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

Announcing RSN's 17th Annual Essay Contest Winners!

The Warrior by Mary Wu
1st Place Winning Essay

Sex, Meds & CKD
How to work around the challenges of CKD for fulfilling intimacy

Is it Safe to Keep My Pets?
RSN Founder & President Lori Hartwell's infection safety tips

Exercise for People who have Chronic Kidney Disease
Tips for getting started and sticking with it!

Live&Give is now KidneyTalk™ magazine!
Check out RSNhope.org to read this issue and all past issues online. PDF available for Download too!
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.
Anyone who knows me or follows me on social media will tell you I love animals. I often post an orphaned animal in need of a second chance at life or a cherished pet that needs a new home due to the passing of a family member. My husband, Dean, and I also foster animals from local rescue organizations to help them transition from a shelter to a new home. Our family comprises of four dogs and one cat, but the star of our menagerie is our African grey parrot, Johnny. With a vocabulary nearing 300 words, many of them rather cheeky, Johnny keeps us all in stitches.

If you are a pet owner, you know the many benefits of the companionship they provide. The unconditional love that my pets shower on me has brought immeasurable joy to my life. I can’t imagine life without them.

My animals always appear to be happy. It takes so little to please them! A bone, a toss of a toy, or a cuddle creates excitement that is spirit-lifting.

Scientists are now agreeing with those of us who know the benefits of pet ownership. Pets help improve their owners’ mental health and reduce their anxiety. People tend to be happier in the presence of animals. Studies have also shown how pets can reduce their owners’ blood pressure and improve the outcome of those who have suffered a heart attack.

Therapy dogs that make the rounds in hospitals demonstrate how they benefit our well-being. During one of my long hospital stays, my anxiety dropped immensely when a beautiful standard poodle came by to say hello to me. I forgot about my situation as I gazed into the dog’s eyes and ran my hand over his beautiful curly fur.

Yes, having a pet is a responsibility, and if you have chronic kidney disease you must take extra precautions to stay safe and avoid infection. Consider the following quick tips, but also check out the additional resources I listed at the end of this article.

• Wash your hands after petting, touching, or feeding pets, and after cleaning up messes. Before taking medicines and handling food, dishes, or other things in the kitchen, always wash your hands.

Continued on page 20

Lori Hartwell is the Founder & President of Renal Support Network (RSN) and the host of KidneyTalk™ Podcast Radio show. 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.
At the tiny tyke age of three years old and back in 1985 when kidney donation/transplantation was not as advanced as it is now, I was diagnosed with renal agenesis. Renal agenesis means that my kidneys never fully developed. I had one kidney shrinking and the other deformed. I was put on peritoneal dialysis immediately. No one in my family could donate a kidney to me, and so it was a scary reality that for me to live my life off of a dialysis machine, someone had to die. At age 5 and again at age 12 I received kidney transplants, both from deceased donors. There is not a day that goes by that I do not think of both of my kidney donors and their loved ones.

For over 30 years, anything and everything related to “kidneys” has been ever-present in my life. In all those years, I have come to experience that dealing with a lifetime and lifelong chronic illness demands much from us day in and day out. We struggle with ongoing issues: control issues and a constant give and take; struggling to see the big picture when there are loads of little details to recall and execute (medications, doctor appointments, etc.); and, most of all, picking our battles.

I do not know about you, but I often feel that battles pick us. It always feels that it is a fight, and it is never easy or simple. Being a warrior means standing up rather than sitting down even when we are at our worst and most vulnerable. Yet, it also means not being scared to show our weaknesses, because, to be at our strongest, we have to embrace our weakness. Our worst and weakest points have made all of us stronger.

Being a warrior is not being defined or controlled by what happens to us, but what we can make happen in the best of ways from the worst of ways and to ALWAYS look at the bigger picture and have hope—essentially, picking our battles from the battles that have picked us.

Every fight cannot be fought. Every battle cannot be won. We will lose. We will win. We learn as we lose, win, and go to live life to the fullest, for we do not know the gift of life until we are about to lose life.

I wrote this poem “The Warrior” as reminder to all of us about the warrior within all of us that comes out brighter and fiercer when battles must be fought. We are all warriors. Kidney Warriors. Always wear your bean badge(s) proudly.
Managing your emotional health

Finding balance between life and dialysis

You may feel a range of emotions as you begin life on dialysis. Your care team will be there every step of the way to help you manage your emotional well-being and answer questions you may have.

Learn more at FreseniusKidneyCare.com/EmotionalHealth
When is the best time to admit to a deep desire to own a cape? A desire so strong, you have to pursue the notion with bold determination? Ignoring judgements some may have by following through with conviction and announcing to the world, “I really, really, really want a cape. A cape to wear with confidence whenever the mood strikes! Oh! And can you make that a purple cape with bits of lightning slivered across it?”

It’s more than just owning a cape, it’s wearing that cape with attitude. An attitude of triumph, strength, and grit. A pile of attitude bursting forth like a Navy Seal going in for the rescue. An attitude releasing into the world a thunderous roar of triumph. A well fought triumph over those four little words that change a person’s life in a heartbeat:

“You have kidney disease.”

Shock.
Disbelief.
Stifled tears of panic.
Deep gulp and a question. “Are you sure?”

“Quite sure. All blood work and tests confirm the diagnosis.”

Bam! So, now what? Kidney disease sounds pretty scary. It’s devastating to hear and challenging to wrap your head around. Yet, while end stage renal disease is a life changer, it’s a far cry from being a life stopper.

Attitude is the game changer. And if you have a cape to go along with the plan? Well, let’s just say, your warrior self is born. Grab that cape knowing you are a force to be reckoned with.

Hah! Take that, ESRD! You are in for a battle like no other. Doing a daily happy dance is the mission.

“Stay Strong” is the motto.
Wearing your cape of TRIUMPH is the anchor.
Time to take stock and flesh out the plan.

First, listen to the experts. Ask lots of questions. Learn all you can about options. Do everything possible to follow the program. Pull in your support and back-up team. Know that you are surrounded by a community interested in successful navigation of the mine field of blips and detours.

“What needs to be done to get this cape party started?”

Find a bona fide cape maker and give her your ideas for the design. My cape has a purple background. The lightning flashes swirling around the foreground are a blueprint of the kidney journey that gently swallowed me 27 years ago. With a collection of beautiful scars to work with, each one is living proof of victory. Reminders to say thank you.

Dates, faces, and names fill in the borders on my purple cape. Each one diving deeper into the adventure that is my now. There have to be at least 17 smiley faces, three puppy dogs, four bouquets of purple lilacs, marigolds, and two giraffes. Lastly, the cape will be embroidered with gold edgings and glow-in-the-dark pineapples.

Everyone deserves a cape. From dialysis to transplants, to fistulas and hospital stays, it’s always better with a cape. Cape of TRIUMPH. Wear it. Throw some attitude, it’s warrior time.

* End Stage Renal Disease (ESRD)

I get my kicks from walking, waking up early and staying up late, pretend gardening, taking naps, hanging with my favorite peeps, sharing home-baked cheese and carrot cakes, organizing stuff, and playing with words. I received my first kidney transplant from my brother Brian in 1994. I received a second transplant on April 8, 2014 after 8 years of home hemodialysis. I am a self-proclaimed life learner with arms stretched to the sky in triumph!
AMGEN helps support the
NEPHROLOGY COMMUNITY
In the beginning I was a painfully shy, embarrassingly awkward, and endlessly imaginative little toothpick of a boy who was completely unaware of the shenanigans deep within the recesses of my fist-shaped kidneys. Simply put, they were lonely.

They yearned to live beyond themselves and create offspring. Unfortunately, their attempt to spawn led to horribly unforeseen circumstances. Instead of fostering fellow filtering systems, they ended up inviting harmful and rather unpleasant cysts to invade their nether regions. Thus began my fateful journey as a reluctant survivor of kidney disease.

In glancing back through 38 years of narrow grafts, bulging fistulas, soul-draining dialysis and life-granting transplants, here is the wisdom and advice I’ve garnered through reaching nearly half a century of survival on this spinning blue ball of happenstance.

**You Are NOT Your Kidney Disease (and Vice-Versa)**

During my third year of endurance squirming in that plain beige chair, planted on those egg white square foot tiles, surrounded by bland pictures affixed to off-grey walls, an epiphany of sizable proportions struck, nearly toppling my dialysis machine.

My identity had been completely engulfed by my condition. From conversations to social media to navigating daily life—the physical side effects had managed to burrow themselves deep into my psyche and manhandle my personality.

With this knowledge fully realized, I returned to the Stacy Basics by reacquainting myself with what made life thrillingly fantastical for me: engaging film classics, politically incorrect conversations, and the complete satisfaction of a well-digested taco.

Fatigue, chronic pain, nausea, weakness and fourteen other ailments associated with kidney disease will combine forces to steal what you so richly deserve. Reignite your passions and allow them to be the personal distraction from your present state of existence. Failing to address this will drown you in confusion, invite depression, and rob you of everything that matters. Trust me, I know whereof I speak and I don’t wish the same for you.

**Strengthen Your Backbone**

Human beings cannot deny human nature. More specifically, whether it’s medical personnel or random patients, people may associate your weakened physical state with a lack of personal resolve.

Whether you’re stepping past that imposing fire door entrance to the dialysis clinic floor or undergoing tests to qualify for the vaunted transplant list, you will have to be your own singular advocate for your treatment and well-being.

For many treatment sessions, I was forced to be seated far too close to King Dullard. Once the needles had invaded his arm and his blood was making a mad dash to escape his presence, he would turn HIS MUSIC up to FULL VOLUME because he was ENTITLED to said BEHAVIOR.

There was also a gentleman who I privately referred to as Shuffling, Hulking Tech who would ignore my suggestions for needle insertion,
claiming his technique was fostered over twenty years of experience, and he would go full bore into my arm causing pain, bleeding, and discomfort.

Speak up. Defend yourself. Don’t take any guff from anyone. ANYONE.

For bonus points (if you can control your understandable anger) approach the proper individuals with a calm, measured tone, but with a look in your eyes that shows you mean business.

"Stacy’s kinda weird. Silly and funny and awkward and weird. And, like, really sleepy. We don’t go on many adventures cuz of that. When I woke up I was really scared and confused because there were four other kidneys in here just like me, but, um, well... not like me at all. His Mom’s kidney is over there and his sister’s is right near me. I talk to them, but they never talk back. Stacy makes me sad sometimes because he doesn’t feel like he deserves any of us. And sometimes, on the good days, we have lots and lots of fun together. I think I’m done now. Did I mention he’s kinda weird?” –Filbert the Kidney

Embrace Warmly, Nourish Often, and Never Neglect Your Best Friend: HOPE

"Remember Red, hope is a good thing, maybe the best of things, and no good thing ever dies.” - Andy Dufresne, The Shawshank Redemption

If there’s any film that has ever been created that symbolizes the shock, struggle, and eventual redemption of an individual fighting to survive harrowing circumstances, it’s this one. Hope is the guiding force of the entire narrative and I have found that it completely encapsulates what we are enduring without directly referencing our circumstances.

Hope flickers when you successfully complete a dialysis session and travel home refreshed. Hope flutters when you finally find the perfect altruistic donor to save your innocent life. Hope flutters when the phone call you’ve been waiting endlessly to arrive rings true with the offer of a healthy kidney transplant.

Yet hope flounders when you cease to acknowledge its presence.

My hope for you is to stand tall, acknowledge your worth and fight for every smidgen of health you can.

YOU deserve it. And I’m rooting for you wholeheartedly.

And that, my fellow Kidney Warriors, is how you freaking win.

Renadyl™ utilizes highly targeted, specific strains of probiotics to stabilize the gut flora and remove harmful uremic toxins which the impaired Kidney does not remove.

- All-Natural
- Non-GMO
- Available without a Prescription!

Order direct at www.renadyl.com or call toll-free 1-888-271-2560

*These statements have not been approved by the Food and Drug Administration. This product is not intended to diagnose, treat, cure, or prevent disease.
As a young girl, I distinctly remember my mother’s toolbox. It was a large black box that held a variety of helpful tools—a hammer, wrenches, and screwdrivers of all sorts. I would see this toolbox come out to solve numerous everyday problems, like exchanging batteries in toys and hanging curtain rods. My mother was a strong, handy woman that often took it upon herself to fix things. All she needed was her toolbox.

I would like to think that I am like my mother. As a young girl, I was also a young kidney patient, battling nephrotic syndrome, then end stage renal disease, then dialysis, then a transplant surgery, then rejecting said transplant, then more dialysis, then another transplant surgery. I was constantly in battle. However, I feel victorious. I may have battled treatments like large doses of prednisone, biopsies, and both hemodialysis and peritoneal dialysis, but I have come out ahead. This is because, like my mother, I had my toolbox.

The day in 1998 that I awoke, abruptly and confusingly, with my eyes swollen nearly shut, was the day I found out I was chronically ill. It was a scary time for a child, who would eventually lose much of her childhood due to the lows of kidney disease and treatments. However, I started assembling my toolbox at an early age.

That day when I was diagnosed with kidney disease was the day I earned my first tool—courage. It takes courage to wake up and keep battling kidney disease, especially in the face of mass uncertainty. “Will the medicines work this round?” I would ask myself. “Will I survive this?” With a healthy sense of courage, I faced every day at my best, listening even as a ten-year-old to the words of my doctors, taking notes to keep myself healthy. I had the courage to face every day as my best, adhering to a sometimes frightening treatment and medication regimen while coping with uncertainty about life.

Then there was the day at the age of sixteen when my doctor told me, exasperated and visibly upset, that I would need dialysis or a transplant. I would feel relief, but also some apprehension. Would the surgery be successful? Would the kidney respond well to my body? What will life be like afterwards?

However, one emotion trumped them all—joy. This was pure, unadulterated joy at a new lease on life. Choosing to experience joy completed my toolbox. Joy helped me celebrate and stay positive even when my lab results would come back unsatisfactory, when I lost my first transplant, and when everyday stressors of transplant life started to affect me. Joy is something that I choose every day, regardless of external circumstances.

I believe that my battle with kidney disease is won on a daily basis when I use the tools from my toolbox: courage, patience, and joy. Like my mother solved everyday household problems with her handy toolbox, I solve my everyday kidney disease-related problems with the tools I have earned by battling this disease for most of my life. Every day, I carry my toolbox with me wherever I go, earning new tools as I continue to battle.

Right now, I am living with my second transplant, utilizing courage to get me through the anxiety that creeps in as a remnant of my prior rejection. I continue moving forward in my life, making up for lost time, using patience to remind myself that I am on my own life schedule and that I will “get there” where I want to be if I just keep moving. Then I choose joy and smile through it all, because where joy is not present, neither is abundant life. These tools, packed neatly away in my box, ready to be wielded at any time, give me the ability to battle kidney disease and win.

Joy Araujo is a former hemodialysis and peritoneal dialysis patient who now living with her second new kidney! She is a Biblical Studies student at Anderson University in Indiana and enjoys volunteering and spending time with her dachshund, Franklin.

Joy Araujo is a former hemodialysis and peritoneal dialysis patient who now living with her second new kidney! She is a Biblical Studies student at Anderson University in Indiana and enjoys volunteering and spending time with her dachshund, Franklin.

Joy Araujo is a former hemodialysis and peritoneal dialysis patient who now living with her second new kidney! She is a Biblical Studies student at Anderson University in Indiana and enjoys volunteering and spending time with her dachshund, Franklin.
Akebia + Keryx
Better Together

UNITED BY A PIONEERING SPIRIT. DEDICATED TO IMPROVING THE LIVES OF PEOPLE WITH KIDNEY DISEASE.

Akebia Therapeutics and Keryx Biopharmaceuticals are now one—creating a fully integrated company that will continue to be fully dedicated to the renal community. For years, each organization has gone to great lengths in their commitment to people living with kidney disease—and now that they’ve merged, you can expect even more.

Together, we hope to build stronger relationships with healthcare providers—so we can collaborate in making an even bigger difference in patients’ lives.

At Akebia Therapeutics, reshaping the future starts with reinforcing our commitment to the millions living with kidney disease. Keep up with our progress at Akebia.com.
YES, I AM
A 40-year Survivor’s Declaration
President’s Pick Essay
By Tim Atkins

I watch the young man, shivering, curled up in a ball at the end of the couch I’m sitting on. You hear about addiction, but hearing about it and seeing it are two different things. Heroin withdrawal is a nasty beast... especially when it’s going on a few feet from you. I know he’s fighting a battle with that beast. And I’m supposed to encourage these guys?

I was asked to come here tonight and speak about my life with kidney disease, how I “overcome the challenges.” Man, I wish they had never asked me to come—to tell my story, to try and make life a little brighter for these “kids” who, just a few weeks ago, were on the streets in LA, Chicago, Seattle, and every other city in between. Lost in that world, fighting to stay alive.

What am I going to say? WAIT! A common ground! I’VE been fighting to stay alive... 60 years now, 40 of those years while on dialysis! And at one point, even having the Guinness world record for the longest time doing hemodialysis. Maybe I can do this. Maybe I WILL do this! I CAN connect with them. I’ve got needle scars too, you know, not for the same reason, but I’ve got them!

They say public speaking is one of the most feared things to do, but as I am introduced, a very defined calmness envelopes me. I know I’m going to help someone tonight. Someone will say, "If Tim can go through all that dialysis stuff when he was just 13 years old and now he’s 60, and still making plans? That guy’s a fighter, and I can be a fighter too. I’ve got to be strong!"

I see faces looking and listening. I tell them about missing every Tuesday at school because of my treatments at the clinic, about losing my first transplant after three months in the hospital. I tell them... WAIT, WAIT! they don’t want to hear what happened so much as how did I make it, how did I continue to fight my beast and win!? They want to SURVIVE, man! They want to survive and LIVE!

I start telling them what I’ve done, not so much what I’ve been through. Oh wow! Now they are leaning forward, eyes and ears focused and listening. I say, "This is not about me, guys, we ALL have a story. I want you to tell your story someday. You’re going to beat this addiction, it’s not the end—just as I have determined dialysis is not the end of my story. It’s not an end, it’s a new chapter in a new book that has been given you to author. Don’t make your book a bummer. Make it a new challenge, a new start, a new adventure, a new life!"

“Chapter one: I WILL LIVE LIFE TO ITS FULLEST! No matter what the ups and downs are. I’ve put my armor on, I’m ready for the battle, whatever that battle is... addiction or disease or you name it.”

I start seeing tears in eyes that have not known tears in a very long time. I see hope in eyes that have seen despair and pain for too long. Now, tears are running down my face! This isn’t supposed to happen. I’m supposed to be the encouraging one. Stop it! Man up, Tim! Then I realize what "man up" means to me. Letting others see you can cry with them. Maybe that’s better than crying for them.

"Hey Tim, are you ready?" the director of New Life drug and alcohol rehabilitation center asks. As I jerk back to reality from my stare into space, time, and the future, I peek at the young man, still curled up and shaking. He looks over at me and with a slight grin says, "You talking tonight bro?" I say, "Yes, I am, I AM talking tonight!" just as Alex the director of the program says, "Please welcome this evening, our dear friend Tim, whose story I pray inspires you."

Tim Atkins has been on hemodialysis 40 years, at one time holding the Guinness world record for longest time having dialysis. His passion is missions, working with Compassion International helping sponsor third world children, and New Life drug rehabilitation center where he speaks to encourage spiritual growth, as well as One Spirit, a Native American group helping those in need on the Indian reservations. Tim and his wife Lorie are planning on working in missions in South Africa soon.
“Limiting the amount of procedures needed to fix my fistula allows me to spend more time helping others.”

Steven, Potter

You have enough to deal with when it comes to managing your dialysis 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

Lutonix AV Clinical Trial, data on file. Number of patients = 285. Number of reinterventions performed to maintain AV fistula function at 6 and 12 months were 44 and 115, respectively, in the Lutonix® 035 DCB arm versus 64 and 138 in the standard balloon arm. At 6 and 12 months, the Lutonix® 035 DCB arm required 31.3% and 16.7% fewer reinterventions, respectively, compared to treatment with a standard balloon. 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. Please consult product labels and instructions for indications, contraindications, hazards, warnings, and precautions. Models for illustrative purposes only. Actor portrayal.
SEX, MEDS & CKD

HOW TO WORK AROUND THE CHALLENGES OF CKD FOR FULFILLING INTIMACY

By Robbi Waller, LCSW, and Amy Weissman-Hunt, MSW, LCSW
The frequency according to a study on treatment report having issues with intimacy failure with in-center dialysis, men who begin treating kidney disease (CKD), and 80 percent of dialysis and have chronic kidney.

Fifty percent of men who are pre-dialysis and have chronic kidney disease (CKD), and 80 percent of men who begin treating kidney failure with in-center dialysis, report having issues with intimacy according to a study on treatment options for CKD. Approximately 55 percent of women on dialysis report concerns with sexual dysfunction, according to the same study. An analysis of the general population found that while women are more likely to feel dissatisfied with their sex life, men are more likely to express this dissatisfaction.

One avenue that people who have kidney disease have successfully explored is working with their care providers to try different modalities of dialysis. Nocturnal dialysis, home or in-center, has been found to be the best modality for people who are experiencing sexual dysfunction. The frequency of this form of dialysis, coupled with the lower blood flow rate, can help men who may find challenges having or maintaining an erection. For the same reasons, other home modalities tend to be a good choice for this group.

In one study, 426 patients in British Columbia at the end stages of their lives were asked what had been most important to their quality of life. Healthy relationships, health status, and sexual relationships topped the list. Being able to connect deeply with others through various types of intimacy, including sex, is not just a luxury, but rather a necessity for lasting happiness. Maybe that is why, even with the stigma associated with discussing one’s sex life, patients are still coming forward looking for answers.

### BEING ABLE TO CONNECT DEEPLY WITH OTHERS THROUGH VARIOUS TYPES OF INTIMACY, INCLUDING SEX, IS NOT JUST A LUXURY, BUT RATHER A NECESSITY FOR LASTING HAPPINESS.

Vaginal atrophy, a side effect often experienced by women, is the thinning of the walls of the vagina caused by decreased estrogen levels. Women on dialysis who are experiencing vaginal atrophy can try prescription medications that may alleviate or reverse the sexual issues they are experiencing, including pain during intercourse.

Transplant has been identified as the best treatment modality for concerns with sexual dysfunction for both genders.

### SUPPORT AND SOLUTIONS EXIST

SUPPORT AND SOLUTIONS EXIST Fifty percent of men who are pre-dialysis and have chronic kidney disease (CKD), and 80 percent of men who begin treating kidney failure with in-center dialysis, report having issues with intimacy according to a study on treatment.

### UNDERSTANDING THE EMOTIONAL CAUSES OF SEXUAL DYSFUNCTION

Relationship dynamics are impacted by chronic disease, often making both the loved one and the patient feel isolated in the experience of treating the chronic disease and living with its impacts. This effect, which can create rifts in relationships, is amplified when a patient’s spouse is their primary caregiver. The lifestyle changes that a patient experiences can cause a person to lose a sense of self and feel a drop in self-esteem. This all may impact the shared sexual experience.

For couples who are struggling to connect in the bedroom, marital counseling can be a meaningful option, often helping each partner understand their evolving role in the relationship and how that relates to their feelings and desires for one another.

### WHERE TO START

WHERE TO START If you or your partner are someone living with CKD or if you have it yourself, know that these challenges are normal and surmountable.

The first step, though it may seem intimidating, is reaching out to a trusted member of your care team. You might start by researching questions that you can pose to your care team member or asking if a change in dialysis modality or other interventions might be right for you. Let your care team member know that you are looking for solutions, and that this is an important aspect of your well-being.

Organizations like the Renal Support Network also offer meet-up groups for people living with CKD. As with any emotional challenge, it can be helpful for people to meet others who are experiencing the same setbacks and to share the journey toward finding solutions.

As for the patient who circled, highlighted, and pointed to his sexual function challenges, his bravery in bringing forward the issues led to improvement. My team worked with his physician privately to connect him with a urologist who provided interventions. He transitioned to home hemodialysis and has experienced improvement in his sex life and overall intimacy with his partner.

Continued on page 18
Getting started with an exercise plan can seem impossible when you are managing CKD, and it can be hard to find the time and energy to fit it in, but the benefits can make it worth the effort. The Kidney Disease Improving Global Outcomes (KDIGO) guidelines recommend that individuals with CKD should exercise regularly—with a goal of 30 minutes, 5 times a week—to improve cardiovascular health. If you are not used to exercising you can start slow and progress at your own pace toward this goal. Before starting any exercise program, be sure to speak with your doctor about the best approach for you.

Benefits of Exercise
Studies have shown that people with CKD who don’t exercise regularly tend to have reduced physical functioning and poorer quality of life than those who exercise, and that regular physical activity may improve health outcomes. For example, aerobic exercise training has been shown to significantly improve aerobic capacity in people with CKD, and may result in the ability to perform physical activities for longer periods of time. Meanwhile, resistance training can increase muscle mass, which may improve survival in people who are on hemodialysis. In addition, exercise may improve an individual’s sleep and good cholesterol (HDL), and it could possibly reduce the need for blood pressure medications as well.

Some studies even suggest that exercise could slow the rate of kidney disease progression, and though more research is needed to verify this, the data suggests that exercise is not harmful to kidney function.

Just do it
Getting started with an exercise plan can seem impossible when you are managing CKD, and it can be hard to find the time and energy to fit it in, but the benefits can make it worth the effort. The Kidney Disease Improving Global Outcomes (KDIGO) guidelines recommend that individuals with CKD should exercise regularly—with a goal of 30 minutes, 5 times a week—to improve cardiovascular health. If you are not used to exercising you can start slow and progress at your own pace toward this goal. Before starting any exercise program, be sure to speak with your doctor about the best approach for you.

Exercise Choices
The type of exercise that you choose is not as important as finding something that you are likely to continue as a regular part of your lifestyle, and which you enjoy doing. Although lifting weights at the gym is an excellent way to gain muscle, even walking around your neighborhood or taking the stairs is beneficial and can improve your health. Making small efforts to increase your activity every day can help you take control of your health, and you will soon start to feel stronger and have more energy.
Include Your Team

Of course, it is important to check with your physician before starting any exercise plan to make sure that you are healthy enough for physical activity. Your doctor can be an excellent resource to guide you toward the type of exercise that may be best for you. Your dietitian can also help make sure that you are fueling yourself adequately. An experienced personal trainer is an excellent resource to make sure that you are performing exercises safely.

Any physical activity is better than none at all, so get out there, start moving, and have fun!

Find the Time

One of the biggest issues for anyone starting an exercise program is finding time to fit it into a busy schedule. Juggling multiple doctor’s appointments or dialysis treatments adds an extra challenge, but this can be overcome by planning ahead. If you go to dialysis three times a week, try to schedule some time to be active on your days off. Do whatever works best for you. By incorporating physical activity into your life, you can take charge of this important part of your health and wellbeing.

Fun Ways to Get Active

- Take a walk or join a walking group
- Try a yoga class
- Dance
- Go for a bike ride
- Plant a garden
- Go to a gym or fitness center
- Sign up for fun classes like Zumba or Pilates

How to Begin an Exercise Program

- Start with an activity that you enjoy and are likely to continue.
- Set small goals that you know you can reach.
- Set a time to exercise every day, and stick with it.
- Find a friend to exercise with who will support you and keep you on track.
- Search for online exercise videos or classes that you can do in your home.
- Lay out your exercise clothes the night before so you are ready to go when you wake up.

“"For twenty years, exercise has given me energy during hemodialysis, peritoneal dialysis, and a transplant. I have strength and stamina to do everything I want to do… like travel the world!" — Shari Gilford

References:


Meredith Marinaro, MS, RD, CSR is a Registered Dietitian and Medical Science Liaison with Akebia Therapeutics, Inc. She has worked with patients with chronic kidney disease for almost 15 years and is passionate about the importance of maintaining a healthy lifestyle through diet and exercise. She is currently working on a PhD in Health and Human Performance.
21st Annual Renal Teen Prom
Sunday, Jan. 19, 2020 in Los Angeles, CA

For 21 years RSN has presented this life-changing event that young people living with kidney disease can look forward to every year. The Prom brings them together to share experiences, strengths, hopes... and a great party! They feel special for a night, and forget about the difficult things they have to go through. They discover that they are not alone and that 'one friend can make a difference'.

The Prom is open to people ages 14 to 24 who have kidney disease, and one guest at no charge. Sign up to let us know you want to attend the 20th Annual Renal Teen Prom. You’ll receive email updates and an invitation for you and your guest.

See highlights from the 20th Annual Renal Teen Prom at RSNhope.org/Prom

Do you have gently used or new formal wear and/or accessories that you would like to donate? All donations are tax deductible!

Need a dress to look fabulous for the Prom? RSN will have dresses available for prom attendees to select at no charge.

Email info@RSNhope.org or call (818) 543-0896 to make a donation or an appointment to get your dress.

Help give a teen who has kidney disease and their guest something to look forward to with a tax-deductible donation. Use form on page 22 or visit RSNhope.org/Donate.

Start your own campaign to raise funds for RSN’s Prom in lieu of receiving gifts for your special occasion. See page 22 or visit RSNhope.org/fundraiser for more details.

SEX, MEDS & CKD
continued from page 15

CITATIONS


Additional CITATIONS

Amy Weissman-Hunt, LCSW is the Arizona Regional Lead Social Worker for Fresenius Kidney Care. Amy serves on the Fresenius Kidney Care Social Work Advisory Board and is a co-editor for the Social Work Navigator Newsletter. Amy and her husband live in Scottsdale, AZ.

Robbi Waller, MSW, LCSW is the Regional Lead Social Worker Fresenius Kidney Care. She currently covers a large geography with 60 clinics in 6 states. Robbi has been in medical social work for 15 years and enjoys focusing on quality of life improvement.
According to the latest U.S. Renal Data System Report, more than 660,000 Americans are being treated for kidney failure, also called End-Stage Renal Disease (ESRD). Of these, 468,000 are on dialysis and more than 193,000 have a functioning kidney transplant. Each year 100,000 people are newly diagnosed with stage 5 chronic kidney disease (CKD) which is the same as ESRD. About 30 million U.S. adults are estimated to have CKD and most are undiagnosed. Over 103,000 people in the U.S. are waiting for a kidney transplant.

RSN’s advocacy program focuses on local, state and federal regulatory and legislative issues that impact or improve the care of people who have chronic kidney disease, including dialysis and kidney transplantation.

Our online advocacy portal provides information on current legislation that is on the table regarding kidney care and how to support getting bills passed.

CURRENT FEDERAL LEGISLATION

The Chronic Kidney Disease Improvement in Research & Treatment Act of 2019 (H.R. 391/S.1676)

If passed, this legislation would allow for significant improvements in critical areas including guaranteed access to Medigap policies to all ESRD beneficiaries, expanding kidney care access in underserved areas, and incentivizing innovation for new drugs, biologicals, devices, and other technologies.

Living Donor Protection Act (H.R. 1224/S. 511)

Organ donation saves lives and saves money, cutting health care costs by as much as two-thirds and saving Medicare millions of dollars every year. The Living Donor Protection Act would protect living organ donors and promote organ donation.

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

Nutrition Support Designed for Those on Dialysis

23g of Protein per 8.45 fl oz serving

Optimized Potassium, Phosphorus, and Sodium for those on dialysis*

NOW Available at Walgreens

*Based on nutrition guidelines for patients on dialysis

USE UNDER MEDICAL SUPERVISION.

Speak with your healthcare provider about whether this formula is right for you.

Visit NovasourceRenal.com for more information, sipping tips & recipes.

Additional flavors (Strawberry and Café Mocha) available on: Walgreens.com, Amazon.com or NestleNutritionStore.com
I Have CKD. Is it Safe to Keep My Pets? continued from page 3

**HOPEline**
Peer Support Hotline

If you are a person who has chronic kidney disease, a family member, or caregiver, and don't know what to expect, call us. Connect with another person who has lived with kidney disease and can share their experience, strength and hope with you. Learn what they have done to successfully navigate this illness.

Call (800)579-1970
Call toll-free 10:00am to 6:00pm (Pacific Time)

- Wear gloves and a mask when cleaning a cat litter box or bird cage, or picking up dog droppings. Or better yet, have someone else do it!

- Keep the claws on your dogs and cats trimmed so that you're less likely get scratched. If you do get scratched, clean the scratch well and cover it until it heals. I carry a band aid and a packet of Neosporin in my purse, and I keep them on hand at home.

- Keep your pets clean and up to date with vaccines and flea-and-tick repellent and be sure to give them regular check-ups.

My beloved black poodle, Pepi, was better than a therapist when I started dialysis as a teenager. For eighteen years he kept me active by sharing walks with me a couple of times a day and giving me some good cuddles as I underwent peritoneal dialysis (PD). Although I made sure he was not in the room when I did the PD connection, he stayed by my side at night when I was on the machine. And my beloved black poodle, Miles, laid on my lap while I was doing home hemodialysis. I never got an infection from my furry best friends.

And yes, I must admit, my furry best friends pile onto our bed each night, but I keep my home and environment clean and I groom and bathe my animals regularly. However, in 2011, when I had my transplant, I took extra precautions because I knew my immune system was at its weakest. No three-dog nights for me during that time.

Maybe you're ready to bring a pet into your family. If owning or adopting an animal seems too big of a responsibility, why not try fostering one? Many rescue organizations and humane societies have companion-animal and foster programs that you may enjoy.

One thing I know is how the pets I have had throughout my life helped me tremendously while living with a serious illness. I love the quote by George Eliot, “Animals are such agreeable friends—they ask no questions; they pass no criticisms.” I have never been at a loss for a best friend.

Find more information on the RSN website at RSNhope.org. Enter "Web ID" and the numbers shown below in the search bar.

KidneyTalk™ Podcast Radio
- Don't Bug Me! Understanding Infectious Disease
  - Web ID 993
- Pets & Kidney Transplant Safety
  - Web ID 3041
- Collection of information about pets and infection safety including the CDC Guidelines and Public Health Reports.
  - Web ID 01Pets
Fine Art & Jewelry by Lori Hartwell

Meaningful gifts that support RSN’s life-enriching programs.

Lori Hartwell’s Artwork Prints and EmbraceHOPE Jewelry are available at RSNhope.org/Shop

2020 Creativity Cures the Soul Calendar
Featuring artwork by Lori Hartwell accompanied by inspiring quotes by past essay contest winners.

Order Artwork, Jewelry or the 2020 Calendar Online or Call (818) 543-0896

LOW PHOSPHORUS FOODS WORD SEARCH
Find the words on the list at right within the puzzle. Words may go across, down or diagonal.

| R S U F B L U E B E R R I E S | CHICKEN  | GARLIC |
| O E O T C H E R R I E S C L K | PORK     | BASIL  |
| S B Y O C E D P E E U Y F K T | BEEF     | PARSLEY|
| E R W M U T P G A G T E Z S F | TUNA     | ROSEMARY|
| M O Q A R H A P A R E F R U R | SOURDOUGH| SAGE   |
| A C S Y R S S R E B S E W E W | ASPARAGUS| MAYONNAISE|
| R C C O Y X A G L A P L W L S | PEPPERS  | KETCHUP |
| Y O H N U P W I A P R O E R S | BROCCOLI | MUSTARD |
| K L I N S R S M E R L S E Y P | CAULIFLOWER|
| E I C A H A D P U F L B G S O | CUCUMBERS|
| T E K I B R Y O I S M I V O R | APPLES   |
| C M E S T W R L U U T C C K K | CHERRIES |
| H B N E N U U L C G I A N A Z | PEARS    |
| U P T Y A A N U M T H R E A | BLUEBERRIES|
| P D U L C R C A P P L E S D S | CURRY    |
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
READ KIDNEY TALK™ ONLINE
Current issue, printable version, articles, and archives can be found at: www.RSNhope.org

EDITORIAL TEAM
EDITOR-IN-CHIEF
Lori Hartwell
CREATIVE DIRECTION
Suzette Maffi
DISTRIBUTION
Mica Spalding

CONTACT INFORMATION
Renal Support Network
1146 North Central Ave. #121
Glendale, CA 91202
info@RSNhope.org
866-903-1728 Toll Free
818-543-0896 Local
E-Fax: 818-484-2070
9 AM–5 PM Pacific Time
Monday–Friday

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

Donate online at RSNhope.org
Click Contribute in top menu bar
Donate by Phone, by Mail
Use form below and see contact information above
Donate via PayPal to donation@RSNhope.org

YOUR GIFT, NO MATTER THE AMOUNT, helps RSN continue to offer our life-enriching programs at no charge to people whose lives have been affected by chronic kidney disease.

START A PERSONAL FUNDRAISER Create your own fundraising page for RSN today. It’s easy to get started, and we’ll give you all the support and tools you’ll need to make your fundraiser a success. Learn more at RSNhope.org/fundraiser

CONSIDER A TRIBUTE DONATION Make a donation in honor of an organ donor, a transplant anniversary or as a holiday or birthday gift. Use space below/right for tribute details and the form above for your address. You will receive a receipt and note with details of your tribute that you can share.

DONATE ONLINE AT RSNhope.org Click Contribute in top menu bar
DONATE BY PHONE, BY MAIL Use form below and see contact information above
DONATE VIA PAYPAL to donation@RSNhope.org

Method of Payment for contributions:
☐ Check or Money Order (payable to Renal Support Network)
Credit Card: ☐ Visa ☐ Mastercard ☐ Amex RSN accepts all major credit cards

Donation charge to card $ ___________________ Billing Zip ____________
Card#: __________________________ Exp. Date: _____ / _____
Cardholder Name: ________________________________
Signature: _______________________________________

(To receive a receipt, please use form above to give us your address.)

© 2019 by Renal Support Network, All Rights Reserved
A 501(c)(3) non-profit organization EIN#95-4672679

RSNhope.org

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.

JOIN RSN - THERE ARE NO FEES
☐ Yes! I would like to receive a free subscription to KidneyTalk™ Magazine.
☐ Yes! E-mail me RSN’s RenAlert electronic update.
☐ Yes! Sign me up to receive updates about special events.

Name ________________________________
Address ____________________________________________________________
City __________________ State _______ Zip __________
E-mail ____________________________
Phone ____________________________ ☐ home ☐ work ☐ cell

Please check all that apply:
☐ Patient: ☐ Transplant ☐ PD ☐ Hemo ☐ Other _________________
☐ Family Member ☐ Administrator ☐ Physician ☐ Nurse
☐ Dietitian ☐ Social Worker ☐ Technician ☐ Company Rep ☐ Other

CONTRIBUTE TO RSN - ALL DONATIONS ARE TAX-DEDUCTIBLE. THANK YOU!

Contribute to RSN - the...
10th Annual

BEAT the ODDS

Celebrity Bingo & Texas Hold’Em Tournament

Save the Date!
Saturday, April 18, 2020

Congratulations Joe Marcel (kidney transplant recipient) who was the 1st Place winner of our 9th Annual Texas Hold’Em Tournament. He is pictured with his living donor Mark Shulman.

How you can help:
The 10th Annual Celebrity Bingo & Texas Hold’Em Tournament is RSN’s only annual fundraising event. We hope that we can count on you to help us make this our best one yet!

Please consider donating a silent auction item for the event, such as local business products or services, gift cards, gift baskets, artwork, signed memorabilia, getaway and spa packages, sport event or concert theater tickets, artisan jewelry or decor, and tickets/passes to museums, theaters, theme parks and other entertainment venues. RSN will recognize all individual and corporate donors at the event.

Thank you in advance for your contribution. I hope to see you next April! - Lori Hartwell

Visit RSNhope.org/poker for details
If you have a change of address, phone number, or email address, please contact us to update it.

KidneyTalk™ magazine is proudly supported by:

Find and listen to any show at RSNhope.org by entering in the website search bar the "Web ID" and ID number, or download at iTunes by searching for "KidneyTalk. All the latest shows and more are on the KidneyTalk™ page at RSNhope.org

Listen in to these inspiring shows:

**Dialysis Basics of Dry Weight and Fluid Management**
with Anne Diroll, RN, CNN Web ID 3035

**Cooking for your Kidneys**
with Chef John Vito Web ID 3037

**Having a Baby on Dialysis**
with Madeleine Pahl, MD Web ID 3038

**Opt-In vs Opt-Out Organ Donation Practices Around the World** with Tom Mone Web ID 3039

**The Role of the Nephrology Social Worker**
with Vernon Silva, LCSW Web ID 3040

**How to Tell Your Story**
with Henriette Ivanans Web ID 3043