

## THE TAKING CONTROL ISSUE



Many people reading this newsletter have been living with chronic kidney disease and chronic co-morbidities for years. Living with any chronic illness is not a walk in the park. It is an uphill hike, which takes inner strength we climbers find along the way. On this journey, I must continually adjust to my ever-changing health. Initially, there was quite a learning curve.

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# DISCOVER THE MANY WAYS TO RAISE AWARENESS OF CKD AND SUPPORT RSN

Web ID: 931

## EMBRACEHOPE JEWELRY by lori hartwell

Our EMBRACEHOPE Jewelry is hand-crafted by people with kidney disease.

Visit [RSNhope.org](http://RSNhope.org) and click EMBRACEHOPE link or see the entire line at [www.etsy.com/shop/EmbraceHopeJewelry](http://www.etsy.com/shop/EmbraceHopeJewelry)



### Messages of Hope Cabochon Necklaces

A meaningful gift for a special caregiver or loved one living with chronic illness.

## RSN's HOPE Shop



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T-Shirts & Clothing

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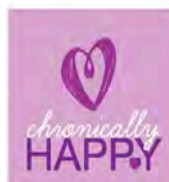
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Customize quality merchandise from housewares to accessories & apparel with your favorite RSN graphics at [cafepress.com/rsnhopeshop](http://cafepress.com/rsnhopeshop).



PICK UP A COPY OF LORI HARTWELL'S BOOK CHRONICALLY HAPPY: JOYFUL LIVING IN SPITE OF CHRONIC ILLNESS AT [AMAZON.COM](http://AMAZON.COM).

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# HOW TO BE A PROFESSIONAL PATIENT

by Lori Hartwell  
Web ID: 983

People are often shocked to learn that I have lived with kidney disease for over 46 years, surviving 40 plus surgeries, 13 years of dialysis and now living with my fourth kidney transplant. I can tell you one thing that has helped me survive: being as educated as I can about my illness. When you are knowledgeable and engaged about your illness, health care professionals quickly take notice. I think they deliver the best of care as a result.

**“No one will force the information on you – you must seek it out!”**

Becoming educated about your illness is something you must want to do. No one will force the information on you – you must seek it out! Information is your most powerful ally. It will help you choose the right doctors, make good decisions about your healthcare, gain confidence, and feel less out of control.

**Have high expectations about getting the care you need.** I have certain expectations of how doctors will interact with me. I'll never forget the time I saw a new cardiologist. He looked at my chart for a couple of minutes, asked me for minimal information then directed me to

follow him as he proceeded to walk out of the treatment room door and around the corner. He handed my chart to the receptionist and said, "I'll see her in 6 months." I looked at him, then looked at the receptionist and said, "I don't think so!" The entire visit may have taken three minutes max. This was unacceptable to me. I knew I had to find a new doctor to get the care I deserved.

**Clear communication is key to good care.** I know I have to be an active participant during an appointment, but so does the doc! When I see a new doctor, I bring a list of my medications, a brief bullet point typed medical history, and names and phone number of my other doctors. This always gives me more time to discuss my medical issues. Doctors are required to do a lot of documentation and I gain more time for communication by doing some of it for them.

I prepare a list of questions, and if I don't understand a diagnosis, treatment, or medical jargon – I ask. I let my doctor know if I think a prescribed treatment will be hard for me and I ask if any other options are available. It is great to ask doctors open ended questions as you get more information. I might ask: "How do most of your patients feel after the procedure?" I do ask that all medication prescribed be cleared by a Nephrologist. Some common

prescribed medications are not good for the kidneys or may have different effects if you require dialysis.

**Be alert and purposeful about what you want to take away from every interaction.** I only take a friend or family member when I can't think clearly or am very emotional about a doctor visit. It isn't realistic for me to arrange for or ask for a friend or family member to go to all my routine doctor appointments.

Before I leave the doctor's office, clinic or hospital, I make sure I know what I am supposed to do. I also ask the doctor what is considered an emergency. I can rest more easily knowing when I need to call if I have a temperature, pain or blood pressure problems.

**Give your schedule and your condition the attention they deserve!** I keep my appointments or I call and reschedule if I can't make them. This is so important. I never want to be labeled as a "no show" as my life depends on the doctor and staff knowing I take this seriously.

**There is always more to learn.** If I am having a new healthcare issue, I ask for written information, videos, websites and any other information that can help me continue my education toward my self-proclaimed degree as a professional patient. Knowledge saves your life.

*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.*



BLOOD PRESSURE & DIALYSIS

By Sandra Corrigan  
FNP-BC, CNN  
Web ID: 984

**What is Blood Pressure?**

"Blood pressure" is the force of blood against your artery walls as it circulates through your body. Blood pressure (BP) normally rises and falls throughout the day. It can cause health problems if it stays too high for a long time or if it is too low to deliver enough oxygen to the organs.

Blood pressure is measured using two numbers. The first, systolic blood pressure, represents the "working" phase of your heart, or the pressure in your blood vessels when your heart contracts. The second, diastolic blood pressure, represents the pressure in your blood vessels when your heart "rests" between beats. Though individuals vary, generally a blood pressure before dialysis should be less than 150/90 and after treatment should be less than 130/80.

**What happens when BP is too high?**

Common dangers of high blood pressure are stroke, heart attack, and vessel diseases. High BP can cause

congestive heart failure due to an increased load on the heart. Damage to vessel walls leads to atherosclerosis. In many dialysis patients, it is high blood pressure that prompted renal failure in the first place: the high force of blood pushed into very small vessels of the kidney causing scarring and thickening of those vessels and leading to permanent damage.

High blood pressure often has no warning signs or symptoms, so many people don't realize they have it. Some symptoms may include headache, blurred vision, nervousness, sweating, difficulty sleeping or facial flushing. Even with no symptoms, hypertension needs ongoing treatment to protect the heart, kidneys and other organs from further damage.

**What to watch out for with low blood pressure**

Blood pressure is checked in all medical settings, but it is even more significant for patients on dialysis. Low blood pressure, or hypotension, can create problems during dialysis. Know the symptoms so you can alert staff and get treatment quickly.

Common symptoms of low blood pressure can include dizziness, nausea, headaches, muscle cramps, and, in more severe cases, chest pain and loss of consciousness.

Blood pressure may drop at any time during treatment. Often, the cause is a decrease in the volume of fluid in the bloodstream. Hypotension can occur even when your tissues are fluid overloaded.

**What can you do to control blood pressure?**

To minimize the risk of hypertension, control sodium, potassium, and other essential electrolytes the body uses to maintain fluid balance. The recommendation for patients with kidney disease: limit sodium intake to no more than 1,500 mg per day. Most sodium in today's diet comes from processed foods and restaurants foods. Unhealthy lifestyles choices, such as smoking tobacco, obesity, and

excessive alcohol consumption, may also contribute to hypertension.

To prevent hypotension during dialysis, take in adequate protein, as it helps fluid move from tissues into the bloodstream. The protein level is usually reflected as albumin in the lab. Patients are often encouraged to increase consumption of fish, eggs and chicken when albumin is low.

Another important way to avoid hypotension is to keep fluid intake low between treatments so the change in body fluid isn't so drastic. Removal

**SYSTOLIC - CONTRACTION**  
Blood pressure rises as blood moves out along vessels

**DIASTOLIC - REST**  
Blood pressure falls and blood fills the heart.

of large amounts of fluid makes the treatment much harder on the heart. Weight gains between treatments should be no more than 5% of dry body weight.

Exercise can both improve high blood pressure and diminish hypotension during treatment. An exercise plan appropriate for a patient's condition should be supervised by a physician to avoid injury.

**Notes on medications**

Patients with cardiovascular conditions frequently require multiple blood pressure medications that work in different ways. One medication may increase urine output, another relaxes the blood vessels, and another improves heart rate, contractions or output. Some medications are available



in combination, so patients may want to ask their doctor for options.

Blood pressure medications can affect dialysis. A doctor should advise patients when to take medications on dialysis versus non-dialysis days. If a patient takes BP medication at night, and then arrives at dialysis with very high blood pressure in the morning, either: 1) fluid gains are too high or 2) the evening dose is not adequate. This is dangerous. Patients' checks of blood pressure at home morning and evening can help the doctor optimize timing and dosages.

The doctor may recommend postponing some medications before treatment on dialysis days, especially if a patient's blood pressure falls during treatments. However, some medications protect the heart. Any alteration must be supervised by the doctor.

Ask your doctor or nurse if your blood pressure readings are at goal. If your high blood pressure is not well controlled or you experience low blood pressure during treatment, review the above with your doctor. Controlling blood pressure is key to lowering the risk of complications and achieving more comfortable treatment.

**References available at [RSNhope.org](http://RSNhope.org) see web ID: 984**

**Learn more about this subject by listening to Sandy's interview with Lori on KidneyTalk.**

*Sandra Corrigan MSN, FNP-BC, CNN is a Nurse Practitioner in Ventura County, Ca where she cares for patients on hemodialysis at several dialysis facilities. Practicing in nephrology for over 30 years, her background includes clinical and education experience in dialysis, as well as the management of earlier stages of kidney disease.*



## RENAL SUPPORT NETWORK INVITES PEOPLE WITH KIDNEY DISEASE TO ENTER OUR




13<sup>TH</sup> ANNUAL

♥ ESSAY

CONTEST

### 2015 Theme:

How Have You  
Used Your  
Experiences  
to Give



**HOPE**  
to Others  
with Kidney Disease?

**Visit [RSNhope.org/essay-contest](http://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



# 10 TIPS

## to a healthier heart

By Martha Preciado, MD

Web ID: 985

*Heart disease is common in people with chronic kidney disease (CKD). Underlying conditions that cause renal disease, such as high blood pressure and diabetes, put people at greater risk for cardiovascular disease. Reduce your risk! Commit yourself to watching over your heart and keeping it as healthy as possible.*

1

Keep your cholesterol within normal range via diet, medication and exercise. Excess cholesterol can form plaque along artery walls, making it harder for your heart to circulate blood. Plaque can break open and cause blood clots or a stroke.

2

Keep your glucose level within normal range. Keep track of your blood sugar, eat right and take medications as prescribed.

3

Control blood pressure. If you have high or low blood pressure, take action by monitoring and recording it at home in the morning and evening. Share the results with your physician to make sure you are taking the right medications in the right dosages at the right times.

4

Know how much fluid you need. Fluid build-up in your body can elevate blood pressure, and higher blood pressure contributes to heart disease. People on dialysis often have fluid restrictions, whereas people who have transplants may be required to drink more water. Ask your nephrologist.

5

Get sufficient sleep. People who sleep fewer than seven hours a night have higher blood pressure and higher levels of the stress hormone cortisol. Sleep is essential for relaxation, rejuvenation and healing.

*Taking all these steps shows our heart that we are committed to our health. Our hearts, in turn, will have more strength to give us for life's daily challenges.*

6

Manage stress. Cortisol, and other stress hormones, cause excess glucose production to provide energy for a “fight or flight” response. Cortisol inhibits insulin production, narrows arteries and increases heart rate. Chronically elevated cortisol can affect weight, immune function, and susceptibility to disease.

7

Reach and maintain an ideal weight. Obesity, or elevated body mass index (BMI), are major risk factors for hypertension, Type 2 diabetes, coronary heart disease and several other pathologies. A body's excess weight puts additional stress on the heart's functioning and can also cause breathing problems such as sleep apnea.

8

Don't smoke. Smoking hurts every organ in the body including the heart and blood vessels. It's the main preventable cause of death and illness in the United States.

9

Exercise your heart – it's a muscle, too! Muscles used regularly become stronger and healthier. Exercising helps the heart pump more blood through the body, and helps to keep arteries and blood vessels flexible.

10

Take prescribed medications regularly and as prescribed by your doctor. Any patients, beyond those who are elderly, can lose track when they have to consume multiple medications on a complex schedule. Use apps, a written schedule, or “memory aids” such as pill boxes to take your medicine at the right times.



*Dr. Martha Preciado, MD is board certified in Internal Medicine and Cardiovascular Disease. She is the President and CEO of Preciado Cardiology, Inc in Los Angeles, CA.*



# the NEW Normal

By Julie Glennon  
Web ID: 986

## ADJUSTMENTS

Once you are a pre-dialysis patient, some nephrologists recommend limiting your protein intake. This may be a challenge for some patients. If and or when you start dialysis, you must increase your protein and limit your fluids, another adjustment. If you get a transplant, there are many medications to take, another new normal.

The long term use of medication, whether a dialysis patient or a transplant patient, can take a toll on our bodies. In my case, years of medications for Lupus and my transplant have affected my bones and skin.

## EDEMA

I was diagnosed in 1988 at the age of twenty with Lupus Nephritis. This eventually caused my kidney failure. For me, pre-dialysis was a bumpy road. I had Nephrotic Syndrome at that time, which caused significant edema throughout my body. Over time, my legs became so heavy I had to use a wheelchair. If I wanted to go out and about that was my only option.

It amazed me how much people stared at me, and how many times people just walked into me. I gained real insight into what wheelchair bound individuals live with.

## ORTHOPEDIC ISSUES

Healthy kidneys help keep your bones healthy. They do this in two ways: Healthy kidneys keep the right

amounts of phosphorus and calcium in your body. When your kidneys are not working, too much phosphorus can build up in your blood. This can cause your body to pull calcium from your bones, making them weak. And, Healthy kidneys help your body use vitamin D. When your kidneys are not working, your body may not be able to use vitamin D like it should. This can also cause your bones to get weak.

I have suffered many bone breaks in my feet due to my 24 years on prednisone. For me, spontaneous breaks in my feet are common. I have worn casts for some breaks, and used boots for others. Each time I suffered a break, I used crutches for weeks at a time.

Other patients may need hip or knee replacements due to prolonged steroid use. Getting the proper diagnosis and treatment is imperative to proper bone healing. Surgery, physical therapy and the use of a cane, crutches or a walker are all part of the package.



Accepting the reality  
of my lifelong health  
issues is still a process,  
even after 27 years.



Some patients feel they are too young to use a cane or walker. With kidney disease we know that being an active participant in our medical care is imperative. If we have a kidney transplant, we take our medications religiously. If we go to inpatient hemo dialysis, we know that to stay alive we must follow our treatment schedule. If we are told to use durable medical equipment, we do so as instructed. Adhering to the prescribed regimen is a must.

Continued from page 1

## SKIN

Skin cancer can be a common side effect of transplant medications. As a former competitive swimmer and sun lover, years of medications have taken an added toll on my skin. An active role in my healthcare, for me, means visiting my dermatologist four times a year. I have my entire body checked to see if any of my moles and or freckles have changed color, shape or size. Many times, I do have skin cancer.

In 2009, I had a serious infiltrated basal cell carcinoma on my nose. I lost the bottom half of my left nostril. After many reconstructive surgeries, I sort of have my nostril back. Through the year-long process of rebuilding my nostril from my ear cartilage, I was self-conscious in public. I even contemplated not having the surgery at all. I am quite vain.

My dermatologist called me the night before the surgery and spoke with me for one hour. Knowing deep down that the cancer could spread anywhere in my body, I knew I had to go through with the surgeries. I now wear skin colored tape over my deep scar, which gives me a bit more confidence. Hey, whatever works!

Accepting the reality of my lifelong health issues is still a process, even after 27 years. Do I like taking medicine? No. Do I like having arthritis everyday? No. But ultimately I have learned to continue on the uphill path. I work year after year, hand in hand with my doctors, to keep my life moving forward.

Julie Glennon was diagnosed with Lupus and chronic kidney disease in 1988. She is currently transplanted for 15 years. She volunteers with the Renal Support Network, the Kidney Association of South Florida and Network 7. She lives in Florida with her husband and beloved Cockapoo.





# From FitBit to Fit Chick

Web ID: 987

By Cher Thomas

Throughout my life, I've always had to keep an eye on my weight. Unlike my siblings, I could put on weight with the blink of an eye. Luckily, I was athletic and as long as I watched meal portions carefully, I was able to keep a healthy body weight as an adult. That changed in 1998, when I heard news many of you have gotten as well, about elevated protein (creatinine) in my urine. I listened to and followed directions: "...eat this, but not that..." I found I was tired all time.

The cause of my kidney disease was an autoimmune disorder. On top of the dietary restrictions, chronic fatigue, and the sensory and emotional impacts of end stage renal disease, I was prescribed prednisone and gained a whopping 30 pounds in 3 months. Unfortunately, this time my weight gain didn't end easily.

Although we haven't all had exactly the same experiences with kidney disease, I'm sure we've each been frustrated by body image issues, by depression due to medication or a special diet, or by difficulties times in life due to our illness!

So how is a girl (or guy) supposed to preserve or regain a healthy figure while living with CKD? The good news is once you develop a plan and begin to see results, the awkward feelings about CKD diminish and life becomes more enjoyable.

**Make a plan** Those of us with kidney disease are lucky to have access to frequent medical visits and renal dietitians. We can use this access to get personalized help with developing a strategy. The first step is to find out what is safe for you. In consultation with your doctor and dietician, create a plan including Diet, Exercise and Technology, addressing every specific medical need you have.

**Diet** First, determine with your physician that losing weight is safe and appropriate for you. Second, make an appointment with the renal dietitian to develop a dietary plan that is safe for your medical condition.

**Exercise** Next, ask your physician what type of exercise has been beneficial for patients like you, and what type of regimen is likely to work for you, and that you will enjoy. You are more likely to keep at it if you are having fun.

**Technology** Use the Internet to research diet, exercise, and fitness trackers that suit your needs. Before you adopt any plan, be sure to have it approved by your physician. Helpful technology available online includes the new tracking devices Fitbit and Jawbone, which have online applications to help you monitor your exercise, dietary intake, and fluid intake. Shop around, ask around, and ask your physician if one of these devices would benefit you. My health insurance plan allowed me to have a small Fitbit as part of my health benefits.

**Find a Buddy** Seek out and invite a family member, friend, or colleague to join you on your journey. Obesity is a national problem. Finding someone to join you will help to provide motivation. Having trouble finding someone with the same schedule? Reach out to find online buddies through social networking, Facebook or Twitter.

An appropriate body weight, healthy diet, and beneficial exercise are all achievable when you make a plan, confirm it with your physician and dietician, utilize technology and/or the internet, and adopt the Buddy System. Best of luck on your journey toward a healthy, fit enjoyment of life.



*Cher Thomas, RDH is a Registered Dental Hygienist and a renal transplant recipient. After her kidneys failed due to ANCA positive vasculitis, her brother, Robert, was her donor in 1999. Cher utilized her experience with peritoneal dialysis and organ transplantation to explore the relationship between oral and renal health. She lives in Galveston, Texas.*







# The Chronic Kidney Disease Improvement in Research and Treatment

## ACT

### of 2015

H.R. 1130 S. 598

Ask your Senators and Congressman to support The Chronic Kidney Disease Improvement in Research and Treatment Act:

- ✓ Improve the coordination of care
- ✓ Promote patient access and choice
- ✓ Expand research and enhance coordination

... **E-Mail**   **Fax**   **Call**   **Write**   **Meet** ...

Tell Your Friends and Family to Reach Out to Their Elected Official.

If you have a personal connection to an elected official, please contact us at RSN.

Learn more by visiting [RSNhope.org](http://RSNhope.org) and clicking on advocacy.



# DONATE & CONNECT

Renal Support Network  
relies on **charitable**  
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We appreciate your help!

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## MAIL CHECKS TO:

Renal Support Network  
1146 North Central Ave #121  
Glendale, CA 91202

RSN accepts all major credit cards  
Gifts are tax-deductible

# Live & Give

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

## LIVE & GIVE ONLINE

Current issue, printable version,  
articles, and archives can be found at:  
[www.RSNhope.org](http://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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# SUPPORT

NEXT EXIT 

## What is RSN?

Renal Support Network (RSN) is a nonprofit, patient-focused, patient-run 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, special talents, and employability 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 and connect with someone who can offer EXPERIENCE, STRENGTH and HOPE.

## Support Group Meetings

RSN hosts a monthly support group on the 4th Sunday of the Month in Glendale, CA. Check RSNhope.org for all location and time details.

Are you concerned about policies and news affecting people with kidney disease?

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](mailto:wekan@rsnhope.org) or call 866-903-1728

## RSN Event Calendar

August 1, 2015:

Essay Contest Deadline

September 27, 2015:

RSN Patient Educational Meeting

November 14, 2015:

6<sup>th</sup> Annual Celebrity Poker Tournament

January 17, 2016:

17<sup>th</sup> Annual Renal Teen Prom

CHECK RSNhope.org FOR ALL EVENT DETAILS

## What did you learn from this issue of

# Live & Give

Take our Quiz and find out.

Send us your completed quiz to be entered into our prize drawing.

### Last Issue's Quiz Winners!

Betty Watson, Greenfield, Wisconsin  
Joann Hall, Jersey Shore, Pennsylvania  
Sally Walker, Jacksonville, Florida  
Olivia Hairston, Atlanta, Georgia

1. What is something Lori might ask after a procedure?
2. Blood pressure is measured by what 2 numbers?
3. What is the theme of RSN's 2015 essay contest?
4. What tip do you find most helpful to have a healthier heart?
5. When was Julie Glennon diagnosed?
6. What 5 steps did Cher Thomas do to become fit?
7. What is the name of the new CKD bill introduced in Congress?
8. What KidneyTalk show title is your favorite?
9. What number can you call if you want to connect with a peer?
10. Do you plan on contacting your legislator regarding the new CKD bill?

Send your responses to RSN (mail, fax or email) by August 1, 2015 to participate in a drawing for a \$25 American Express Card. Four winners will be chosen and announced in the next issue. See RSN address on page 10.





Service to those affected by chronic kidney disease

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RSNhope.org: Enter the Web ID listed below in the search box in the right hand corner located on RSNhope.org to stream.

 *Don't Let A Wound Get the Best of You!* Web ID: 959


 *Overcoming Acute Kidney Injury* Web ID: 974

 *Working Through Your Illness* Web ID: 970

 *Laughing Your Way to Living Donation* Web ID: 968

 *5 Star Dialysis Rating System Explained* Web ID: 971

 *My Life, My Dialysis Choice* Web ID: 972

 *Let's Make the Kidney Wait List to Zero* Web ID: 978

 *CrowdMed: Solving Medical Mysteries* Web ID: 981