

KidneyTalk™



Fall/Winter 2019

by **Renal Support Network**

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

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!

Announcing RSN's
**17th Annual Essay
Contest Winners!**

The Warrior

by Mary Wu
1st Place Winning Essay

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KidneyTalk™ magazine!
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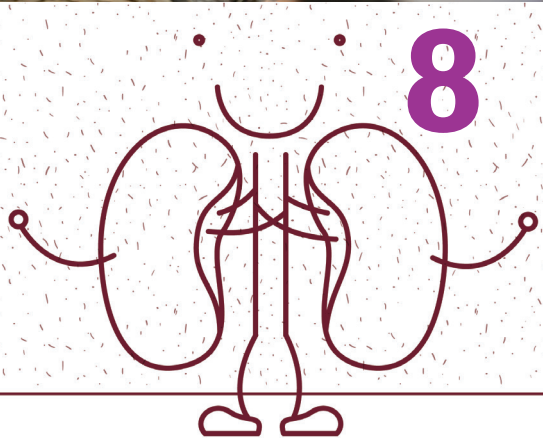
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KidneyTalk magazine (formerly Live&Give) is a program of Renal Support Network (RSN). The magazine's articles are written by people who have kidney disease and by healthcare professionals. Those with kidney disease share their knowledge and experiences 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.





Web ID 4019



I Have CKD. Is it Safe to Keep My Pets?

By Lori Hartwell



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.

That is why I am disheartened whenever I hear about someone with kidney disease who is about to undergo home dialysis or a kidney transplant being told by their doctor to give up their pet. Having lived with animals all my life, I would go over the edge if someone gave me that advice. My animals are part of my everyday life; they are part of my family. They help me in immeasurable ways.



12 year old Lori Hartwell and Pepi, 1978

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.

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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.



The Warrior

Web ID:5019

1st Place Winning Essay
By Mary Wu

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.

The Warrior

You take me back
To a time and place
That I do not want to be
That I do not want to face
That is my worst enemy
Where I question me
Where I will stare
In the mirror
If the warrior
Is still there
To fight
For what is fair
For what is right

You take me back
To all my cracks
Fade to black
You know all about
My kryptonite
My shadows of doubts
Why is it always a fight?
Why is it never easy?
Making me feel small
Letting me fall
For me to
Prove to you
That I am tough enough
That I am good enough
For me to rise up
To defend and defy
To stay alive
As the survivor
As the warrior

I am wired
I am tired
I am the fire
I am the flame
Let's play this game
You will know my name
You will no longer play me for the fool
You will know this to be true
Do not mistake
My kindness
For weakness
Do not think
My silence
Is acceptance
You can try to shake
You can try to break
You can try to take
My spirit
My soul
Does not shatter
I may be bruised
I may be battered
It is mind over matter
For I am the warrior
I pick my battles
To win the war

As a two-time kidney transplant recipient with extensive personal and professional backgrounds in healthcare and social services, Mary is a nationally-recognized advocate on behalf of the organ donation and transplantation community. She works individually and with various other organizations to increase education, awareness, and especially registration through public speaking, published written articles, connections with political and celebrity figures, and social media outreach.





Managing your emotional health

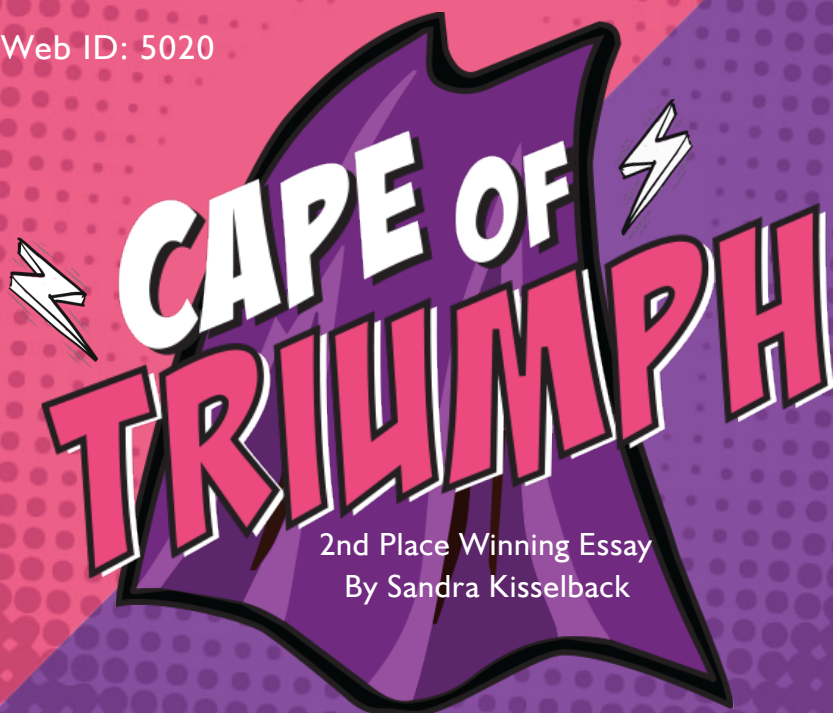


Finding balance between life and dialysis

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](https://www.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!





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PATIENTS & CAREGIVERS

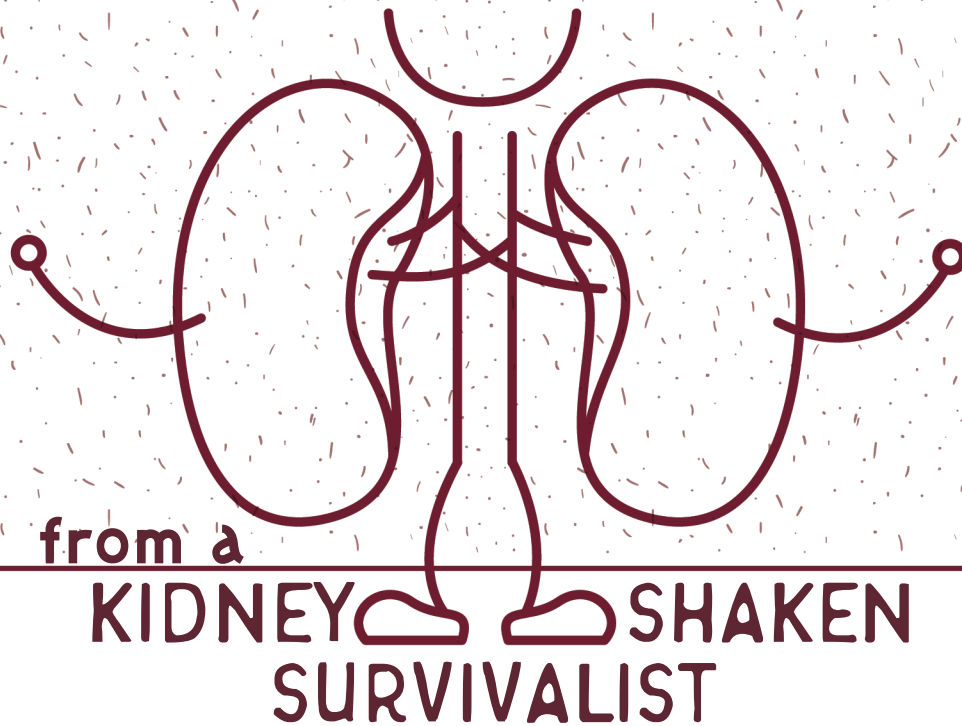


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NEPHRONS OF WISDOM

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from a KIDNEY SHAKEN SURVIVALIST

3rd Place Winning Essay
By Stacy Hoblitzell

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

**SPEAK UP.
DEFEND
YOURSELF.
DON'T TAKE
ANY GUFF
FROM ANYONE.
ANYONE.**

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,

NEVER NEGLECT YOUR BEST FRIEND: HOPE

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 flatters 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.



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my mother's toolbox

4th Place Winning Essay By Joy Araujo

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 screw drivers 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 tool box.

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

these tools give me the ability to battle kidney disease and win

to survive. Facing this news, I gained another tool for my box—patience. Long hours of dialysis and long years of waiting for a transplant required the ability to withstand the odds of time gracefully. Every day was a battle... jumping at the sound of my phone ringing (it could be a kidney!) and passing the time when it wasn't my turn, holding onto the notion that this was my life regardless of transplant status and that I was going to live my best life right now.

In addition, I will always remember the days I received the calls for

my first and second transplants. 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.



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Fully integrated.
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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've "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

*I'VE been fighting
to stay alive... 60
years now, 40 of
those years while
on dialysis!*

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

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SEX, MEDS & CKD

HOW TO WORK AROUND THE CHALLENGES
OF CKD FOR FULFILLING INTIMACY

By Robbi Waller, LCSW, and Amy Weissman-Hunt, MSW, LCSW

I pick up a patient survey and in the section on dialysis side effects, circled several times in red pen with arrows drawn around it, is “sex life.” The patient reported he was “very much bothered.”

Like many people, this gentleman had been reluctant to raise the topic with his care team, and perhaps even avoided the issue with his partner. Yet, he was desperate for answers and support.

The majority of patients on dialysis report being bothered by changes in their sex life. People who begin dialysis treatment for kidney failure frequently find that side effects from new medications, the awkward maneuvering around unfamiliar access sites, the changes in blood pressure, and the new levels of dependency on a partner, can cause an abrupt end to intimacy and the sex life they once enjoyed.

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.

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.¹ 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.

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

options for CKD.² 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.³ 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.

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.

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

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



The Importance of Exercise

for People who have Chronic Kidney Disease

By Meredith Marinaro, MS, RD, CSR

Many people living with chronic kidney disease (CKD) tire easily and often feel that they don't have the energy to exercise. However, a regular exercise program has been shown to improve energy levels and overall quality of life. Even though it may not feel possible, taking that first step can help you feel you are taking back control of your health.

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.³ 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.³ Meanwhile, resistance training can increase muscle mass, which may improve survival in people who are on hemodialysis.⁴ 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.^{4,2}

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.⁴



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' guidelines recommend that individuals with CKD should exercise regularly—with a goal of 30 minutes, 5 times a week—to improve cardiovascular health.¹ 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.



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.



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

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.



"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

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!

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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](https://www.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](https://www.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](https://www.rsnhope.org/fundraiser) for more details.

SEX, MEDS & CKD

continued from page 15

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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 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.

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Call (800)579-1970

Call toll-free 10:00am to 6:00pm
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**Support from someone
who has been there.**



I Have CKD. Is it Safe to Keep My Pets? *continued from page 3*



- 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**

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LOW PHOSPHORUS FOODS WORD SEARCH

Find the words on the list at right within the puzzle. Words may go across, down or diagonal.

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O	E	O	T	C	H	E	R	R	I	E	S	C	L	K
S	B	Y	O	C	E	D	P	E	E	U	Y	F	K	T
E	R	W	M	U	T	P	G	A	G	T	E	Z	S	F
M	O	Q	A	R	H	A	P	A	R	E	F	R	U	R
A	C	S	Y	R	S	S	R	E	B	S	E	W	E	W
R	C	C	O	Y	X	A	G	L	A	P	L	W	L	S
Y	O	H	N	U	P	W	I	A	P	R	O	E	R	S
K	L	I	N	S	R	S	M	E	R	L	S	E	Y	P
E	I	C	A	H	A	D	P	U	F	L	B	G	S	O
T	E	K	I	B	R	Y	O	I	S	M	I	V	O	R
C	M	E	S	T	W	R	L	U	U	T	C	C	K	K
H	B	N	E	N	U	U	L	C	G	I	A	N	A	Z
U	P	T	Y	A	A	N	U	M	T	H	H	R	E	A
P	D	U	L	C	R	C	A	P	P	L	E	S	D	S

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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

READ KIDNEYTALK™ ONLINE

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

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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



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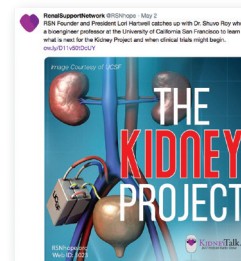


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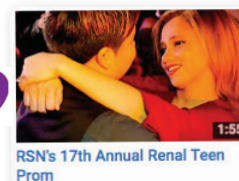


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RSN EVENT CALENDAR

Visit RSNhope.org for details

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4th Sunday of the Month

Visit RSNhope.org for details

Studio Hope Workshops

Visit RSNhope.org/Studio for details

21st Annual Renal Teen Prom

Jan. 19, 2020

10th Annual Celebrity Bingo & Poker Tournament

April 18, 2020

27th Annual Patient Conference

Sept. 2020

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23



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