

# Live & Give

Fall/Winter 2017  
Vol. 12 Issue 2

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

**THE RESILIENCE ISSUE**

## 1st Place Winner, 15th Annual Essay Contest



## Making lemonade out of lemons

by Brad Chaffee



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*In this issue I thought it would be useful for me to share my perspective after living with kidney disease for decades and hosting KidneyTalk™ for over ten years. In this Q&A I share some of the valuable lessons I've learned during my journey.*

**How did you meet your husband?** Prior to meeting and marrying my husband, Dean, I secretly bought into the old line, "I wouldn't want to join any club that would have me as a member." You see, I felt comfortable with the game players, despite the self-doubt they dredged up. With them, one thing was guaranteed: I wouldn't have to get too close. I could tell, even on that first date, there was no such guarantee with Dean. I was making up reasons not to like him because I didn't want to be rejected. I was afraid I was too imperfect to love, and once he saw how difficult a relationship and my multiple health issues with me would be, he'd take off. I had to learn to communicate about my illness and to accept that I was more than my illness! I've learned that everyone has "something." And if you allow kidney disease to run your entire life, people may have difficulty relating to you. I have been married to Dean for 20 years and he gives me an anniversary card every month since we have been married! You can find love.

## What causes itchy skin?

**What causes itchy skin?** When I was on dialysis, symptoms like itching were commonly due to high parathyroid or phosphorus levels. Be aware of your lab values and talk with your doctor on how to best keep them in normal range. Medications and dialysis can also cause dry skin.

Lori Hartwell is the Founder & President of Renal Support Network (RSN) and the host of KidneyTalk™, a radio podcast 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.

# Q&A

## WITH LORI HARTWELL

Web ID: 4000

I've found quality moisturizers can help soothe and repair dry, itchy, and irritated skin. It's always best to apply moisturizer when your skin is still a little damp after your shower or bath. Dr. Yuval Bibi, is a dermatologist and explains what can cause itchy skin and ways you can best treat, care for and protect your birthday suit. Web ID 1014

**Have you experienced dry mouth?** It is no fun to have a dry mouth. Kidney disease can cause dry mouth, bad breath, and sometimes even leave a metallic taste. I've learned this can be a side effect of medications, fluid restrictions, and/or breathing through the mouth instead of the nose. I found that limiting my salt intake helped me not to feel so thirsty. Chewing gum, and using a product called Biotene, also helped me with dry mouth. Chronic dry mouth can lead to dental problems so try to find a solution that works for you.

**What did you eat when on dialysis?** I was thrilled to interview Sarah Carlson, RD for KidneyTalk™. She describes what she would cook for me if she was my personal renal chef for the weekend. You can listen to all the enticing foods she would prepare for me. The way she describes food and the different seasoning she uses will leave you hungry. Web ID #926

## Are you worried about having pets and infection?

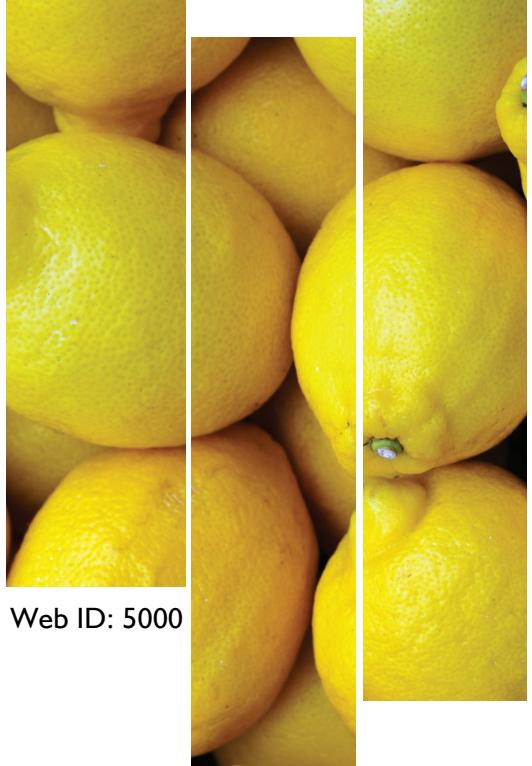
I love my pets! I have 4 dogs, a cat and a parrot. I know I would be devastated if I was told that I had to get rid of my furry/feathered friends because of my disease. Over the years, I've learned to take precautions against pet-borne infections. I interviewed Phillip Zakowski, MD who is a specialist in infectious diseases and he shared several strategies on how to handle animals and stay healthy. Web ID #993

## Did you tell your employer that you have kidney disease?

I have worked since I was 18 years old, and having a job/career has added so much meaning to my life. I always sold my work capabilities before relaying any information about my illness. I came to all my jobs through networking and having someone vouch for my expertise. It's also important to know your rights and how to communicate your illness to an employer. Dr. Nissenson provides some insight for this question. Web ID #734

See page 11 for more information about how to access and listen to the KidneyTalk™ shows mentioned in this article on iTunes or at [RSNhope.org](http://RSNhope.org).

You should not use this information in this article to diagnose or treat a health problem. Contact a qualified healthcare provider.



Web ID: 5000

## Making lemonade out of lemons

by Brad Chaffee

1st Place Winner, 15th Annual Essay Contest

"I'm afraid it's time for your husband to start dialysis!" the doctor declared. The room fell silent as the news percolated in our heads. The expression on my wife's face dropped like a sad puppy dog, and she became teary-eyed.

It was clear she was having a hard time with this new reality. She took it much harder than I expected, and it was crushing to witness. As the day went on, she broke down crying many times at work. It had been almost 4 years since I was diagnosed with Polycystic Kidney Disease. We knew this day

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Avoiding victimhood and keeping that mindset from infecting all aspects of my life was paramount"

*Brad Chaffee is happily married with 4 beautiful children that he adores. After receiving his kidney transplant, he hit the ground running and quickly enrolled in college to pursue a degree in cybersecurity. He eagerly returned to the Pickleball courts and plays obsessively. His fondest memory is the time his 5-year-old daughter came into his room and said, "Daddy, I love your new kidney!"*

would come, but it's hard to comprehend the severity of such a horrible disease until it begins to impact your life. Quite honestly, watching the fear in my wife's eyes was 100 times harder than my new diagnosis. I couldn't help feeling personally responsible for her pain even

though I didn't cause it. I wondered how to ease her troubled heart as we began to navigate the sure-to-be bumpy road that was end stage renal failure?

I felt completely helpless, especially since I wasn't even sure what to expect myself. I was scared and facing my own fears as a result. I knew my life would look different, but to what degree? I had no clue. I did know that I needed to be strong for my family's sake. Then it hit me, like the sweet aroma of grandma's homemade cookies. There was nothing I could do to change my circumstances, but I could do everything in my power to make the very best of things. In

that moment, I decided to embrace an idea that had been completely foreign to me. I was going to "make lemonade out of lemons". I had heard the adage many times in my life, but I never thought it applied to me until that moment. I was going to seek out the positive in every struggle I faced, which was going to be challenging since my tendency to always spot the negative was second nature. It was time to turn over a new leaf. I wasn't sure I was capable of such a thing, but I knew I had to try.

As suspected, 10 hours a night on dialysis proved to be quite a trial. Fatigue, nausea, vomiting, and severe muscle cramps, among

other symptoms, tested my resolve. It certainly made it more difficult for me to make the best of my situation. However, my determination was strong, and I pushed through for my family. No matter what happened, I tried not to complain. I reminded myself that regardless of the struggles I was facing, there was always someone else who had it worse. That's not to say I didn't sometimes succumb to negative feelings about my situation, but what was fascinating was that my new outlook seemed to help me come around much faster. It also helped that I surrounded myself with positive and uplifting people that I could turn to for support and encouragement. Little did I know, my decision to be positive had a profound impact in ways I didn't expect.

I initially made the decision because I was concerned about my family, but as time passed I realized it literally changed me as a person. I transformed from a devout pessimist to someone that went out of my way to see the positive in everything I faced. It not only helped me appreciate my blessings,

it also helped me cope with PKD and all of its terrible symptoms. It became, quite literally, the best decision I ever made concerning my health. Avoiding victimhood

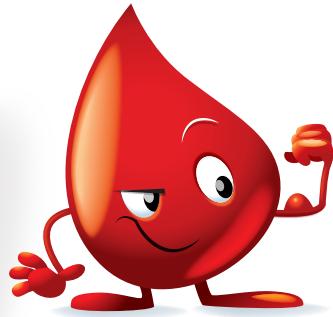
and keeping that mindset from infecting all aspects of my life was paramount. I was going through something that is known to cause depression, and I thrived despite it. As a result, my stress levels were substantially lower, and I was motivated to exercise, which introduced me to a sport I now love called pickleball. I lost 54 pounds in 9 months which helped me become a better candidate for transplant! On March 2, 2017, I had that kidney transplant and felt victorious.

Life certainly pummeled me with lemons, but instead of allowing the situation to sour my disposition, I made the best lemonade I could, and it most certainly paid off.

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## IMPORTANT SAFETY INFORMATION

### Warnings and Precautions

Serious hypersensitivity reactions, including anaphylactic-type reactions, some of which have been lifethreatening and fatal, have been reported in patients receiving parenteral iron products. Patients may present with shock, clinically significant hypotension, loss of consciousness, and/or collapse. Monitor patients for signs and symptoms of hypersensitivity during and after hemodialysis until clinically stable. Personnel and therapies should be immediately available for the treatment of serious hypersensitivity reactions. Hypersensitivity reactions have been reported in 1 (0.3%) of 292 patients receiving Triferic® in two randomized clinical trials. Iron status should be determined on pre-dialysis blood samples. Post dialysis serum iron parameters may overestimate serum iron and transferrin saturation.

### Adverse Reactions

The most common adverse reactions ( $\geq 3\%$  and at least 1% greater than placebo) in controlled clinical studies include: headache, peripheral edema, asthenia, AV fistula thrombosis, urinary tract infection, AV fistula site hemorrhage, pyrexia, fatigue, procedural hypotension, muscle spasms, pain in extremity, back pain, and dyspnea.

For full Safety and Prescribing Information please visit [www.triferic.com](http://www.triferic.com).

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[www.triferic.com](http://www.triferic.com)

# LIFE or DEATH



by Debby Ramsey  
2nd Place Winner, (tie) 15th Annual Essay Contest

Why am I am so nauseous? Why am I so tired? Why am I so dizzy? In October of 1979 I continued to ask myself these questions for a few weeks. I had just established myself with a new nephrologist and was on track to better care for myself and my chronic kidney disease. I had been diagnosed with chronic glomerulonephritis several years prior to this and was just getting used to not having my parents involved in my health care decisions. I had graduated from college, gotten married, and landed my first professional job all in the previous year and was very enthusiastic on starting my new life.

When I was twelve, my doctor told me I would not be able to have any children. I accepted this fact and turned my sights on a career. While in college, I investigated many possibilities and decided the best fit for me would be in Recreation for Special Populations. While in college, I met the best friends, participated on the Women's Gymnastics Team, joined the collegiate circus and met a young man I fell for deeply. I made sure he knew my medical history but that didn't stop him from asking me to marry him. We were married in the spring of 1978 and began our new life together.

Everything was going smoothly until the fall of 1979. I just didn't feel well.

I made an appointment with my new doctor but on a whim, I purchased a home pregnancy test. To my great surprise...I was pregnant! Well, that explained my periodic nausea, lack of energy and dizziness. I went to my appointment elated with my new findings.

Unfortunately, the doctor was not as ardent as I was. He and his staff were very troubled about my health and the health of my baby. I continued to have a positive attitude and made it no secret that I was excited and ready for this challenge no matter what it took to ensure a positive outcome. They, on the other hand, continued

"I CONTINUED TO HAVE A POSITIVE ATTITUDE AND MADE IT NO SECRET THAT I WAS EXCITED AND READY FOR THIS CHALLENGE NO MATTER WHAT IT TOOK TO ENSURE A POSITIVE OUTCOME."

to be negative and gravely cautious. Finally, the doctor made his intentions quite clear. He told me it was in the best interest for me and the baby to terminate the pregnancy. I was aghast!

At that point, I told him I wanted to at least try to have this baby and I would do everything it took to have as

normal and safe pregnancy as possible. I would quit my job and stay in bed the whole time if I had to! Still, he wouldn't change his attitude. When he said, "You know, prayer isn't the only thing that is going to help you," I knew I needed to make a decision. And I made it. I left his office upbeat that day. I continued to smile, continued to be optimistic and did not utter a harsh word. However, I knew I would not be returning.

I found a wonderful doctor who was supportive of my decision. He too, was cautious and concerned but he respected my ultimate decision. He let me know from the beginning that if things got too complicated he would refer me to a specialist, but he was willing to help me through this major chapter of my life. I did not go back to the nephrologist who recommended the abortion and seven months later, on April 28, 1980, my son Kevin Alan was born. He had a rocky start and spent three weeks in the neonatal unit of the hospital, but on Father's Day, 1980 he came home.

He is now 37 years old, and works for a company that takes him all over the country setting up for major sporting events. He has been my best friend, confidant, and truly the joy of my life. At four years old, he answered the call that wonderful morning when the transplant center informed me that a kidney was waiting for me. When he was ten, we were blessed with the adoption of two beautiful twin girls, and he instantly became the best big brother they could ever have. Every day is a gift, especially since my transplant, and major decisions are often to be made. My decision to take a leap of faith and face the challenge of a very high risk pregnancy under the guidance of a very caring doctor was the best one ever!

*Debby Ramsey is a mother of three and has an adorable grandson. She would not have been able to share in these joys without the most generous spirit of her unknown donor family. She owns the oldest business in Zion, Illinois, the Aiupy Feed Store that her grandfather established in 1924. Since her transplant in 1984, she regards each day as a gift and wants to use this gift to live life as though her donor is watching and encourage others to never lose hope.*



# SQUIRMING TOWARD MY NEW NORMAL

by Sandra Kisselback

2nd Place Winner, (tie)  
15th Annual Essay Contest

A chance meeting in a random hallway led to changes.

Echoes of conversations filled my mind.

"You should opt to get yourself back on the transplant list."

I fidgeted in my seat.

"Take a chance Sandra. It will be worth it."

I'm doing reasonably well.  
Treatments are working. I'm handling the regimen.

"It'll be better for you. Trust me," Dr. Schumacher, nephrologist extraordinaire chimed. He encouraged me to try for a second transplant every office visit. Assuring me benefits would abound.

Everybody was pressing me to do it. I'm aware a bounty of positives flock along-side successful transplantation. The first transplant, donated by my brother Brian, was wonderful. "Bartholomew" worked for 11 years, 11 months and 11 days.

"Sign up. Get the tests. What's holding you back?"

Squeamishly replying to the concerted efforts of health care professionals and friends, I always voiced the same concerns:

"Ok. Suppose I try for a new kidney and a match is miraculously found. Three years post-transplant, Medicare ends. I would need to find and fund a complete fresh health plan. Plus the cost of the drugs can be huge."

"Well, maybe you could get a full time job with health benefits."

Hahahahahahahaha! My insides were busting up with laughter. Whooping it up with a mixture of held back tears and silent resistance to change. I officially qualify for senior citizen discounts. Who's gonna hire me full time and give me health insurance? Maybe I could become the next runway model with a million-dollar contract. Or, how about the new Commander of the Navy Seals elite squad. That would be outstanding. I'd enjoy that one!

I know you care. But...will you pay for my transplant drugs or health insurance? I didn't think so. Thanks anyway. It's all working just fine the way it is.

This was clearly the right decision. Stay on dialysis 'til the end. It's manageable. I held faithfully to this truth like a lifeline. Even as surprise bumps rose up on the seemingly smooth ride, I fought through challenges to get back to my "normal"- home hemo-dialysis five hours a day, five days a week. Two needles poked in my arm, blood filling the IV lines, scrunching under the multiple blankets as the machine scrubbed away the toxins.

Riding one particular storm of hospitalization, I roamed the hallways between treatments. Popping out a side door, I came face to face with my future.

"Hi, Dr. Conti."

"Hey, you. What are you doing here?"

"I'm looking for a new kidney," I blurted out.

Dr. Conti volleyed back, "Call my secretary Alice and set up an appointment." He gave me the number.

Later that day, I timidly dialed the number and set a date for orientation. Dragging my heels over the next few months, Still resisting changes to my routine, I slowly completed the testing for placement on the transplant list.

A bit over a year later, I received a call from Albany Medical Center. I was setting up to do a treatment, so I let the answering machine pick up. Right before plugging in, I figured I should check the message and was directed to call Jennifer.

"Hello, this is Sandra Kisselback returning your call."

"Hi, this is Jennifer. We have a kidney for you. How long will it take you to get to the hospital?"

Twenty-one hours later I was being wheeled to surgery. I successfully celebrated my third anniversary on April 8, 2017.

I had been protecting myself in a box of comfort. Making excuses for playing it safe. Sticking to what was working and leaving the risk taking to experts. I now realize, life will improve by having confidence enough to question your standard operating procedure. In the potato chip caper I was told I could do anything I set my mind to. But that's another story.

Deciding to go forward with a second transplant and living dialysis free is my new normal. They were right. It was well worth it!

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**Kidney Transplant and Organ Donation Resources:**

National Kidney Registry  
Phone:(631) 517-9546  
[kidneyregistry.org](http://kidneyregistry.org)

National Living Donor Assistance Center  
Phone:(703) 414-1600  
[livingdonorassistance.org](http://livingdonorassistance.org)

United Network for Organ Sharing (UNOS)  
Phone: (804) 782-4800  
[unos.org](http://unos.org)

Donate Life  
[donatelifenet](http://donatelifenet)

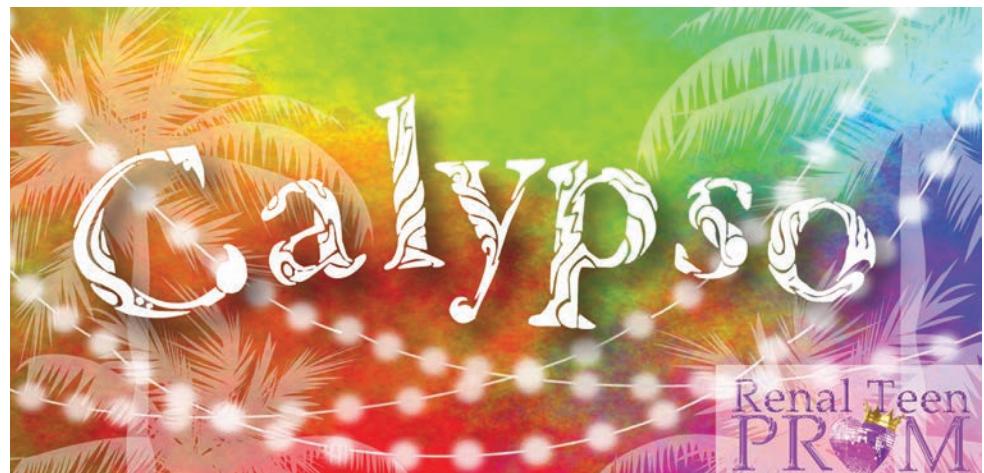
**Find more transplant and donor resources at [RSNhope.org](http://RSNhope.org)**

Sandra Kisselback has a passion for wood, unicorns, writing and learning new things. She received a kidney transplant in 1994 and 2014. Sandra lives in East Berne, New York



# 19th Annual Renal Teen Prom

Sunday, January 14, 2018



Prom season comes early for teens and young adults who have been diagnosed with kidney disease, who are on dialysis or who have a kidney transplant. *Find out more and download the Invitation at [RSNhope.org](http://RSNhope.org)*

EMBRACE HOPE JEWELRY by lori hartwell

Pavé Kidney Necklaces

a thoughtful gift for your  
stylish friends

The EmbraceHOPE Artisan Jewelry Collection is hand-crafted by people who have been affected by chronic kidney disease, providing them with the opportunity to express themselves creatively and share their experiences, strength, and hope with one another at the same time. Each hand-crafted piece arrives packaged in a keepsake Organza Bag with an RSN Embrace Hope Card as a token reminder that your purchase of this special gift helped benefit those with kidney disease.

*Proceeds help RSN life-enriching programs.  
Available at [embracehopejewelry.com](http://embracehopejewelry.com)*

# TONY'S KIDNEY

by Ferris "Tony" Anthony

3rd Place Winner,  
15th Annual Essay  
Contest

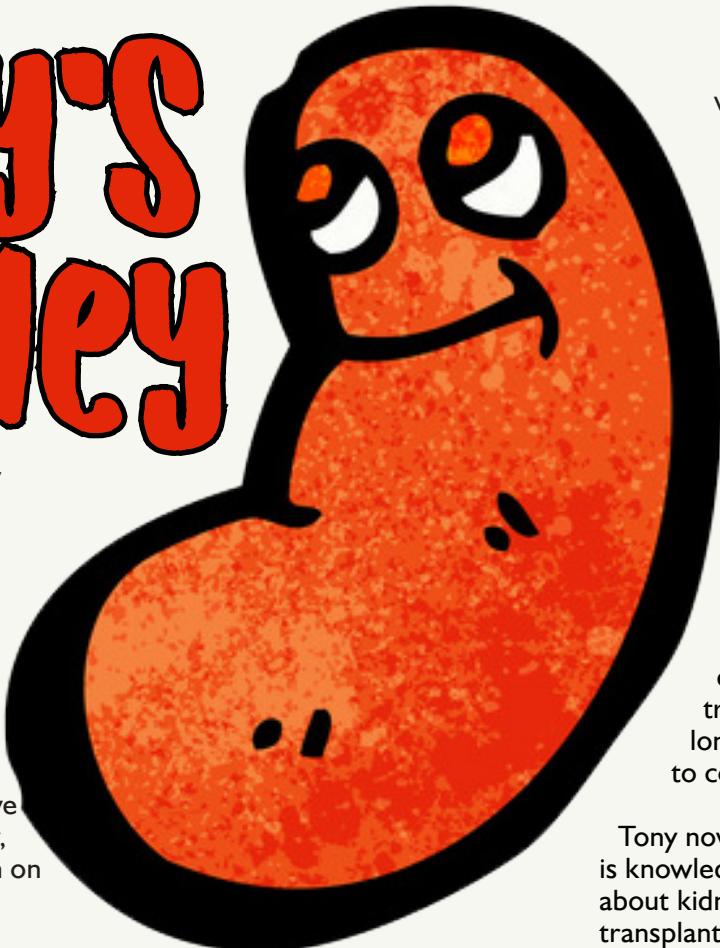
I am Tony's kidney, and this is my story. I have a twin brother. Each of us is the size of a fist, and shaped like a kidney bean. We live about half way down Tony's body, one on each side of his spine. I'm on the left; my brother is on the right.

We don't get a lot of respect, not like other parts of Tony's body. People always talk about the heart and the lungs as if they are the most important organs. But we kidneys do some important jobs for Tony.

One of our most important jobs is to filter the waste products that Tony produces when he eats food and when he moves his muscles. We remove waste by producing urine that passes out of his body. If he does not get rid of the waste, Tony gets sick. He can even die.

We kidneys also get rid of water and salt, and that helps control Tony's blood pressure. And we make things called hormones that help produce red blood cells. The red cells are very important because they carry oxygen and nutrition throughout Tony's body.

We do our job 24 hours a day and we rarely cause any problems. Yet Tony does not always take care of his body. Then we have problems.



Tony didn't control his blood pressure, and he developed a disease called diabetes. High blood pressure and diabetes caused what's called kidney failure, so now my brother and I can no longer do the job we were designed to do.

**TONY NOW KNOWS HIS BEST DEFENSE IS KNOWLEDGE, SO HE IS LEARNING ALL ABOUT KIDNEYS, KIDNEY FAILURE, KIDNEY TRANSPLANTS, AND DIALYSIS.**

However, Tony got smart, and he went to a doctor, a nephrologist,

who deals with kidneys. The doctor identified symptoms that pointed to kidney failure, and he began treating Tony's blood pressure and diabetes. He prescribed medicine, put Tony on a diet, and got him to start exercising.

The nephrologist helped Tony keep us working as long as possible. He also taught Tony about different types of dialysis, a procedure that can help us do our job. He even talked about a kidney transplant. That's a bit of a long shot, but it's something to consider.

Tony now knows his best defense is knowledge, so he is learning all about kidneys, kidney failure, kidney transplants, and dialysis. He recently chose PD dialysis, that's peritoneal dialysis, a procedure he does at home, and he's feeling better each day.

He knows how important we are, and he is doing everything possible to keep us working, along with our brothers the brain, heart, lungs, blood, and pancreas. He made a positive decision about his health by scheduling regular doctor visits, by learning all about us, and by making lifestyle changes. My brother and I are thrilled. We are ready for whatever may happen in the future.

Thanks for listening to our story. Please make a positive decision. Learn all you can about your kidneys. It may save your life.

Ferris Anthony is from Brunswick, Ohio. Because "Ferris" is an unusual first name, his friends call him "Tony." Tony earned his Ph.D. at Michigan State University. He is a retired Dean and Professor of Education. He has been living with kidney disease for four years and began peritoneal dialysis in May, 2017. He plays cello and harp, and he draws, paints, and sculpts. He volunteers with several non-profit organizations.

# KIDNEY DISEASE

Can Be a Real



By Raffi Minasian, MD

Pain is a common and complex problem in people living with chronic kidney disease. The risks and benefits of treating pain itself need to be understood. Pain medications can cause dependence, depression, itching, constipation, dizziness, light-headedness, feeling faint, abdominal distention, bloating and increased risk of falling. Patients are often unaware of these risks.

According to the Centers for Disease Control and Prevention (CDC), the United States is experiencing an epidemic of drug overdose. The most common drugs involved in prescription opioid overdose deaths include Methadone Oxycodone (such as OxyContin®) and Hydrocodone (such as Vicodin®).

To reverse this epidemic, we need to improve the way we treat pain. We must prevent abuse, addiction, and overdoses before they start.

Patients with chronic kidney disease often have pain due to specific causes. Peripheral neuropathy is an extremely common problem for my patients, especially those with diabetes. This type of pain is due to nerve damage, which causes burning and numbness sensations in the legs. It responds better to drugs usually prescribed for other reasons, i.e., for other diseases that involve the nervous system. For example, the seizure and antidepressant medications that include Gabapentin and the controlled drug Lyrica®. The major concerns with these drugs are the possibility of sleepiness and the fact that they may interact with other drugs that affect the brain and as a result cause confusion. For these reasons, these drugs are usually started at a very low dose. The dose is gradually increased

until pain is controlled. Dosages cannot be raised for patients who have serious side effects.

Another commonly-used pain medication is in its own unique class. It is called Tramadol. Though it is a controlled substance, it is less likely to cause addiction than opioids because there is no euphoria or "high" associated with it. Tramadol poses no problems for kidney function, so doctors can prescribe this drug for chronic kidney disease patients. Tramadol is commonly given with regular Tylenol® to boost its strength as a pain killer. The major problems associated with Tramadol are that some patients feel a bit sleepy with the drug, and about one out of 20 patients experiences nausea from it.

Nonsteroidal anti-inflammatory drugs (NSAIDS), which include Advil and Aleve, can cause kidney failure and reduce urine output. Therefore, we do not recommend them for patients who have chronic kidney disease and still make urine. Dialysis patients who no longer make any urine, however, do not need to worry about protecting their kidneys. They may sometimes still use this class of drugs. But NSAIDs can cause stomach problems like ulcers, and pose a higher risk of internal bleeding. Because of these risks, NSAIDs are only to be used under your doctor's supervision, even though they are sold over the counter. They also require you to have some food in your stomach prior to use.

Finally, if opioids are used they should not be prescribed on a regular schedule for chronic problems. Opioids are morphine and similar drugs derived from opium. Daily regular use of opioids causes dependence and addiction, and develops drug tolerance. Built-up tolerance means that the same dose of

opioid medicine will not stop pain as it used to after a period of regular use.

Most opioid addiction occurs when well-meaning doctors prescribe these drugs for a sudden pain situation, such as after a surgery or trauma. Later, patients find it hard to stop using these drugs. After all, they have a sense that they "feel no pain" while on the opioid drugs. It does not take long before patients start "needing" opioids. Dependence quickly develops.

Depression, poor appetite, and constipation are serious side effects frequently seen in regular users of opioids. Patients need to take great care to avoid this recent and familiar cycle which has become so common it is branded as a "national opioid epidemic".

Pain is a terrible thing, but so are some of the approaches to alleviating it. Consult your doctor and always report any problems associated with the medications you are given.

## Possible Pain Relievers

**Cognitive behavioral therapy** – a psychological, goal-directed approach in which patients learn how to modify physical, behavioral, and emotional triggers of pain and stress

**Exercise therapy**, including physical therapy

## Exercise and weight loss

**Gel packs** – these are simple packs that can be warmed or chilled and used to ease localized pain

## Acupuncture and massage

**Relaxation techniques** – guided imagery, hypnosis, biofeedback, breathing techniques, and gentle movement such as tai chi

Source: Centers for Disease Control and Prevention [www.CDC.org](http://www.CDC.org)

Dr. Minasian is a practicing nephrologist in the Los Angeles area with over 34 years of diverse experience. He serves as medical director for several facilities he has focus on managed care/ACO issues as they relate to the CKD/ESRD population as well as home dialysis modalities. Dr. Minasian is currently serving on the California Dialysis Council and Renal Support Network Board of Directors.





# Deciding I Could Lose Weight

by Karen Delfin Peacock

President's Pick, 15th Annual Essay Contest

Nobody asks for end-stage renal disease. I'm still not even sure what started the process of IgA nephropathy I was diagnosed with a few years ago. I took my medicines, watched as my hair fell out from the chemotherapy drugs and my face get round from the high dose of prednisone. I followed all the recommendations and instructions on what to do, what to take, what to eat. Despite that, because of the nature of kidneys, I found myself at stage 5 kidney failure and getting my first surgery to prepare my arm for the dialysis that I would need at some point.

During that time, I felt like everything I was doing was as a result of what was happening to me. To be honest, I felt a bit helpless. Nothing I did made my kidneys better. Nothing would heal them back to normal. I would soon need dialysis. I would later need a kidney transplant. It was inevitable. No matter what I did, these things were going to happen.

Then we moved from Indiana, where I had lived all my life, to Utah. My first

*Karen Delfin Peacock is a veterinarian living in Utah with her husband and two pugs. She still works and goes to in-clinic dialysis three times a week. Karen loves all things geeky and enjoys going to conventions in costume, playing computer games with her husband and watching Star Wars movies.*



appointment with my new nephrologist went something like this: "You'll have to begin dialysis when you start to feel bad, but we'll try to postpone that as long as possible." Then the news that I knew, but didn't want to hear: "They will not give you a kidney at your current weight. You need to lose over 50 pounds." There it was. I have struggled with my weight most of my life. I had lost some weight a couple of years earlier, but gained most of it back. At first I was devastated, thinking I would never get there. I was really struggling because I really wanted a kidney, I wanted to be able to not only be alive, but be able to live again.

My husband was compassionate, but told me: "You don't lose weight because you don't think you can. You have to believe that you CAN do it." Thinking about how much I wanted more time with him and the rest of my family and friends, how much more of the world I wanted to see, how many more things I wanted to experience, I made the decision to lose the weight. I told myself that I COULD lose the weight! After years of feeling helpless about my kidney disease, I was empowered to do something to help myself.

It certainly started out slow and rough. I paid more attention to my diet, especially after starting dialysis. I was already limiting my sodium and potassium intake, but now I had to watch my phosphorus also. I

remembered to take my phosphorus binders when I ate. I would think about snacking, then remember being hooked up to the dialysis machine, and would decide I really didn't need a snack.

I started working out with my friends, doing toning exercises, light cardio, etc. I was really out of shape, so it was very difficult at the beginning. Gradually it became less tortuous and I was gradually losing weight. I could see the results of my decision, which encouraged me to press on. Fifty pounds seemed so far away at times, but it took me years to add all this to my body, so it was going to take some time and work to get it off my body.

The day came when I got on the scale and had not only reached my goal but surpassed it. In less than 18 months I lost 70 pounds. The transplant team has started my testing, screening, vaccinating, and anything else I need to do to get closer to being placed on the transplant list. That is where I am today, jumping through hoops, but each jump gets me closer to getting a new kidney and a new life.

**Then the news that I knew, but didn't want to hear: "They will not give you a kidney at your current weight.**

I would not be where I am today if I had not made the serious decision to seriously lose weight. I would also not be here without the loving support of my family and friends. I am proof that you can lose that much weight on your own without programs or surgeries. You have to decide to do it, decide that you can do it, and decide that your life is worth fighting for.



# KIDNEYTalk®

24/7 Podcast Radio Show

Hosted by Lori Hartwell

Informative. Inspirational. Entertaining.

Tune in to RSN's online podcast talk show hosted by Lori Hartwell on iTunes or RSNhope.org

iTunes: Enter "KidneyTalk" into the search tool at the iTunes store to access or download any show 24 hours a day.

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with Stanley C. Jordan, MD, Director of Nephrology & Transplant Immunology at Cedars-Sinai Medical Center. Web ID:1107

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### Holiday Eating Tips: Eat, Drink, and Be Careful with RD Sara Colman

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### KidneyWorks™ Job Retention Program for People with Chronic Kidney Disease with Paul Conway and Richard Knight

Web ID 3000

## Urge elected officials to support these bills:

Chronic Kidney Disease Improvement in Research & Treatment Act of 2017 (H.R. 2644)  
This bill will increase funding for research, improve coordination of care and allow kidney patients to have access to Medigap.

The American Health Care Act of 2017 (H.R.1628)  
This bill will promote early detection and improve care of people who have kidney disease.

The Living Donor Protection Act of 2017 (H.R.1270)  
This bill will protect living organ donors rights and promotes organ donation.

Visit the RSNhope.org advocacy page to learn about these bills and take action today!



**LEARN ABOUT IMPORTANT  
LEGISLATION AND HOW TO CONTACT YOUR  
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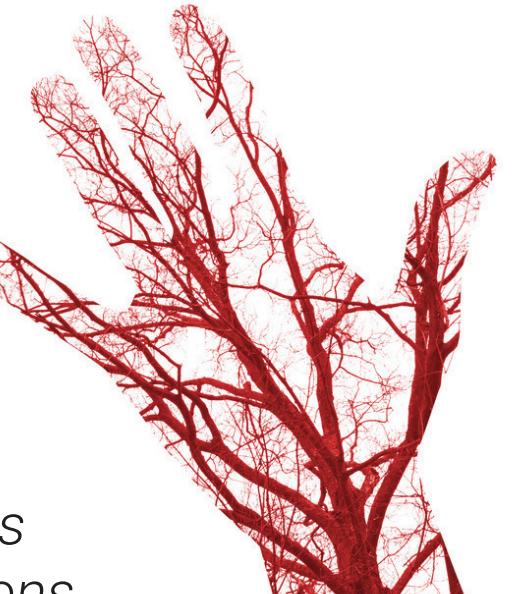
# Know Your Lifeline

How to recognize and prevent dialysis access complications

By Lana Kacherova, RN

Dialysis is a life-sustaining treatment and whether you choose hemodialysis or peritoneal dialysis, the success of your treatment largely depends on safe dialysis access.

There are different dialysis types depending on the modality you choose to treat your kidney insufficiency. If you are active during the day, then peritoneal dialysis (also known as PD) may be the most suitable treatment modality for you. You can do your treatments in the privacy of your own home. Most people choose to do it at night using a special Cycler machine. If you are not a candidate for PD, then hemodialysis (also known as HD) is another treatment option. You can either go to an outpatient center three times a week or do it at home. During hemodialysis, your blood travels through a special filter that resembles a function of the kidneys by removing toxins, waste, and extra fluid from your body.



Web ID: 4001

## Hemodialysis Access

For hemodialysis, there are three types of vascular accesses, each of them created surgically:

1. Arterio Venous Fistula (AVF): surgeon uses your own veins to create a vascular access under the skin. Fistulas are considered the “gold standard” of vascular access because they last longer and clot less, but they need at least three months to mature (become usable).

2. Arterio Venous Graft (AVG): surgeon places a specially-made bio-compatible plastic tube under your skin and connects it to your own blood vessels. Traditionally AV grafts could be used in 10-14 days, but with new advances, some grafts can be used the day after the surgery.

3. Central Venous Catheter (CVC) – a special plastic tube placed into your neck and tunneled into the right atrium of your heart, with the lumens still located outside of the body. CVCs are the fastest way to offer hemodialysis,

but they are not considered safe in the long run and they may lead to serious complications if left in one's body for longer than 90 days.

There are a limited number of places in the body where an access can be placed (the arms, legs, neck or chest), and proper access care is essential for patients to preserve longevity of vascular access.

## Tips to prevent vascular access complications:

- Wash your fistula or graft site prior to initiation of every dialysis treatment – each center must have a designated sink to do that. Besides cleaning it yourself, make sure your nurse or technician also cleans it with special disinfectant prior to placing the needles.
- Avoid wearing tight clothes, jewelry, or carrying heavy bags around your vascular access, or sleeping on top of it – this may restrict blood flow and create clotting of your access.
- During your blood pressure check, make sure the cuff is placed on your non-access arm
- Get familiar with your vascular access by checking it every day: feel the “thrill” – vibrations sensation, and listen for the familiar sound of the bruit, the whooshing sound. If it sounds or feels differently, or you are not able to feel or hear either, don’t wait until your next trip to the dialysis center - call your health care team immediately.
- Always examine your vascular access site for signs and symptoms of infection. If there is any redness, swelling, numbness, hot to touch feeling, itching, or fluid drainage around the vascular access, or you experience fever or chills, contact your healthcare team right away.
- If you have a Central Venous Catheter (CVC), don’t get your dressing wet between treatments; your nurse will be checking the exit site when performing CVC care every time you receive treatment. Ask your nurse how to change the dressing yourself in case of emergency and have an extra set of supplies at home.

Remember, a CVC is a temporary vascular access and you are at increased risk for infection. Talk to your health care team about creation of permanent vascular access.

- Ask your doctor or dentist for a prophylactic use of antibiotics before you have any dental procedures, because during the procedure bacteria from the oral cavity may enter the blood stream and cause harm to your vascular access.

## Peritoneal Access

Even though majority of people with kidney failure receive hemodialysis, there are more and more of you that try to do Peritoneal Dialysis treatments. This treatment modality is a more natural way to remove toxins from the body because it uses your own peritoneal membrane as a natural filter, and it preserves your residual kidney function if there is any left. Just like kidneys work around the clock cleaning blood and producing urine, the peritoneal membrane filters body fluids in a similar way. This seems gentler to the body compared with hemodialysis, where toxins are removed aggressively during 4-hour sessions.

There are certain criteria for PD patients and the home environment that has to be cleared prior to PD catheter placement. Therefore, your health care team conducts a home visit to ensure that the home environment is suitable for PD treatments. Sometimes only slight modifications are necessary, and your health care team will guide you on what needs to be changed.

Peritoneal dialysis access is created surgically: the surgeon places a PD catheter inside your peritoneal cavity and leaves the "exit site" outside of the body, normally below the belly button to the right or to the left, depending on your anatomy and/or preference. Sometimes the exit site can be located much higher than belly bottom – this is called pre-sternal PD catheter. The most common complication from a PD catheter is infection – it could be either an exit site infection or peritonitis, which could lead to the catheter loss, therefore each person on PD must learn how to recognize the early signs.

## Tips to prevent PD catheter infections:

- After new PD catheter is placed, you will be given instructions by your surgical

team and asked to come back in a week or two. Normally, you should leave the dressing unchanged for that period of time and you cannot take any showers or baths. It is important to let the exit site heal without it being compromised.

- Your PD nurse will teach you proper catheter exit site care as well as how to secure it properly in one place so it does not get pulled or shifted under your clothes. There are special "Belts" on the market specifically designed to wrap about the PD catheter to keep the exit site secured.
- Your PD nurse will also teach you how to perform daily exit site care and which disinfectant agents and sometimes antibiotic creams to use.
- Avoid bacterial contamination by not swimming in fresh water such as lakes, ponds, and rivers. Swimming in your own chlorinated pool or ocean may be OK – ask your PD nurse about this and how to clean your exit site immediately after the swim.
- Avoid taking baths or soaking in a hot tub, unless you have a pre-sternal PD catheter and the water line is far below the exit site so the dressing remains dry (check with your PD nurse first!).
- Prophylactic antibiotic use prior to dental procedures is also recommended for PD patients.

## Take Away Points:

Dialysis Access is your lifeline and you are the Most Valuable Player (MVP) on your team. Infection could become a serious health problem affecting other organs or systems in your body well beyond your vascular access. Daily access assessment and care is essential to prevent complications and prolong the life of your access. Remember that communication is the key. If you experience serious symptoms at night when your health care team is not available, go to the nearest hospital Emergency Department or call 911 if necessary. You are in charge of your own body and your health. The health care team is there to support you.



Lana Kacherova, RN has been working in the dialysis industry since 1993 in different capacities, taking care of people with kidney disease. She started as a dialysis technician, then became a nurse, later transitioned to clinical coordinator of a hemodialysis unit, quality improvement professional, and case manager. While working full-time, Lana attended California State University Northridge, and received a BS degree in Nursing and Master of Public Health in Health Education. She recently joined Kaiser Permanente of Southern California as a Renal Case Manager.



# HOPEline

## Peer Support Hotline

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

**Call (800)579-1970**

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



Support from someone  
who has been there.



# DONATE & CONNECT

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

Use this form to make a donation to RSN and/or sign up to receive Live&Give in the mail or the RenAlert E-Newsletter, or both!

## JOIN RSN - THERE IS NO FEE

Yes! I would like to receive a free subscription to the *Live&Give* newsletter

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### Please check all that apply:

Patient:  Transplant  PD  Hemo

Family Member  Administrator  Physician  Nurse

Dietitian  Social Worker  Technician  Company Rep  Other

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

Your gift, no matter the amount helps RSN continue to offer our life-enriching programs at no charge to people whose lives have been affected by chronic kidney disease.

**CONSIDER A TRIBUTE DONATION** Make a donation in honor of an organ donor, a transplant anniversary or as a holiday or birthday gift. Please indicate (in the notes if making a donation online or in the Tribute Donation Details section below if mailing/e-faxing a donation) to whom or to what occasion the tribute donation is for and we will send you a custom receipt and thank you letter.

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## What is 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 make friendships that last a lifetime.



### READ LIVE & GIVE ONLINE

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

### EDITORIAL TEAM

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

### CONTACT INFORMATION

Renal Support Network  
1146 North Central Ave. #121  
Glendale, CA 91202  
[info@RSNhope.org](mailto:info@RSNhope.org)  
866-903-1728 Toll Free  
818-543-0896 Local  
E-Fax: 818-484-2070  
9 AM-5 PM Pacific Time  
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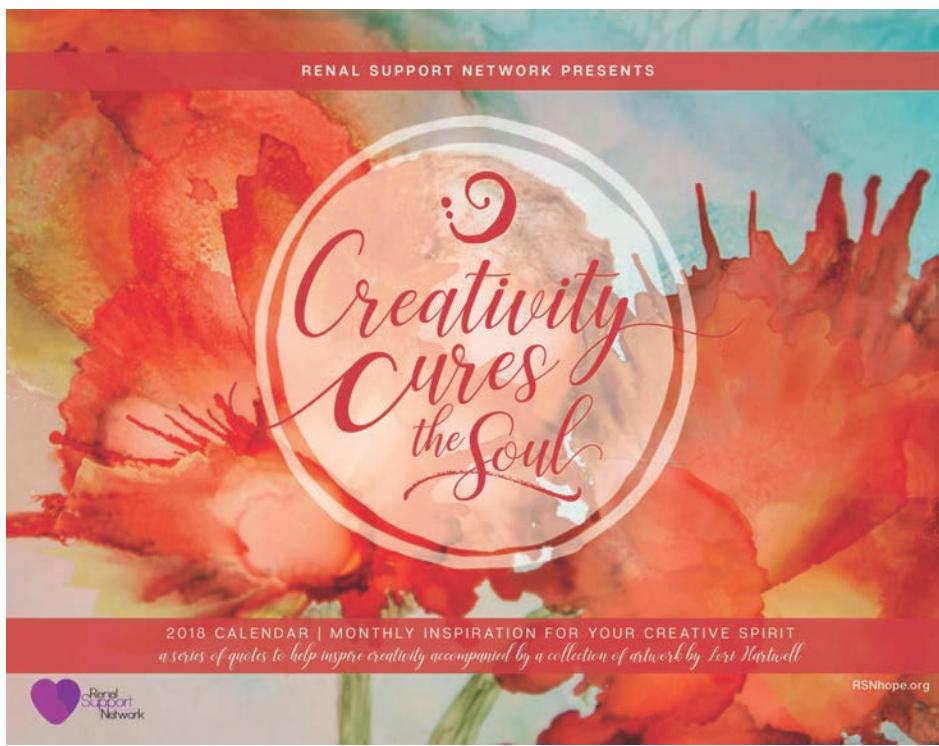
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# 2018 Calendar "Creativity Cures the Soul" Monthly Inspiration for your Creative Spirit.



Treat yourself or show your appreciation with the picture-perfect holiday gift this year and support RSN's life-enriching Programs.

Your gift with a donation of \$25 or more. Use the order form at left or visit [RSNhope.org](http://RSNhope.org) to make a donation.



Creativity is piercing the mundane to find the marvelous. - Bill Moyers



Mystery is at the heart of creativity. That, and surprise. - Julia Cameron



Creativity requires the courage to let go of certainties. - Bob Ross



The chief virtue of creativity is 'good' sense. - Pablo Picasso



Creativity is inventing, experimenting, growing, taking risks, learning, making mistakes, and having fun. - Mary Lou Cook



I think creativity is spiritual. I absolutely believe that. - T. Morris Thompson



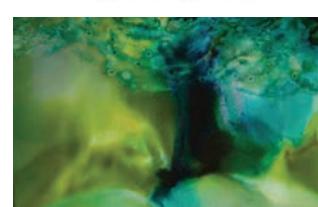
End of art: Can't kill creativity! - Camille Pissarro



Clean out a corner of your mind and creativity will instantly fill it. - Dr. Rick



Creativity is the ability to introduce order into the randomness of nature. - Eric Hoffer



Creativity is contagious. Pass it on. - Albert Einstein



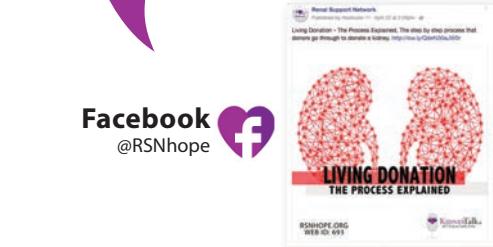
True play is creativity. - John Lasseter



Creativity makes a logo, then looks to see where it is. - Marvin Gaye



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YouTube  @LoriHartwell



## RSN EVENT CALENDAR

Visit [RSNhope.org](http://RSNhope.org) for details

**Monthly Support Group**  
4th Sunday of the Month

**8th Annual Celebrity  
Bingo & Poker Tournament**  
Nov. 11, 2017

**19th Annual Renal Teen Prom**  
Jan. 14, 2018

**World Kidney Day**  
March 8, 2018

**Organ Donor Month**  
April 2018



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## RSN's New Website offers a Hopeful, Informative Experience

Come see what's new  
at [RSNhope.org](http://RSNhope.org)

After a summer of hard work, we are pleased to announce RSN's new website! Visit [RSNhope.org](http://RSNhope.org) and you will find:

- *A mobile device friendly website with a colorful, image driven and easy-to-navigate design so you can get right to what you want to know.*
- *Hundreds of exclusive, personal stories written by people who share how to live successfully with chronic kidney disease. You'll learn something new whether you have just been diagnosed, on dialysis or have a kidney transplant.*
- *New 'Take Action' Advocacy Portal lets you easily contact your local officials about current legislation that will help people who have kidney disease.*