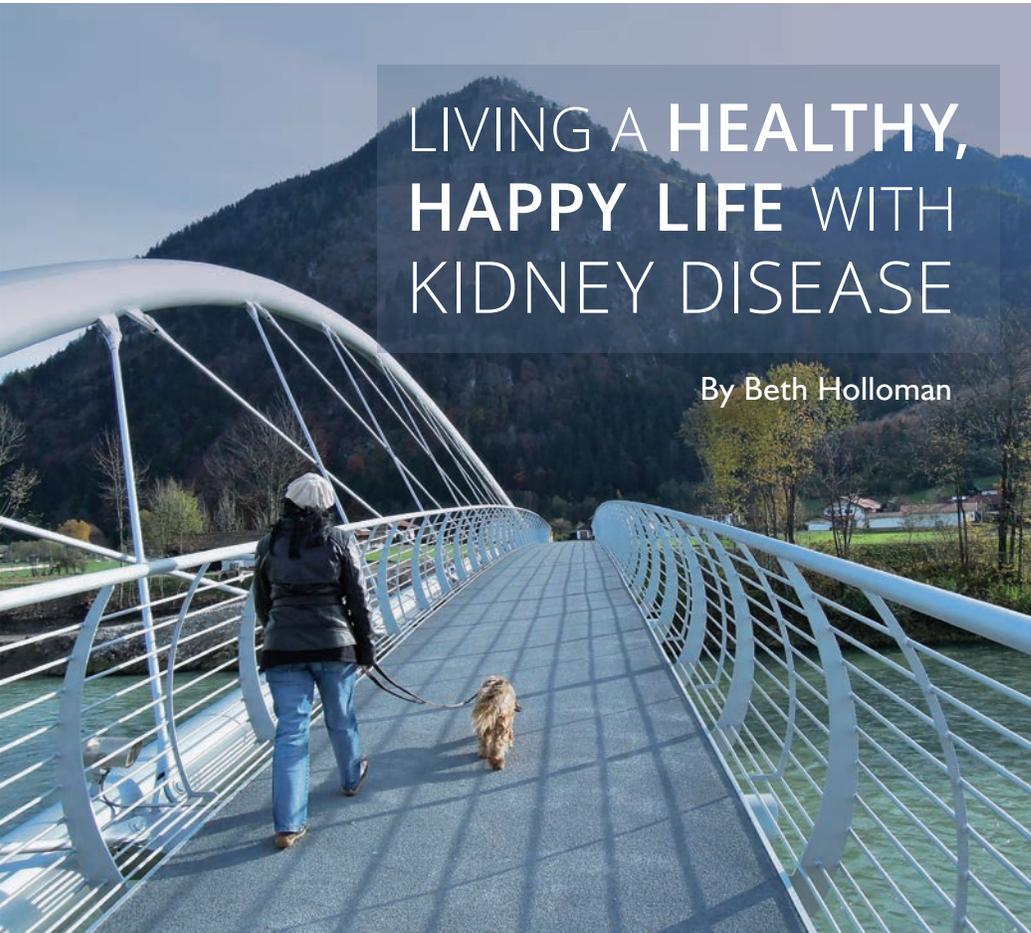


THE MINDFUL LIVING ISSUE



LIVING A HEALTHY, HAPPY LIFE WITH KIDNEY DISEASE

By Beth Holloman

I've been through a lot as a kidney patient, as I'm sure you have, too. After 27 years of life with kidney disease, I sometimes feel a little down or get overwhelmed. I want to share a few things I've done to pick myself up and help me have the best possible experiences and outcomes. Hopefully, some of my strategies may help you to live a happier life in spite of kidney disease.

The most important thing for me is to focus on the positive things in my life. My family, friends, spirituality and faith are of great comfort to me and help me to keep a positive attitude. I am so happy that if I have to have a chronic illness, that the one I have is kidney disease. Kidney disease has many treatment options to keep me alive and allow me to live a healthy, happy life. Many other diseases do not afford patients that opportunity. I'd like to share some of the coping strategies I've developed over the years.

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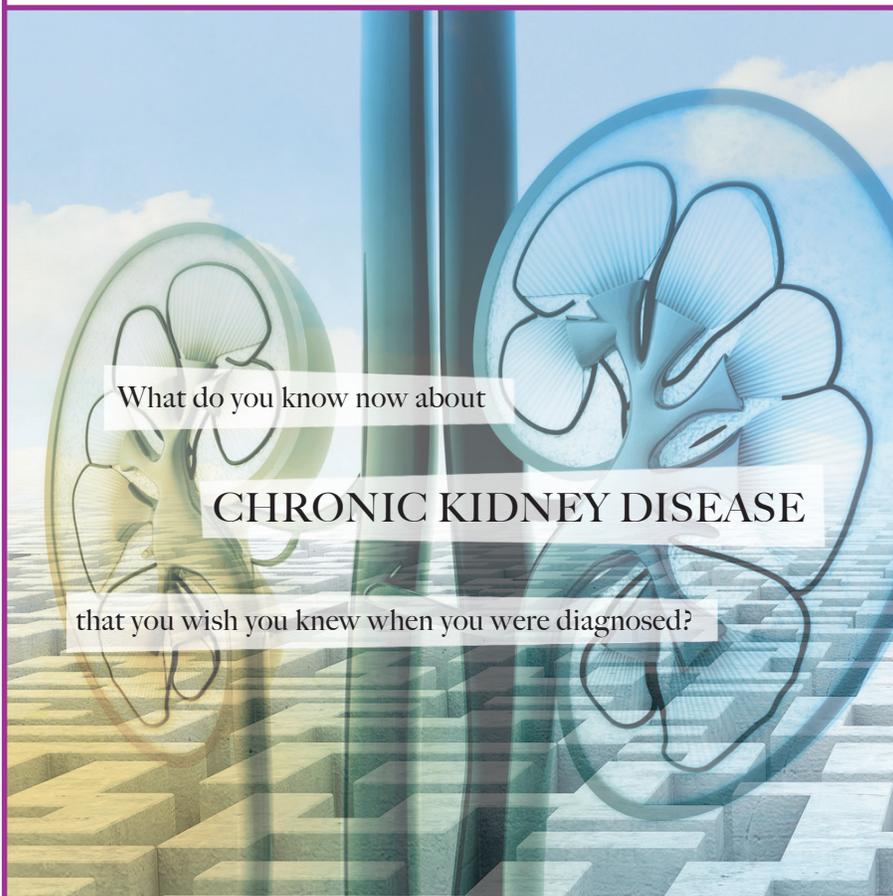
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RENAL SUPPORT NETWORK INVITES PEOPLE WITH KIDNEY DISEASE TO ENTER OUR

14TH ANNUAL
♥ ESSAY CONTEST

2016 Essay Theme:



Visit RSNhope.org/essay-contest for details

"People who live successfully with a chronic illness like kidney disease know firsthand the importance of having an innovative perspective not only toward their illness, but also toward life in general. There is an abundance of talent within the renal patient community, and the RSN Essay Contest provides people who have CKD with a forum where they can share their experiences, strength, and hope, as well as inspire others."

- Lori Hartwell, RSN President and Founder

grat·i·tude
of Living·Treating·Caring

RenalSupportNetwork
relies on charitable
contributions to provide
hope to people
with kidney disease.
We appreciate your help!

Renal Support Network introduces Gratitude of Living, Treating and Caring; a CKD Survivor Fundraising Campaign. Please consider donating \$1, \$10 or \$100 for each year you or someone you have cared for has survived chronic kidney disease and post a message of gratitude. Money raised will help RSN provide education, patient programs and hope to people who have chronic kidney disease.

i·Live

People on dialysis, transplant recipients and kidney disease survivors: *Please consider donating \$1, \$10 or \$100 for each year you have survived this illness.*

i·Treat

Kidney health care professionals and companies: *Please consider donating \$1, \$10 or \$100 for each year you have treated people who have chronic kidney disease and helped patients survive.*

i·Care

Family and friends Please consider donating: *\$1, \$10 or \$100 for each year you have cared for and supported a loved one with chronic kidney disease.*

Visit RSNhope.org/Gratitude or call 866-903-1728 Toll Free to make your tax-deductible donation today. Share your Gratitude of Living via Twitter to [@rsnhope](https://twitter.com/rsnhope) and on Facebook with hashtag [#gratitudeofliving](https://www.facebook.com/hashtag/gratitudeofliving).



»» living in the moment ««

by Lori Hartwell

A popular saying is “Live in the moment!” Sounds good when it rolls off someone’s tongue or when you read it to yourself, but how do you actually do it? I know I am happiest when I am focusing on what is right in front of me. When the committee in my head is not stuck on items not on the agenda, like what happened yesterday or what might happen tomorrow. I can relate to the movie *Inside Out*.

I know what I can’t ignore if I want to preserve my happiness. For instance, I see the following doctors on a routine basis: a cardiologist, nephrologist, gynecologist, dermatologist, orthopedist, ophthalmologist, physical therapist and a dentist.

Doctors are supposed to help us with our health problems, and provide advice and medical recommendations. They went to medical school to learn their specialty. I have a habit of Googling whatever is going on with me, and then become (I think) an expert on the topic. The internet is full of advice. Unfortunately, it can also reveal worst-case scenarios. Don’t get me wrong: you can find information on what questions to ask and about people who have had the same symptoms you are facing, but beyond that, internet surfing is going to rob you of living in the moment!

Often the committee in my head is considering those worst-case scenarios of what could happen to me. When I see my doctors, they put it all in perspective and give me a plan to move forward.

Wow, all that grief and time spent on the internet for nothing! So here’s a tip for living in the moment when you’re concerned about information you’ve gathered: Ask your doctors and clinicians: they are the experts.

Here are a few more ways I have developed for living in the moment:

»» Breathe

Take a deep breath. I love to watch the birds in my back yard and concentrate on my breathing.

Music ««

Singing to a song in my car just brightens my mood.

Call ««

Call a Friend. It is great to catch up with friends and hear what is going on in their life. I prefer the phone to texting or emailing.

»» Create

When I am making something, whether it be a frosted cake or beaded jewelry, I am focusing on the task at hand and my committee is silent.

»» Move

I don’t like the word exercise. It sounds too much like work. I prefer to play with my puppies, go walking around garage sales, or clean by organizing a closet.

No less ««

I find some of the best weekends are when my husband and I do not have plans and can just putter around the house.

»» Stop worrying ««

Stop worrying about the future, or thinking about the past! Focus on the present. Living in the present is the best gift you can give yourself!

*Lori Hartwell, Founder & President of Renal Support Network (RSN), 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.*



Receiving Adequate Iron is Essential for My Good Health

Today, there is a product that can deliver iron consistently at every dialysis treatment in place of IV iron... it's called Triferic.

Hemodialysis patients lose iron with each dialysis treatment due to the consistent blood loss that occurs. Patients lose approximately 5 -7 milligrams of iron every hemodialysis treatment. Therefore, iron is needed every dialysis treatment, to replace the ongoing iron loss that occurs during hemodialysis.

Triferic is the only FDA approved drug indicated for iron maintenance therapy.

Triferic is delivered via dialysate, simply replacing the 5-7 milligrams of iron lost during your regularly scheduled dialysis treatment. Triferic enters your blood and immediately binds to transferrin (the natural carrier of iron in the body) and is taken to the bone marrow, bypassing the liver, similar to normal dietary iron uptake. Your body will use the iron to make hemoglobin. Hemoglobin will carry oxygen throughout your body, providing energy.

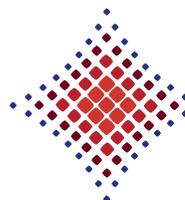
Triferic is the only drug FDA approved to replace iron at every hemodialysis treatment and to maintain hemoglobin concentration.

- Iron delivered at every dialysis treatment
- Replaces the 5-7 milligrams of iron that is needed
- Maintains hemoglobin concentration
- Does not increase iron stores and inflammation (ferritin)

Triferic does not require intravenous infusion. There are no IV's or needles required to receive Triferic. Triferic is simply mixed into your dialysate and administered to you throughout the hemodialysis procedure.

The safety profile of Triferic has been demonstrated in long-term studies and is similar to patients receiving placebo treatment. There have been no severe life threatening hypersensitivity reactions in over 100,000 doses administered.

For more information, ask your doctor about Triferic or call Rockwell Medical at 800-449-3353.



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How **Journaling and Tracking** is helping me **Heal Emotionally and Physically**

by Joanna Galeas

Journaling, self-discovery, and self-help books were not my thing. Even now, I still don't really like one of them and struggle with the other two. That struggle has been incredibly rewarding. Soon after my transplant, I unwittingly started to dive into self-discovery aided by journaling. As I write this, I am celebrating 3 months post kidney transplant. Journaling has become an important tool in my healing process.

I started journaling in my hospital bed, and didn't even know it. After my transplant, I was enthralled with my new creatinine level! I wanted to be constantly updated to prove to myself that it was not a fluke.

I started writing the numbers on the back of my daily food menus. Soon I was also tracking my hemoglobin, BUN, and other indicators. It was a little self-competition, I think.

As I sat there, getting better and better, I had questions, so many questions! And doctors weren't there when my brain was brimming with thoughts so I started to write down my

questions on those same menus. When one of these menus was accidentally discarded, I improved my method: I started texting myself the questions and lab updates. My family started noticing and helping. When I'd say, "Oh, that's a good question for the doctor," they'd say, "Well, text yourself!" And when the doctor came, we'd have a real two-way conversation. Having my questions answered, and not just answering his, made me feel like a member of the team. They weren't

always super receptive, but with a little smile and a lot of appreciation from me, the doctors and nurses started to understand my ways.

I soon decided I wanted to document my hospital days in more detail, so I started a diary. My boyfriend and I were already making progress videos for family but I wanted something for me. Just for me. At first my journals were about concrete things like doctor updates and milestones reached. Slowly, I started adding in my feelings. I started describing how these updates or complications made me feel. This was, and still is, hard for me. I am a doer, not



That emotion was in there, but I hadn't let it out. It needed to be *felt*. I needed to *acknowledge* it and find my way through that emotion.

a feeler. I thought that was good but I realize now that it was a wall to hide my feelings behind. If I don't feel, I won't feel The fear. The sad. The worry.

One of the first feelings that surfaced in my writings was a deep fear that I wasn't worthy of this kidney. Someone passed and I received this kidney. What if I don't live up to her potential? What if I disappoint her? What if I can't honor her memory? That emotion was in there, but I hadn't let

it out. It needed to be felt. I needed to acknowledge it and find my way through that emotion. My journals made that possible. They keep me true to myself; that's their most important benefit. A great secondary benefit is that they make me a very good patient.

I was home in 6 days. I started a small medical pad and kept it close. I wrote down any struggles or questions I had and brought that with me to the doctor's appointment. I found it was a great way to keep track of the constant medicine changes. Then I upped the ante. I added a food tracker app to my life. My journals kept me accountable

to my emotions and to the doctor's orders. Now, I wanted to make sure I knew how I was going to nourish my healing body. In the past, I may or may not have eaten breakfast. I may or may not have had dessert for dinner. Knowing I had a caloric goal, and certain protein and calcium requirements to meet within that caloric goal, made me rethink some choices. Eating out restrictions helped too. And three months later, I am healthier than I've been in years. I have the energy, thanks to my new

kidney and to my good choices, to take my beautiful dog on the long walks he so loves. I am lighter in my heart and in my mind, thanks to my journaling!

Joanna Galeas has had kidney disease since 2009 and recently received a kidney transplant after almost 6 years on the waitlist. She is a Board member of Renal Support Network and serves on the Network 18 Subject Matter Expert committee. She holds a degree in business.



BLOODSTREAM

INFECTION

RISK

CONTROL

PREVENTION

By Lee Cauble BSN, RN
Web ID: 1038

If you hear this diagnosis from a doctor, you should be frightened. Septicemia, a bloodstream infection, is one type of sepsis. In the US each year, three in 1000 people will develop sepsis, and more than 200,000 will die because of it. Early symptoms can be as vague as loss of appetite and fatigue. A temperature above 101°F may be indicative of sepsis (but for patients with kidney disease, who generally run a lower than normal temperature, any temperature rise of 2° or more is cause for concern). A heart rate greater than 90 beats per minute or a respiratory rate greater than 20 breaths per minute are other causes for concern. An initial diagnosis of sepsis requires two of the three common markers:

temperature, heart rate, and respiratory rate abnormalities. The only way to confirm a bloodstream infection is by blood culture.

**3 IN 1000 PEOPLE
IN THE US WILL
DEVELOP SEPSIS
AND MORE THAN
200,000 WILL
DIE EACH YEAR.**

Judy is a 45-year-old woman who wasn't a fan of needles. She started hemodialysis with a large vein catheter, often referred to as PermCath. This is a misnomer. Catheters are temporary and should never be considered a permanent solution for vascular access. (Long-term use of large vein catheters should be reserved for patients who have exhausted their options for a fistula or graft.) Judy did well the first year with her catheter and resisted recommendations to have a fistula or graft placed. Then she had her first catheter infection. She developed fever, chills, and general body aches. Blood cultures confirmed that she had developed a bloodstream infection. She was given a course of antibiotics and the infection cleared. Her catheter was replaced and she did well for about another six months, then she again developed symptoms of a bloodstream infection. This time she ended up at the hospital. When her catheter was removed a new catheter was placed on the other side. Judy did well for the next 6 months and then developed her third bloodstream infection in less than two years. Again she was admitted to the hospital, and began a course of antibiotics. At this point Judy said, "I don't ever want to go through that again!"

We discussed studies showing that patients with large vein catheters had a two to five times greater risk of infection. Since Judy had now suffered through three catheter infections leading to bloodstream infections, her risk of dying had increased by more than 58%. Judy was given the name of a vascular surgeon and encouraged to make an appointment. For the next 2 months she procrastinated. One day, Judy came to the dialysis unit and said, "I think I'm self-sabotaging. Can you call and get me an appointment?" Two weeks later she had an AV graft placed in her right forearm. Once Judy started using her AV graft, an appointment was made to have her catheter removed. Judy has remained infection-free now for 10 months!

Lee Cauble has been a nurse manager for DCI Desert Dialysis. She began her nephrology career as a LPN in 1976. She is actively involved in the community serving on NKF of Arizona Board of directors and Council of Nephrology Nurses and Technicians.

FIVE SIMPLE PREVENTATIVE STEPS

to avoiding dangerous bloodstream infections.

Being aware of changes in your body is your best defense against life-threatening sepsis infection.

1 If you have a catheter, follow your clinic's recommendations for keeping the exit site clean and dry. Be sure the catheter hubs are scrubbed with an antiseptic pad when connecting and disconnecting from dialysis.

2 Meet with a vascular surgeon as soon as possible to arrange to have a fistula or graft placed. Once you have surgery, it will be 2-12 weeks before your access can be used for hemodialysis.

3 Even if you shower before going to dialysis, wash your fistula when you go into the dialysis clinic. Prior to your needle insertion the puncture site must be cleaned with an antiseptic.

4 Check your legs and feet for breaks in the skin. If you have neuropathy (numbness in your legs) you may not feel anything if you bump your leg. Diabetics are especially prone to infections developing from even small wounds.

5 Tell your nurse or doctor if you have any of the symptoms of sepsis: Change/elevation in temperature, rapid heart rate, increased rate of or difficulty breathing.

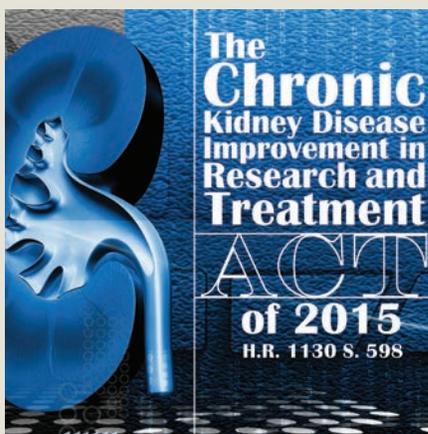
BECOME AN EDUCATED ADVOCATE

Join Renal Support Network's weKAN Program

weKAN promotes self-advocacy and self-determination by showing patients how to become actively involved in medical, regulatory, and legislative decisions affecting their lives.

For more information e-mail wekan@rsnhope.org Web ID: 101

LEGISLATION FOR 2015/2016 THAT NEEDS YOUR SUPPORT



The Chronic Kidney Disease Improvement in Research and Treatment Act will:

Promote patient access and choice and improve care coordination by:

- **Improve the coordination of care:** Providing kidney failure patients access to Medicare Advantage plans and making the Special Needs Plans (SNPs) permanent.
- **Promote patient access and choice:** The legislation would expand patient access to kidney disease education programs and establish renal dialysis facilities as a cost-effective alternative to hospital outpatient departments.
- **Expand research and enhance coordination:** The legislation would improve federal research efforts and will require improved coordination among the various federal agencies conducting CKD research and require a study into the progression of kidney disease and treatment in minority populations.



The Living Donor Protection Act will:

Help increase access to kidney transplants by:

- **Protecting Donors:** The bill prohibits life, disability, and long-term care insurers from denying or limiting coverage or from charging higher premiums to living organ donors.
- **Securing Jobs:** The legislation clarifies that living organ donors can use FMLA time to recover from donation surgery and maintain their job security.
- **Educating Americans:** The bill directs HHS to educate Americans about living organ donation.

Learn more about these important bills, contact your legislator and track their progress at RSNhope.org,

Web ID: 139



FLUID CONTROL

for energy to live a full life

By Susie Gonzalez

Web ID: 1039

I started dialysis when I was 24 years old. I resolved then to take good care of myself, because I had a one-year-old child to raise and a long life ahead of me if I could manage my health. I've kept that resolution for 20 years on dialysis, and I've discovered how to control my fluid intake to maintain a good quality of life.

I live alone now. I cook, clean my own apartment, and do my own laundry. I like to walk and swim, and I actually lift weights for my legs. If I have too much fluid in my system, all these activities are difficult. I need to have energy to take good care of myself, and that energy partly comes from good fluid control. Staying as close as possible to my dry weight goal is critical to maintaining my health. If I were to become overloaded with fluids, it could lead to cramping, heart failure and breathing problems and possibly congestive heart failure or pneumonia (due to water in the lungs).

By sharing my story, I hope to inspire others to persevere in controlling their fluids. I know this can be difficult, but with consistent effort I've discovered what works for me. I started with a positive attitude, and I've been able to manage my fluids and keep my fluid weight gain to a minimum.

MY PERSONAL STRATEGIES FOR CONTROLLING FLUIDS:

- I try to eat a low sodium diet, probably 1000-1300 mg of sodium per-day.
- I keep spicy foods to a minimum.
- I rarely buy anything yummy to drink at the grocery store.
- I keep ice cold water in the refrigerator at all times.
- I drink very small amounts of water with medications.
- I usually try not to drink anything with meals or very little, ½ cup or less.
- When going to a restaurant I normally drink a small ice water and occasionally treat myself to a Sprite or ice tea mixed with lemonade.
- Sometimes I chew gum.
- When I'm very thirsty I suck on a large lemon wedge and then take a swallow of ice water.
- Sometimes I squeeze fresh lemon juice on peeled and cut apple slices.
- I order food in restaurants, if possible, without salt.
- I dialyze four times a week.

FLUID CONTROL IDEAS THAT OTHERS HAVE SHARED WITH ME:

- Have a bottle of water that holds the amount of your daily allowance.
- Hard candy and sugarless gum.
- Biotin spray or a water pick can lessen thirst.
- Popsicles or frozen grapes.
- Tiny water bottles or small cups.
- Remember everything counts! Ice, juice, fruits, soups, etc.
- Try taking medications with apple sauce.
- Fill a small spray bottle with lemon- or mint-flavored water and spritz your mouth to quench thirst.
- Salt or sodium makes you thirsty. Know your restrictions, learn to read labels.
- If diabetic, keep sugars under control. That will help to lessen thirst.

I hope I have helped you realize that it's possible to manage your fluids while being on hemodialysis. I know it can be difficult, especially if you're a diabetic. But, you can do it! And once you manage fluids, your well-being and quality of life will improve: you'll be able to do things you enjoy doing and live your life to its fullest. Please remember to always consult your dialysis healthcare team before making any changes to your diet, fluid intake, or treatment plan.

Susie Gonzalez had kidney failure in 1981. She has been on peritoneal, nocturnal and in center hemodialysis. She has had two kidney transplants and is awaiting her third. She is a Board member of Renal Support Network. She taught school for several years and enjoys volunteering.



LIVING A HEALTHY, HAPPY LIFE WITH KIDNEY DISEASE

MY CHRONIC ILLNESS COPING STRATEGIES

Keep a routine. I get up, get dressed, and participate in life whether I feel like it or not.

Exercise. Exercise sends the feel good hormones rushing through my body for nearly two hours after I exercise. I do what I can. Walking, riding a stationary bike, and yoga have been exercises I enjoy.

Don't hang out with negative people. I surround myself with people who build me up and support me with positive thoughts and wisdom. I also focus on the positive things that could happen if everything went right.

Do enjoyable things with friends and family regularly. Whether we're going out to eat, to the farmer's market, a concert, the theatre, a movie, playing games at one another's home, or just catching up to take a walk on the greenway, I hang out with my friends and family regularly. It's important to stay connected to the people in my life.



Beth Holloman is a retired Business Education teacher living in Raleigh, NC with her husband, Mike. Beth has performed peritoneal dialysis and has been lucky enough to receive two kidney transplants at UNC Hospital. Her most recent transplant was October 2015. She is a volunteer and advocate of RSN.

Get enough sleep, but not too much. I find that 6-8 hours is perfect for me.

Eat a healthy diet. Through the Internet and dieticians available at my clinic and doctor's office, I learned to create a diet that fits my needs as a kidney patient. Eating a proper diet has helped my lab values and my weight, and makes me feel better. This motivates me to eat like I should and makes me feel more in control of my disease.

Accept that feeling down is normal, and quite common in patients with chronic kidney disease. The treatments, the medications, the constant testing, and educating myself about the disease all can seem like a lot to deal with sometimes.

Join a cause close to your heart. I joined the Renal Support Network (RSN). RSN allows me to advocate for kidney patients while also educating myself. It's been wonderful to help others, and the things I've learned have helped me personally to manage my disease.

Speak to your doctor. Some medications may occasionally need to be changed or added. Some kidney medications tend to cause issues and side effects. My doctor may be able to prescribe a better medicine or some other form of treatment for me like a support group, or she/he may refer me to a psychologist. Nephrologists deal with these types of concerns in their patient populations daily.

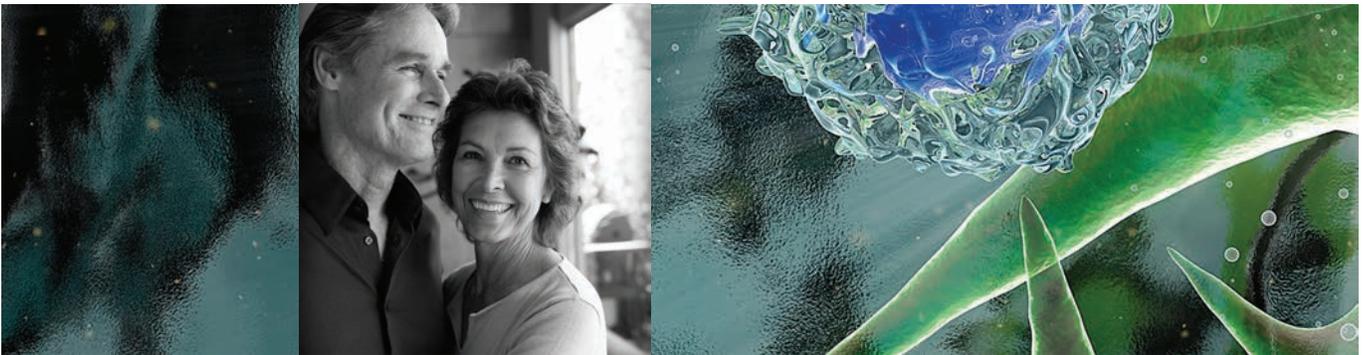
Keep up with lab values by getting the results after every blood draw. Seeing the positive or negative changes in my lab values allows me to take responsibility for my health, keeps me informed, and makes sure somebody is routinely checking my lab values. Knowing and understanding my lab results allows me to adjust my diet or lifestyle to improve my outcomes. Realizing that I do have some control over this disease tremendously helps my outlook.

Ask for help when you need it. I have friends, family, co-workers, doctors and nurses that are all part of my health care team. They all want to help me live the happiest, healthiest life I can live.



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LIVE & GIVE ONLINE

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

MISSION

The Renal Support Network is a patient-run nonprofit organization whose mission is to identify and meet the non-medical needs of those affected by chronic kidney disease.

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Connect with RSN

Would you like to receive a free subscription to Live&Give and RenAlert, RSN's electronic newsletter? Both provide access to free renal care information. Give us your contact information via phone, fax or mail. Be sure to include your name, mailing address, email address and phone number. [See contact details above.](#)



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EMBRACEHOPE JEWELRY

by lori hartwell

RSN's EMBRACEHOPE Jewelry is hand-crafted by people with kidney disease. Visit RSNhope.org and click the EMBRACEHOPE link.

What is RSN?

Renal Support Network (RSN) is a nonprofit, patient-focused organization that provides non-medical services to those affected by chronic kidney disease (CKD). Through a variety of programs RSN strives to help patients develop their personal coping skills and special talents by educating and empowering them (and their family members) to take control of the course and management of the disease.

HopeLine

If you have questions relating to chronic kidney disease, call (800) 579-1970 toll-free 10:00am to 6:00pm PST and connect with someone who can offer EXPERIENCE, STRENGTH and HOPE.

RSN EVENT CALENDAR

Nov. 12, 2016 7th Annual Celebrity Poker & Bingo Tournament
with special guests Jack Black & Kyle Gass

Jan. 15, 2017 18th Annual Renal Teen Prom

Patient Meetings

Sunday, Aug. 14, 2016
Santa Ana, CA

Sunday, Sept 18, 2016
Glendale, CA

Monthly Support Group in Glendale (4th Sunday of the Month)

CHECK RSNhope.org FOR ALL EVENT DETAILS



Service to those affected by chronic kidney disease

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Hosted by Lori Hartwell

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Itchy, Itchy Dry Skin: What to Do? Web ID:1014



Potassium Problems? New Hope Web ID:1030



Cured from Hepatitis C Web ID:1031



Writing a Letter to your Transplant Donor Family Web ID:1029



Chasing Motocross; How to Care for Yourself and Your Dreams Web ID:1024



Unwanted Habits & Feelings: Hypnosis Can Be A Solution Web ID:1032



Asking for Help Can Be a Gift to Others Web ID:1015



The Kidney Project Web ID:1027