (g)	Sodium (mg)	Potassium (mg)	Calcium (mg)	Phosphorus (mg)
Italian Roots	158	14	11	183	159	97	215
Mediterranean Style	114	12	8	245	192	119	157
Dessert for Breakfast	173	9	6	73	167	42	185
The Taste of Country Time	126	6	5	74	165	61	106
Eccentric Taste	158	14	10	202	172	90	221

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With Bob Loeper
Web ID 3085

Learn how to get help if your local dialysis clinic shuts down for any reason.



With Jessica Frysz
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This busy vet tech tells how she thrived during her 28 years on dialysis.



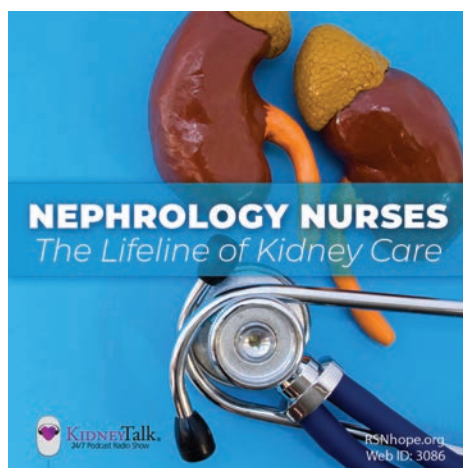
With George Franklin III
Web ID 3084

Transplant Quarter Century Club President sheds light on life with a donated kidney.



With Victor Gura, MD
Web ID 3076

After 20-plus years of research, this pioneer is closing in on an alternative to traditional dialysis.



With Gail Dewald, RN, CNN
Web ID 3086

Gail talks about her three decades of providing personalized care for people with kidney disease.



With Katy Wilkens, RD and Beth Shanaman, RD
Web ID 3088

These nutrition experts talk about how you can manage kidney disease with the foods you eat.

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— Jeff, dialysis patient



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Monday - Friday

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About RSN

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

KidneyTalk

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Renal Support Network's 23rd Annual Teen Prom

Event for people ages 14-24 who have kidney disease

A surreal, colorful illustration serves as the background. It depicts a large, glowing yellow sun or moon in a dark, starry sky. Below it, a small figure of a person stands on a path that leads towards the horizon. The path is flanked by two large, golden, hand-like structures that appear to be holding or supporting the path. The entire scene is reflected in a body of water at the bottom, creating a mirror effect. The colors are vibrant and dreamlike, with a mix of blues, yellows, and purples.

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Sunday, January 16, 2022 4pm PT

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Save the Date for These Upcoming RSN Events!

**2nd Annual RSN Virtual Holiday Concert
Sunday, December 5, 2021**

**23rd Annual Renal Teen Prom
Sunday, January 16, 2022**

**2nd Annual Artistic Contest of Hope
Theme to be Announced March 2022**

**National Kidney Month
March 2022**

**National Organ Donor Awareness Month
April 2022**

**20th Annual Essay Contest
Theme to be Announced May 2022**

