

# KidneyTalk™



Spring/Summer 2020

by **Renal Support Network**

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

## MY MANE EVENT

Finding solutions  
to thinning hair

## BATTLE WOUNDS ARE BEAUTIFUL

Embrace them and  
honor the journey  
they represent

## NUTRIENTS for a Healthy Glow

Tips for healthy skin

## The Skinny On DRY WEIGHT & DIALYSIS

Understanding the  
clinical significance of  
your weight

## WHY WE WALK

A passion for going  
the distance

## YOUR BRIGHT BEAUTIFUL SMILE

## MEET LILI LILE

A Warrior who  
replaced fear with  
a sense of purpose

## LOOKS & LABS

How CKD can effect  
your appearance

## SKIN DEEP

Identify and manage skin  
irritations due to kidney  
disease and dialysis

## RACHEL CLUTHE

A mother determined  
to raise a happy family





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KidneyTalk Magazine (formerly Live&Give) is a program of Renal Support Network (RSN). The magazine's articles are written by people who have kidney disease and by healthcare professionals. Those with kidney disease share their knowledge and experiences about living a full life in spite of their disease. KidneyTalk™ Magazine subscriptions are offered at no charge to people who have kidney disease and their families. Join RSN at [RSNhope.org](http://RSNhope.org) to subscribe.





# Battle Wounds *are Beautiful*

By Lori Hartwell

As I got a little older, I began to understand I was hiding a part of who I was. I came to realize I shouldn't be ashamed of the battles I fought and won. My scars were my story of survival.

The dialysis fistula is the superior vascular access for hemodialysis treatments. It is created by a surgeon who ties a connection between an

artery and a vein. The fistula causes pressure that allows extra blood to flow into the vein. To those of us who know

the options for vascular access, or have a trained eye to recognize the tools needed to survive a long life on dialysis, a fistula is the most coveted tool used by warriors.

Over time, the fistula matures and grows larger. It can grow along the arm and become a bit lumpy, as in the case of beautiful Lili Lile (pictured on this page), but it provides easy, reliable access to the body's blood at a reduced risk for infection, unlike a graft or a catheter.

The gorgeous cover photo of Lili reminds me of the beauty of our scars. Lili's pose with her fistula front and center—her access to life-saving care—speaks volumes. She is a courageous warrior showing what she must do to survive. Her strength

reflects hope and confidence, and her desire to live life to the fullest despite this illness.

In addition to being a sign of strength, a scar gives us an opportunity to share our stories with others. When I see a scar on someone, I ask them what happened. I have heard the most wonderful stories of surviving a war, overcoming an illness or a reckless act, or having an accident like slipping in the shower. I've yet to find someone who didn't want to tell their story. They feel a bit surprised that someone would take the time to notice and care enough to ask.

I love the song, "Scars to Your Beautiful," by Alessia Cara. This is my favorite verse:

*"... And you don't have to change a thing, the world could change its heart.*

*No scars to your beautiful, we're stars and we're beautiful ..."*

I hope this shift in perspective will allow you to see your scars in a different way. Scars are like battle wounds, they show what you've been through and how strong you are. They have a story to tell and it's our job to embrace them and honor the journey they represent.

*"Scars are like battle wounds, they show what you've been through, and how strong you are."*

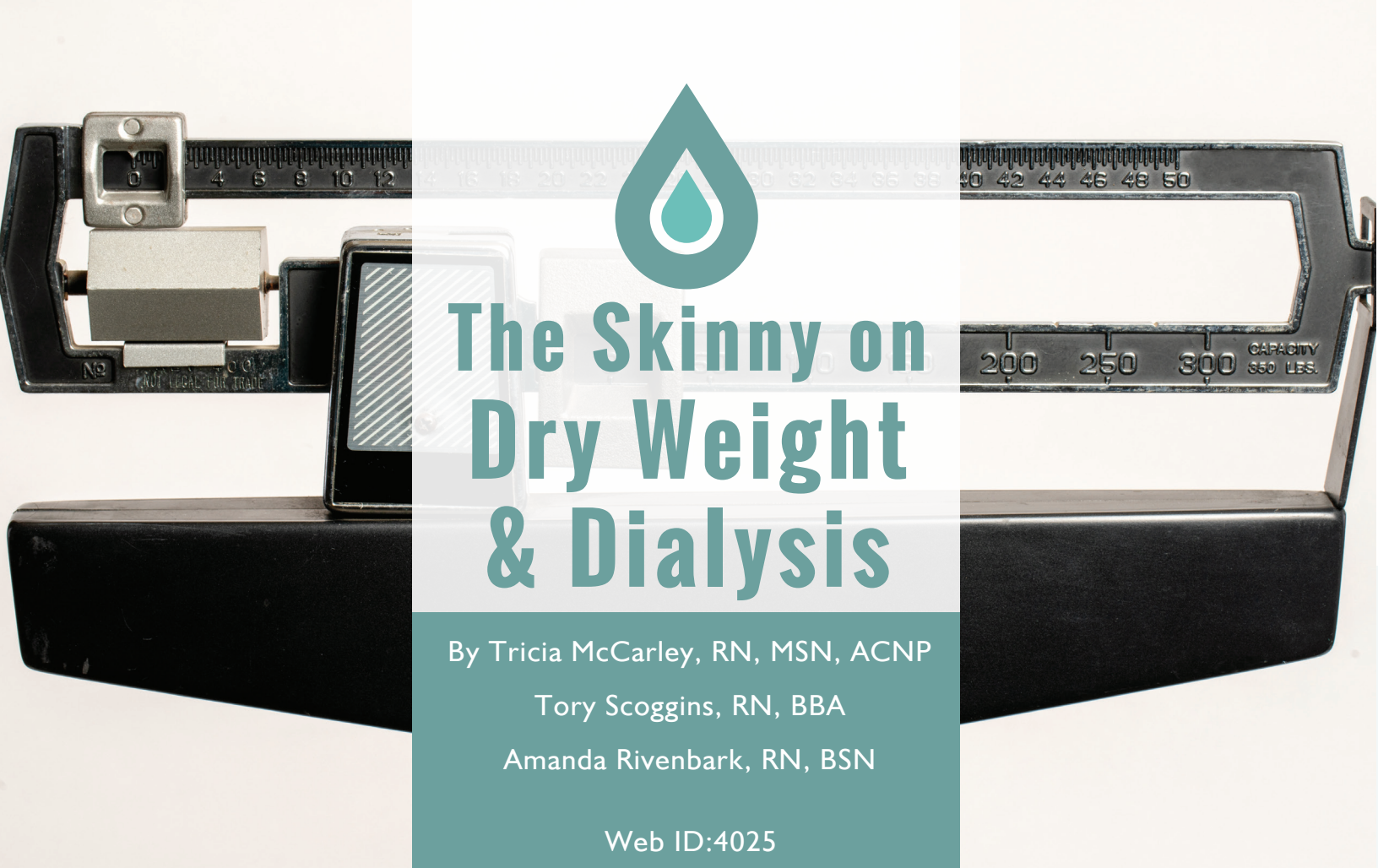
When you're diagnosed with kidney disease you end up with a few battle scars. I've had more than 50 surgeries since being diagnosed in 1968 at the age of two. My life-saving surgeries turned into wounds that turned into scars, and more scars. That has made me tough, or shall I say, a warrior. Every part of my body retains a visible scar that provides a roadmap of my medical history and how I battled and won the fight with this illness.

When I was younger, I used to cover my scars to hide them. The right length of sleeve was required, and I didn't dare show my tummy with its PD scars. I used Cinema Secrets make-up to ensure no one would see my healing wounds. After a hospital stay, my hands and arms, and sometimes my feet, would be riddled with bruises. I didn't know my skin could turn so many shades of the rainbow!

**Lori Hartwell** is the Founder and President of Renal Support Network (RSN) and the host of *KidneyTalk™* Podcast Radio. Lori was diagnosed with kidney disease at the age of two. In 1993 she founded RSN to instill "health, happiness and hope" into the lives of those affected by chronic kidney disease. Lori is also the author of the inspirational book *Chronically Happy: Joyful Living in Spite of Chronic Illness* and is a four-time kidney transplant recipient.







# The Skinny on Dry Weight & Dialysis

By Tricia McCarley, RN, MSN, ACNP

Tory Scoggins, RN, BBA

Amanda Rivenbark, RN, BSN

Web ID:4025

How many of us have squeezed our eyes shut on the doctor's office scale or let our own bathroom scale grow a layer of dust?

Weight is a taboo topic in America. Many of us avoid it at all costs. It can be intertwined with feelings of inadequacy or weakness. Weight can be wrapped up in emotionally charged conversations around wellness and pain. Difficult though it may be, as clinicians our best advice around weight is for people with chronic kidney disease (CKD) to understand the significance of their weight as it relates to overall health.

As care providers, we understand that for people who have been living with chronic conditions, managing weight can feel like an uphill battle. So, keeping a constant eye on it, with weigh-ins at each dialysis session, can be disheartening.

Dialysis, the life-sustaining treatment for people living with kidney failure, helps people with CKD feel their best by helping maintain the right amount of fluid in the body. In order to know how much fluid to remove during dialysis, a person is weighed before and after their treatment. A person's weight—without extra fluid

in the body—is called “estimated dry weight” (EDW). A recent overall weight loss or gain, one that could occur due to changes in diet or exercise, would also change a person's EDW, making it all the more important for clinicians to create a space where people feel comfortable talking about their weight and any challenges they may be experiencing.

People should avoid the temptation to remove more fluid during dialysis to drop pounds on the scale. This can lead to symptoms like lightheadedness and nausea and is not effective for long term weight management.

On the flipside, extra fluid on the body, perhaps due to excessive fluid gain from eating salty foods, could cause a person on dialysis to believe he or she has gained weight. This points to the important role of the care team to ensure that people living with kidney disease have the support and education they need to best manage their condition.

The dietitian and social worker are members of the care team who can help individuals hash out weight issues and work toward building a healthier relationship with diet, exercise, and their own bodies.

*Continued on page 6*





# Living a healthy life



## Feeling your best on dialysis

Chronic kidney disease can cause weight changes. If you're worried about your changing weight, be sure to talk to your dietitian. Fresenius Kidney Care is here every step of the way to help you reach your body weight goals.

Learn more at [FreseniusKidneyCare.com/BodyImage](https://www.freseniuskidneycare.com/bodyimage)





## Tips for weighing yourself at home:

Weigh yourself every day at the same time wearing similar clothes and shoes.



Place the scale on a hard, even surface, not on carpeting.



Record your weight and compare it to your EDW.



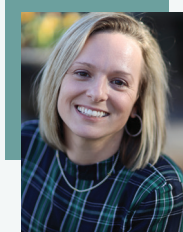
We advise people to connect with their care team providers particularly if they experience cramping, dizziness, fatigue, shortness of breath, swelling, or if their weight is consistently more than one kilogram over or under their EDW. Swelling or puffiness in feet, ankles, or legs, also known as edema, can indicate extra fluid gain.



**Tricia McCarley, RN, MSN, ACNP**, is the VP of Strategic Quality Operations at Fresenius Kidney Care. In this role she develops, evaluates, and implements strategic initiatives to ensure the provision and delivery of quality patient care. Tricia has more than 40 years' experience in Nephrology clinical practice. She lives in Nashville, TN and enjoys spending time with her grandchildren.



**Tory Scoggins, RN, BBA**, is the Functional Vice President of Strategic Quality Initiatives at Fresenius Kidney Care. In this role, he develops and supports innovative strategies to improve the quality of care and clinical outcomes for individuals on dialysis. Tory has worked in the healthcare setting for 25 years and is passionate about making a difference in the lives of patients and their families. As a resident of Atlanta, GA, he enjoys spending quality time with loved ones and playing softball.



**Amanda Rivenbark, RN, BSN**, is the senior director of Value Based Quality Programs at Fresenius Kidney Care. She has been a nurse in the dialysis industry for the last 14 years and currently develops, plans, and implements managed care strategies focused on improving patient outcomes. Amanda lives in coastal North Carolina and enjoys spending time with her family and friends.



According to the latest U.S. Renal Data System Report, more than 660,000 Americans are being treated for kidney failure, also called End-Stage Renal Disease (ESRD). Of these, 468,000 are on dialysis and more than 193,000 have a functioning kidney transplant. Each year 100,000 people are newly diagnosed with stage 5 chronic kidney disease (CKD) which is the same as ESRD. About 30 million U.S. adults are estimated to have CKD and most are undiagnosed. Over 103,000 people in the U.S. are waiting for a kidney transplant.

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

Our online advocacy portal provides information on current legislation that is on the table regarding kidney care and how to add your voice to help get bills passed.

**Learn more about RSN's advocacy program and "take action" to support current legislation at [RSNhope.org/Advocacy](https://RSNhope.org/Advocacy).**



# Stay at Home

## Keep Up With Your Regular Transplant Labs



RemoTraC™

AlloSure®



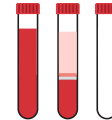
### At-Home Blood Draws for Transplant Patients

RemoTraC at-home blood draw service enables you to continue with your regular testing schedule while avoiding in-person visits to a hospital or lab.



### No Additional Cost to Patients

CareDx will cover the cost of the mobile phlebotomist and ensure you don't have additional out-of-pocket expenses beyond what you typically pay for your tests.



### Complete Testing and Labs

RemoTraC includes a routine panel of transplant labs plus CareDx's surveillance tests - AlloSure and AlloMap.

To learn how it works and sign up, visit [www.caredx.com/remotrac](http://www.caredx.com/remotrac)



For more information please contact CareDx at  
1-888-255-6627 | [customercare@caredx.com](mailto:customercare@caredx.com)

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## Make new friends, learn new things in RSN's Online Support Groups!

RSN's online meet-ups are offered at no charge to people who have kidney disease and their families. Join us for kidney diet recipes, cooking tips, kidney disease support groups, and more. Registration is required. Sign up online today!

### UPCOMING MEETINGS INCLUDE:

- **RSN's Monthly Support Group:** twice per month
- **Get Moving:** light stretching and exercises with a certified personal trainer
- **Kidney Diet Essentials and Plant-Based Kidney Diet:** with a certified renal dietician
- **Get Creative:** share your favorite crafts/hobbies



Sign up today,  
there are no fees!  
Learn more and register at  
[RSNhope.org/events/  
rsn-zoom-room-meetings](http://RSNhope.org/events/rsn-zoom-room-meetings)





# Say Hello to

# Lili

By Mary Nesfield  
Web ID:4026

## A Warrior Who Replaced Fear with a Sense of Purpose

*Like so many people, Lili Lile never gave her kidneys a second thought. That is, until in 2011, at age 20, when she was diagnosed with kidney disease. Fear of dialysis gnawed at her. Hoping to avoid it, Lili was determined to change her lifestyle to become healthier. But at 3:00 a.m., in 2014, a wake-up call came when she was admitted into the hospital. Since first being diagnosed, Lili's kidney functionality had plummeted from 28 percent to 8 percent. It was time to enter the world of kidney dialysis. I spoke with Lili, a strong and courageous singer, songwriter, musician, and certified yoga instructor, during her dialysis session.*

### **How did you feel when you were diagnosed with kidney disease?**

I had no symptoms; I just felt weird, unbalanced. After a doctor visit, I was told to go to the hospital because my kidneys were failing. They did a biopsy and I stayed in the hospital for a week waiting for results. I was afraid of dialysis. They wanted to do a transplant, but the opportunity did not come. Being of Mexican heritage and growing up in America, my diet was rich in meat, carbs, and salt, so after I left the hospital, I went home and switched to a vegan diet and started doing yoga. That sustained me for three years until stress entered my life. Growing up I always had the energy to play sports, but I began to feel nauseous and tired. Protein showed up in my urine and my blood pressure was through the roof. I was admitted into the hospital and it was

a huge wake-up call. They started dialysis through a chest catheter and a month later doctors inserted a fistula into my arm, which lowered my risk for infection.

**How did the dialysis go using your fistula?** The first time I did dialysis the tech infiltrated my fistula and that caused it to blow up like a balloon and bruise my entire arm. Doctors had to perform surgery to fix it, and then I had to wait a month for it to heal. I haven't had any more problems since then, but ever since that day I am very particular about who I allow to put me on the machine and to take me off. I guide the techs on where to insert the needle and let them know they have to proceed slowly with me. Nevertheless, I am grateful to have that control and trust with my dialysis team.

### **What are the benefits of the fistula?**

Dialysis is easier for me; I don't feel the needle going in. My doctor and I agree that I only need to have dialysis 2.5 to 3 hours twice a week because of three things: I still have some kidney functionality that allows me to urinate, I work closely with my dietician to monitor my food intake, and my labs are always stable. After each session I get a bandage and I'm good to go. My arm heals faster and that allows me to swim and work out more, and I can do yoga poses if I'm careful not to place too much strain on it.

**Do you self-cannulate?** Yes, I do. I just started, and it wasn't hard to learn. I actually prefer it now. I'm in the process of switching to home hemo so I don't have to leave my house. I hope to take the machine home soon.

*Continued on page 10*





SUPPORTING NEPHROLOGY  
PATIENTS & CAREGIVERS



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Nephrology

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## Say Hello to Lili Lile

continued from page 8

**What kinds of reactions do you get when people notice your fistula?** It makes them uncomfortable. They think I'm doing drugs and look at me with disgust. Sometimes people ask about it, but many have never even heard of dialysis. I try not to let it get me down because I know it's just a lack of awareness of kidney disease and I have to be willing to educate people to bring it to the public consciousness.

**What gets you through the difficult times?** It's my very good support system. My friends are the nicest people on earth and my siblings are the sweetest kids. Most importantly, my fiancé, Jarl. He's an amazing partner and provides the best caregiving that love can afford me.

**How did it go when you first met this man who would become your fiancé?** The first night we met I told him right off the bat that I have a life-threatening condition and explained how the fistula is my lifeline. It blew his mind, and made him realize how strong I am. Then our conversation turned to common interests like our poodles. They look alike, and even have the same name! It's so "cartoony"—especially when we call one and they both come. Now, after my dialysis sessions, both dogs seem to sense my vulnerability and want to protect me. One guards my arm while the other one lies at my feet.

**Does your fistula make sounds?** Yes! You can hear my blood flow 24/7. It sounds like the ocean. My fiancé is a musician, and he finds it soothing. He says it sounds like music to his ears. If you touch it, it's like a vibrating pulse. Whenever I feel down, Jarl will gently put his hand on it and that small gesture is a reminder that I am strong!



Lili with her fiancé Jarl, photo credit: Meg Riv

**In what ways has kidney disease changed your life?** When I was diagnosed, it encouraged me to become my own chef. I really enjoy cooking. It's an art and a pleasure. Being a vegan is all about adjusting to a plant-based diet for CKD—using

**Are you hoping for a kidney transplant?** That's the goal. There are so many people waiting. I did have some volunteer donors a while back but each one fell through. At first, I felt angry about that. I had hoped that if I got a transplant, I might never have to go back for dialysis, but I have come a long way since then. I am still here, and the bright side is in knowing my diagnosis has given me a greater purpose, and that is to help others with CKD.

**If you could go back in time, what advice would you give your younger self?** Never lose hope! The universe sent me a message to take better care of myself, which meant eating good food, getting my body moving, and doing things that I enjoy. Always get a good laugh in every day, it really is the best medicine. And always remember, we are loved.

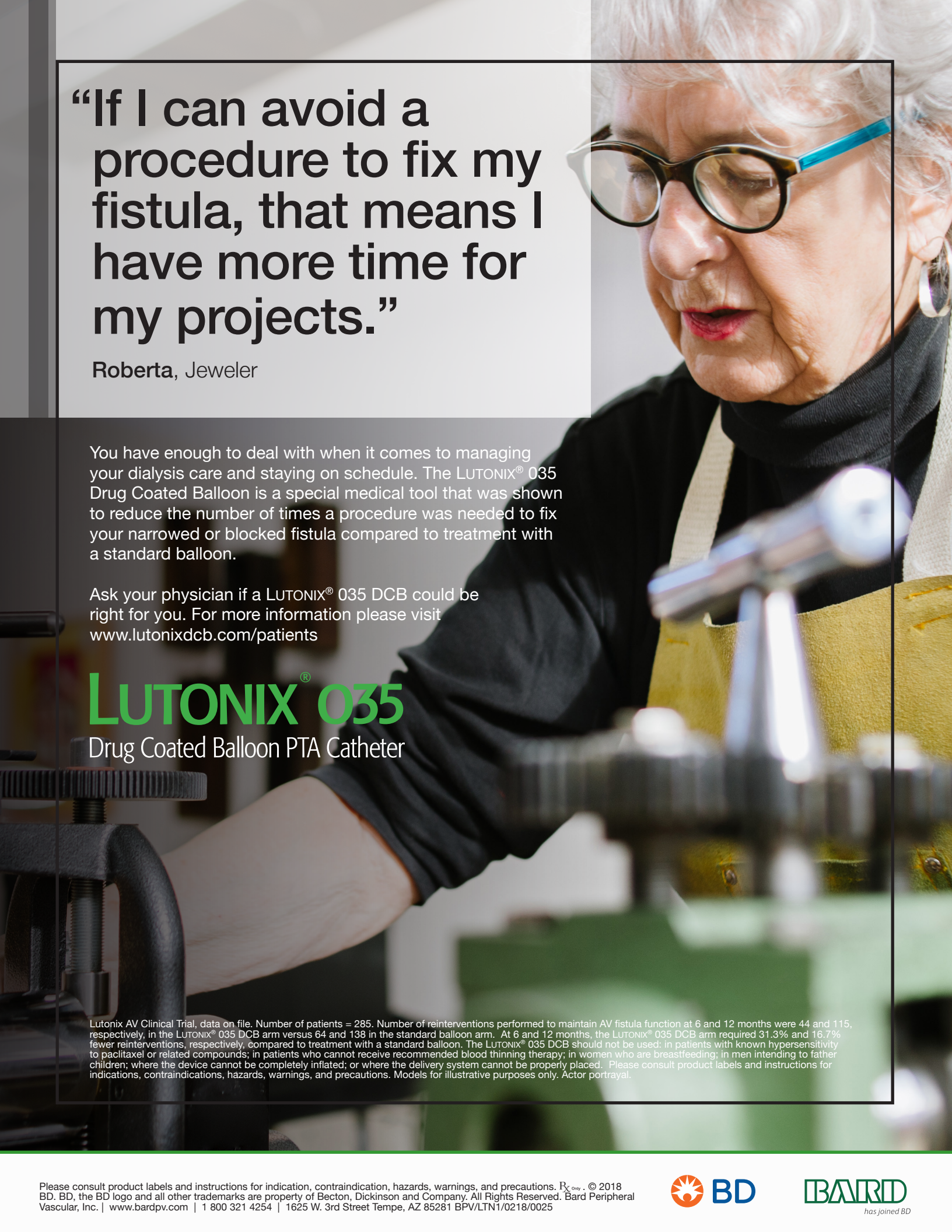
Sometimes people ask about it [my fistula], but many have never even heard of dialysis. I try not to let it get me down because I know it's just a lack of awareness of kidney disease and I have to be willing to educate people to bring it to the public consciousness.

herbs and spices to change things up is key when avoiding excess sodium. It's about having a relationship with the foods that love me, and feeling good.

**Mary Nesfield** has enjoyed a long career in magazine publishing. She is a freelance writer and editor for Renal Support Network and works from her home in Columbia, South Carolina.







“If I can avoid a procedure to fix my fistula, that means I have more time for my projects.”

Roberta, Jeweler

You have enough to deal with when it comes to managing your dialysis care and staying on schedule. The LUTONIX® 035 Drug Coated Balloon is a special medical tool that was shown to reduce the number of times a procedure was needed to fix your narrowed or blocked fistula compared to treatment with a standard balloon.

Ask your physician if a LUTONIX® 035 DCB could be right for you. For more information please visit [www.lutonixdcb.com/patients](http://www.lutonixdcb.com/patients)

## LUTONIX® 035

Drug Coated Balloon PTA Catheter

Lutonix AV Clinical Trial, data on file. Number of patients = 285. Number of reinterventions performed to maintain AV fistula function at 6 and 12 months were 44 and 115, respectively, in the LUTONIX® 035 DCB arm versus 64 and 138 in the standard balloon arm. At 6 and 12 months, the LUTONIX® 035 DCB arm required 31.3% and 16.7% fewer reinterventions, respectively, compared to treatment with a standard balloon. The LUTONIX® 035 DCB should not be used: in patients with known hypersensitivity to paclitaxel or related compounds; in patients who cannot receive recommended blood thinning therapy; in women who are breastfeeding; in men intending to father children; where the device cannot be completely inflated; or where the delivery system cannot be properly placed. Please consult product labels and instructions for indications, contraindications, hazards, warnings, and precautions. Models for illustrative purposes only. Actor portrayal.





*my mane*  
**EVENT**

Web ID: 4027

*By Sasha Couch*



Women have standards of beauty thrust upon us from the time we leave the womb. As we get older, they form the foundation of what we're proud or embarrassed to show the world—even if we know it's poppycock. For women living with chronic kidney disease (CKD), feminine confidence can be a formidable foe. But I'm here to tell my fellow CKD sisters that we're strong warriors, and despite all the pesky physical changes and challenges we go through that are beyond our control, we can "look good and feel good" too.

No two females living with CKD experience the same things or experience them identically. Physical changes vary: discolored skin, weight gain or loss, thinning skin, and my personal favorite, hair loss, are just a few. I've experienced many of the aforementioned side effects (I have more than my share of scars and stretchy pants!) but if a luxurious mane of hair gives us confidence to roar, for many of my dialysis and post-transplant years, I was quietly meowing in my "hairy" situation.

When I started dialysis at age 40, I had a head full of thick, long hair. Though a tomboy, I certainly noticed when it started to fall out less than a year later. Just a few strands in the shower initially, before long it was falling out in clumps. I tried everything suggested to me: vitamins/supplements, specific foods, different shampoos—but "renal life" is a delicate balance of lifestyle, foods, and medications. Iron, zinc, and protein may be low because of a deficiency or because they must be kept low. In turn, our bodies become a canvas for CKD, the unpredictable painter.

But instead of sulking, I vowed to improve the situation. So, I chopped it all off and went short and sassy, albeit awkward. No more long showers laboring with deep conditioners or post-shower styling, just wash and go, easy-peasy. A successful temporary fix until the awkward "growing back" phase, which lasted more than a year. And though I powered through to a cute bob, hair loss wasn't finished with me.

Then came transplant time! With this gift came a new "renal life." Life on dialysis was traded for a permanent life on immunosuppressant drugs. The first few months were spent adjusting, but within three months I noticed something familiar—hair falling out in clumps. I could've donated a wig to Locks of Love with the copious amount lost. The joy of my new organs (oh, I got a twofer, a

*"YOU'LL BE SINGING,  
I Feel Pretty  
IN NO TIME."*

kidney and a pancreas) overshadowed any other concerns, so I assumed it would level out once I was accustomed to my new regimen. But as the months passed, clumps of hair falling out progressed to noticeable empty patches, which taught me how to play creative games like "hide the bald spots!"

For months I was healing swimmingly without any issues. But the toppling tresses remained. Do I start wearing a wig? Could be fun. Make hats my new fashion

statement? I own a ton of baseball caps and beanies. But they were just band-aids.

So, I did my research and talked to my doctor about one medication we could safely switch to fix my "dirty little secret." He was fine making changes that would likely stop my hair from falling out but warned it might make hair appear where I didn't want it. Women of a certain age know that a wayward hair popping up in a random spot can be a harrowing reality. But I said, "Let's do it!" And promptly bought a good pair of tweezers.

Gradually, less hair fell out. My labs remained stellar and no other changes occurred. A few random hairs sprouted up where they weren't wanted, but I was armed and ready. And while my hair doesn't define my confidence and it's not as plentiful as it once was, I'm happy to still have my locks while I still naturally should. As a successful partnership with my new organs blossomed, a renewed productive relationship with my hair follicles did too. I like my current "do" and only use headwear to represent my teams and complement cute outfits.

Kidney disease impacts you physically, but also emotionally, psychologically and mentally. And while men deal with all the issues women do, including feeling blue about changes in their appearance, let's face it, women's appearances are a different animal.

It's easy to think you'll never look good again or feel comfortable in your own skin. But you must approach unexpected physical setbacks like we true renal warriors approach this life-threatening illness every day. Find your inner strength and remember these unexpected trials are just that, setbacks. Trust this confident, hirsute warrior when I say you'll be singing, "I Feel Pretty" in no time.



**Sasha Couch** is an East Coast native living in Los Angeles for over 20 years. She has a BA in International Relations from The University of Pennsylvania and works as a technical writer. Sasha received a kidney and pancreas transplant in 2017. She delights most in her volunteer endeavors, notably working with organizations helping the homeless like the Culver-Palms Burrito Project.



# SKiNDEEP

By Lubna Akbany RD,CSR  
Web ID:4028

**Help! I can't stop this itching!** This is a cry that many of us living with kidney disease are familiar with. Having kidney disease myself, I was not sheltered from this either. Itchy skin can make you miserable, and it's a common problem for many people with chronic kidney disease (CKD), even for those not on dialysis.



Many of us have experienced some form of it. Some feel itchy all the time over their entire body, while for others it comes and goes and may happen only in certain areas. Some also say itching is worse during, or just after, dialysis treatment. What's important is trying to understand the cause and then finding the best way to manage it.

## Types of itchy skin:

### Itching (pruritus)

A common cause of itching is a high level of phosphorus in the body. Because dialysis does not effectively remove phosphorus, a renal diet that limits foods high in phosphorus can relieve pruritus by maintaining a phosphorus level at 5.5 mg/dl or less. Additionally, taking phosphorus binders with every meal and with snacks can help. Staying on dialysis for the full treatment time is also recommended because it can remove some phosphorus as well as other wastes and toxins. If phosphorus levels continue to remain elevated, calciphylaxis can develop.

### Calciphylaxis

Calciphylaxis (kal-sih-fuh-LAK-sis) is a serious, but uncommon, disease in those on dialysis. People with calciphylaxis have an imbalance in the metabolism of calcium, whereby calcium accumulates in small blood vessels of the fat and skin tissues. This causes blood clots, painful skin ulcers, and may cause serious infections that can lead to death.



HYPERPIGMENTATION



PRURITUS



XEROSIS



## Dry skin (xerosis)

Kidney failure may create changes in the sweat glands and oil glands which cause the skin to dry out. Dry skin can lead to infections and excess itching. Skin wounds may heal more slowly when the skin is dry.

## Skin discoloration (hyperpigmentation)

Many reported cases of discolored skin, or hyperpigmentation, happen to people with CKD. One cause of skin discoloration is related to pigments called urochromes being retained in the skin. Normally these are excreted by healthy kidneys. Patients with this condition tend to have a grayish, almost metallic-colored skin. Another discoloration is called uremic frost. This is a white, powdery substance left on the skin surface after sweat dries. When a patient's blood urea nitrogen (BUN) level is high, the concentration of urea in sweat increases greatly. Evaporation of this kind of sweat causes urea to crystallize and deposit on the skin. Uremic frost is prevented by getting adequate dialysis.

## What causes dry, itchy skin?

A combination of things can cause your skin to be itchy and dry.

- **Limited fluid intake:** Your dialysis treatment removes extra water from your body, and your limited fluid intake between treatments can cause dry skin and trigger itchiness.
- **Unmanaged phosphorous:** Often, itching is caused by high blood levels of phosphorus. In your body, extra phosphorus can bind with calcium and lead to feeling itchy. If your healthcare provider has given you phosphate binders, it will help to take them at the same time every day and as instructed. Try to maintain your phosphorus levels at 5.5 mg/dl or less.
- **Not enough dialysis:** Talk to your healthcare team about your symptoms and find out if you are getting the right amount of dialysis. Sometimes too much or too little dialysis can lead to symptoms such as dry, itchy skin.
- **Allergies and other causes:** Be sure you are not sensitive to the soaps, laundry detergents, lotions, or perfumes you may be using. Sometimes the dyes and fragrances in these products can cause allergic reactions that make skin itchy. Also, taking baths with water that is too hot can leave your skin too dry and lead to itchy skin.

## Useful Tips:

- Try to figure out what is causing the itching. Is it better at some times than others? What helps it or makes it worse? Tell your healthcare team what changes you feel and see with your skin.
- Develop a good skincare routine, with daily cleansing and moisturizing. Ask your healthcare team which moisturizers work best for your symptoms.
- Don't scratch your skin! Scratching tends to make the itching worse, and may even damage the skin and lead to infection.
- Stick to the diet given to you by your healthcare team.
- Make sure you are taking your phosphate binders as prescribed.



**Lubna Akbany, RD, CSR**, is a Registered Dietitian Nutritionist and Certified Specialist in Renal Nutrition with over 20 years' experience. She specializes in chronic kidney disease (CKD) management and diabetes with a focus on CKD nutrition. She is a mom, a patient, and an effective nutrition communicator who loves cooking and eating delicious food with friends and family.

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Each set may or may not include  
postcards pictured above.

## BRUISES OR BLOOD CLOTS

### WHAT CAN CAUSE IT

Defects in platelets; thin skin from medications like prednisone, heparin, or baby aspirin

### WHAT CAN HELP

Check clotting; blood thinning agents; vitamins

### ALSO TRY

Body makeup; creams; gloves and/or long-sleeved shirts; elevation; hot/cold therapies

## PALE SKIN

### WHAT CAN CAUSE IT

Anemia

### WHAT CAN HELP

Check anemia lab values; increase dialysis; add vitamins/supplements

### ALSO TRY

Moisturizer; bronzer or tanning cream

## DRY AND ITCHY SKIN

### WHAT CAN CAUSE IT

High phosphorus; secondary hyperparathyroidism (SHPT); inadequate fluid removal

### WHAT CAN HELP

Adhere to prescribed phosphorus, fluid, and sodium allowances

### ALSO TRY

Moisturizer; corticosteroids; antihistamines

## RASH

### WHAT CAN CAUSE IT

Allergies; abnormal phosphorus, calcium, or secondary hyperparathyroidism (SHPT) levels

### WHAT CAN HELP

Check medications; take phosphate binders and manage renal diet as directed; keep phosphorus, calcium, and SHPT levels within range

### ALSO TRY

Creams; cold compress; natural remedies (oatmeal, tea tree oil, aloe vera)

# Look LA

Kidney disease and r...  
an effect on your ap...  
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*\* Recommendations, statements, and advice contained in this infographic are for information only. You should not use the information to diagnose or treat a health problem or disease without first consulting with a qualified healthcare provider. Please consult with your healthcare provider about any questions or concerns you may have regarding your condition, over-the-counter treatment, or dietary regimen.*



# Side Effects & Remedies

Medication can have side effects. Here are some common side effects along with causes and remedies you can discuss with your doctor. Some remedies may also provide a temporary fix.\*

## AMMONIA BREATH

**WHAT CAN CAUSE IT**  
Dehydration; inadequate treatment; too much protein

**WHAT CAN HELP**  
Adjust diet; more treatment

### ALSO TRY

Drink more water; brush and floss teeth and gums regularly; use mouthwash and mouth rinse for dry mouth

## SWELLING OF FACE AND APPENDAGES

**WHAT CAN CAUSE IT**  
Fluid retention; medication side effects

**WHAT CAN HELP**  
Alternative medications; reduce fluid intake; change treatment regimen; adhere to dietary sodium requirements

### ALSO TRY

Wear loose-fitting clothing and comfortable shoes; use support stockings for legs if necessary

### ALSO TRY

Concealer; eye drops; limit sun exposure; meditate; limit screen time and caffeine; exercise; tea bags, cold compress, etc.

## DARK UNDER-EYE CIRCLES OR BLOODSHOT EYES

**WHAT CAN CAUSE IT**  
Medication side effects; high phosphorus; disturbed sleep schedule for various reasons

**WHAT CAN HELP**  
Manage phosphorus levels; determine why sleep habits changed

## HAIR LOSS AND WEAK NAILS

**WHAT CAN CAUSE IT**  
Malnutrition; medication side effects; frequent surgeries; lying in bed

**WHAT CAN HELP**  
Ask your doctor about changing medications or diet; also ask about supplement options

### ALSO TRY

Biotin shampoo and/or supplements; short haircut; silk pillowcase; nail strengthener



# NUTRIENTS to Promote Healthy Skin

By Judith Beto, RD  
Web ID: 4030

*As an organ, skin needs proper nutrients to be healthy and stay healthy. Many foods pack in more than one nutrient for skin health. Therefore, getting proper nutrition and maintaining normal lab values are essential to keeping your skin happy and looking good.*



## Healthy Fats

Choose monounsaturated and polyunsaturated fats. These plant-based oils help your skin stay firm and moist, and are better for your heart than saturated fats. Omega 3 fatty acids provide many health benefits and can reduce inflammation that can lead to skin and cell damage. Seafood, plant-based oils, English walnuts, and Omega 3 eggs are some foods that are rich in Omega 3s. Supplements are also available.

## Protein

Your body needs protein, and protein is made up of building blocks called amino acids. Collagen and keratin are proteins that form the structure of skin. Keratin is the main protein in your skin, and makes up hair, nails, and the surface layer of the skin. Amino acids help shed old skin and can offer protection against UV rays and free radicals. Eggs, meats, and plant-based proteins are good sources for protein.



## Zinc

Your skin has many layers and zinc can help your skin heal after a wound or injury. Zinc will not increase hair growth but can help with hair loss and appetite. Meats, eggs, shellfish, and legumes are good choices for getting adequate zinc. Supplements are also an option.



## Vitamin C

Vitamin C helps produce collagen, a protein that your skin needs to even out skin tones and prevent wrinkling. Vitamin C deficiency can cause your skin to bruise easily. Many topical vitamin C creams and serums are available to apply directly to your skin. Foods that contain vitamin C and are low in potassium are strawberries, grapes, and lemons.







### Advanced Glycation End Products (AGEs)

AGEs are compounds that can cause structural changes in skin when they build up. Spices and herbs such as garlic, cinnamon, cloves, oregano, and ginger can reduce the production of these compounds. Also, moist heat cooking methods such as stewing, steaming, poaching, or boiling can reduce the intake of AGEs, and therefore are healthier than dry, high-heat cooking methods like grilling outside or broiling.



*This list was created to help you develop a platform for having a robust discussion with your healthcare team. Always consult your dietitian or doctor to learn your specific nutritional requirements, prevent any medication side effects, and check safety of oral nutrient supplements.*



**Judith (Judy) Beto, PhD, RDN**, was the first editor of the *Journal of Renal Nutrition*. She is a research consultant for the Division of Nephrology and Hypertension at the Loyola University Healthcare System and an Associate Research Editor for the *Journal of the Academy of Nutrition and Dietetics*.



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# Your Bright, Beautiful Smile

By Cher Thomas, RDH

One of your most attractive features is a bright, beautiful smile. Living with chronic kidney disease (CKD) can create some challenges for beautiful teeth, but here are some tips that you may find beneficial.

A healthy mouth is a beautiful mouth! Regular dental care is really important for those of us living with CKD. Seeking routine dental care with a dental professional and maintaining good oral hygiene at home are equally important.

You should always ask your medical provider about special precautions that may or may not need to be addressed prior to any professional dental procedure.

Those with CKD may incur a dry mouth for various reasons. Fluid restrictions, certain medications, and CKD itself can make it more difficult to remove plaque and tartar. This makes it easy for your teeth to pick up stains. Certain medications can cause your gums to swell and bleed easily. Furthermore, CKD can make your mouth smell bad and look bad.

## Dry Mouth

If you have a dry mouth, there are over-the-counter products available to help. The main ingredient in dental products you should avoid is alcohol. It can dry your mouth out even more and can make it even more difficult to remove stain, plaque, and tartar. Just because you're on a fluid restriction doesn't mean you can't rinse with water and spit it out in the sink. Brushing your teeth at least twice a day will help keep the stain, plaque, and tartar away!

## Medications

Certain medications may cause your gums to overgrow and bleed easily. This can be both unsightly and painful. Again, a little extra time with the toothbrush can minimize this problem.

## Bad Breath

Lastly, CKD can leave you with a mouth that smells and tastes bad. Good oral hygiene AND attending dialysis treatments as prescribed are really important to minimize these complications.

## Solutions

Products that are available over the counter that may help whiten your smile include (but are not limited to), Crest 3D whitening toothpaste and Crest 3D whitening strips. Avoiding alcohol in any dental product will minimize a dry mouth, and can help moisturize it. You may want to sample some oral moisturizers available over the counter such as Biotene, Crest Pro-Health Rinse, and others.

**Some bonus tips:** Wearing a darker shade of lipstick than your natural lip tone will automatically make your teeth appear whiter. Chewing sugar-free gum, like Orbitz or Dentyne, can help moisturize your mouth and make your breath fresher all at the same time! Be sure to get sugar-free, whether you have diabetes or not—chewing sugar over long periods of time is notorious for causing dental cavities.

When you implement these tips, you can smile with confidence and know your teeth are healthy too!

**Cher Thomas, RDH**, is a registered dental hygienist and a renal transplant recipient. After her kidneys failed due to ANCA positive vasculitis, in 1999 her brother became her kidney donor. Cher utilizes her experience with peritoneal dialysis and organ transplantation to explore the relationship between oral and renal health. She lives in Galveston, Texas.







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TransplantNATION is a 68-page, bi-monthly magazine that connects the transplant community. A publication that tells stories of hope and triumph over illness and human frailty, highlights the tremendous progress in the medical and pharmaceutical industry, and chronicles lives filled with courage, TransplantNATION adds focus to the human side of transplantation.

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The Transplant Games are held biennially in the United States to build awareness of the importance and need for organ, eye and tissue donation. The Games continue to grow in size and stature, with over 20 athletic and recreational competitions, and various ancillary events over the course of the 6-day event. The Transplant Games gather everyone connected to donation and transplantation for an amazing celebration of life. Bringing thousands of participants together from all over the U.S. and Puerto Rico, as well as other countries such as Australia, Brazil and India, the Games focus awareness on the medical miracle of transplantation and honor those who have given the ultimate gift of life.

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[www.transplantlifefoundation.org](http://www.transplantlifefoundation.org)



# Why we walk

## A passion for going the distance

By Kathleen Hostert

Web ID: 4031



”

Never in my wildest dreams did I think we could walk 13.1 miles together, but we did. It was an amazing accomplishment! We trained together for several months; it was great to have a goal to work toward.

Craig and I have been married for 35 years, and the key to our marriage, and our emotional and physical health, is walking as a couple. Walking together gives us the opportunity to breathe fresh air, disconnect from our phones, and have some of the best conversations together. We believe in walking and talking and we honestly believe it has made our marriage stronger. It also makes us feel better inside and out.

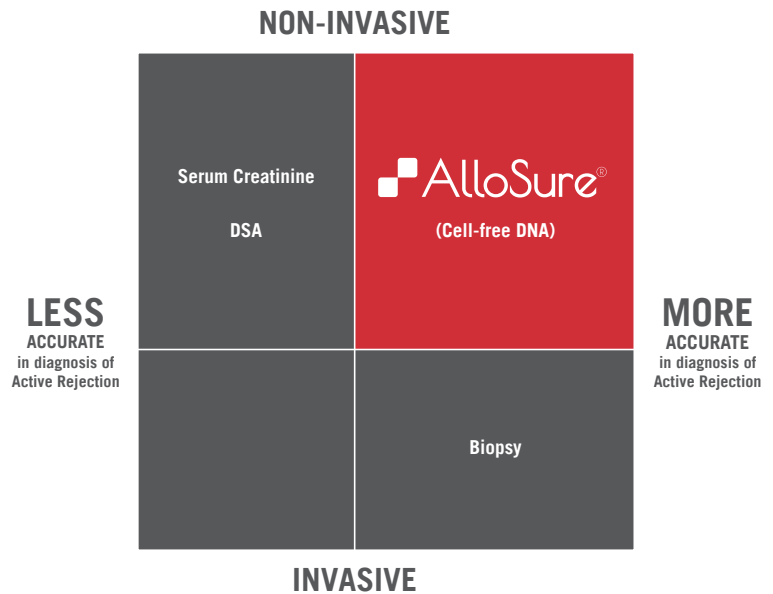
At times, we walk on our own with our favorite music playing, as music has a way of filling the heart while motivating us to walk at a good pace. We both love to walk wherever we camp as we have learned that walking sends us on journeys where we can see things we may have never experienced. Walking allows us to see and appreciate nature at its best. We stop to smell the flowers, hear the birds sing, or witness the flight of a beautiful butterfly or dragonfly.

Walking creates a sense of calm which benefits our blood pressure and overall health. We enjoy walking so much that we were inspired to create the Donate Life Run/Walk to educate and inspire the community on the importance of organ, eye, and tissue donation after I was blessed to donate a kidney to Craig.



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We have had some incredible walks together in our 35 years of marriage. I will never forget our first walk together down the hospital hall in 1998 following Craig's kidney transplant. Craig endured 2½ years on dialysis prior to the transplant and was too tired to walk like we always had in the past.

Another incredible walk was the day we renewed our vows on our 25th wedding anniversary. I realized at that time what an honor and privilege it was to walk down the aisle with my son on my arm and re-marry my soul mate. Often, we all take life for granted and forget what an incredible gift it is to have the ability to move our bodies and exercise.

My son, Justin, and I were honored to walk alongside the Donate Life Rose Parade float in 2014 as living donors to Craig. Justin donated a kidney to Craig in 2012. It truly was the walk of a lifetime as we joined eight other living donors who walked 5 miles to show the power of living donations and the fact that we were able to walk a 5-mile parade route.

Then there was the Ragnar relay race, when I joined a group of 12 who walked and ran as living donors in the event named, "Have you seen my kidney?" We took turns walking and running from Huntington Beach to San Diego in a 24-hour period—a little under 200 miles. It was truly teamwork and passion for one another that we were able to complete the relay. It challenged my mind

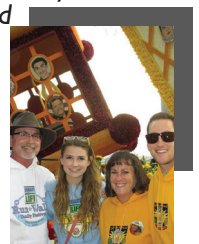
and my body and I felt the pressure as others relied on me to go the distance.

One of the most incredible walks that challenged Craig and I to the core was when we registered to walk a half-marathon! Never in my wildest dreams did I think we could walk 13.1 miles together, but we did. It was an amazing accomplishment! We trained together for several months; it was great to have a goal to work toward as we felt our bodies improve week by week.

We feel it in our relationship when we do not walk. And, as we get into our older years, I can say that motivating each other to keep walking is a daily challenge, but we do our best. We truly believe in the benefits of walking for our health, and for our emotional and mental well-being.

We hope to see you out on a walk!

**Kathleen Hostert** has been married for over 35 years to her husband Craig. She was able to give her husband a kidney in 1998, and in 2012 Craig received a second kidney, donated by his son. This new journey inspired Kathleen and Craig to do all that they can to inspire and educate the community on the importance of organ, eye, and tissue donation. Together, they founded the Donate Life Run/Walk which just completed the 18th annual event, with over 126,000 attendees over the years.





# Rachel Cluthe

a mother determined to raise a happy family

By Mary Nesfield



Rachel Cluthe's day starts early, often before the sun rises. As her husband, Jason, leaves for work, she stays busy raising her two daughters, Emma and Elissa. Meeting the needs of a 4-year-old while home-schooling a 10-year-old is in itself a full-time job, but Rachel also holds down a demanding full-time job in the oil and gas industry. Fortunate to be able to work from home, the 33-year-old mother strikes a delicate balance between family life and professional responsibilities.

Sundays are for planning the week ahead—preparing meals that her husband Jason can heat up during the week if need be, and keeping a calendar of her family's social activities, like Emma's Girl Scout activities and homework assignments, and Jason's night-time performance gigs that he fits in after working a full-time job. Being a drummer in a band, it's important that he not miss a beat. Not missing a beat is Rachel's responsibility too, but in a different way.

Back in March 2018, Rachel had been on her new job as an accounting assistant for only two weeks when she was admitted to the hospital. The fluids she was retaining made it almost impossible for her to walk. She was diagnosed with AKI (acute kidney injury) and learned that her coronary artery was blocked by 85 percent. She was told to see a cardiologist. After doctors put a stent in her heart, she began to feel better. But a few months later the swelling was back, and she ended up in the hospital for a month. Doctors inserted a catheter in her chest and started dialysis to eliminate the excess fluids.

"My new employer was very supportive," she said. "They gave me a laptop so I could work from my

hospital bed. I barely got out of the hospital in time to trick-or-treat with my kids."

Prior to her hospitalization, it was all she could do to feed her two daughters. "I'd get take-out and have Emma feed Elissa."

She wanted to resume her active lifestyle. "I didn't want to be on disability," she said. With Emma in school and Elissa in daycare, she started dialysis sessions. Determined to not miss a beat, she had dialysis treatments at the clinic from 5:00 a.m. to 9:30 a.m. three times a week and was at work by 10:00 a.m. And then, in January 2019, doctors inserted a fistula, which moved her toward her goal of home dialysis. She began self-cannulation at the center in April and started home training in June from 9:00 a.m. to 3:00 p.m. from Monday through Friday. She worked at her job into the evening hours to make up for lost time. She did her first home treatment in July.

"Self-cannulation at home can be nerve-racking, but it's worth it," she explains. Her employer allowed her to work from home, and she rose in the ranks from an accounting position to operations while also pitching in to help her employer in different departments.

To say Rachel is once again leading an active lifestyle is an understatement, because now she must also maintain a steady relationship with "Awsom-O," named after a character on the TV show, "South Park." Their strict standing date is three hours, four times a week.

Naming her dialysis machine is just one of the things she does to maintain her sense of humor. And Awsom-O provides her more than one benefit. "When I'm on

Awsom-O, my dialysis machine, I can give my undivided attention to my work or my kids."

With all that she does, Rachel maintains that keeping a busy schedule is "inconvenient, but not impossible."

"I have an amazing support system: my mom, my husband, and my employer." She credits them for her ability to raise two daughters while working full-time and doing dialysis, all from the comfort of her own home.

And Rachel's determination to provide a fun-filled childhood for her daughters is clear. Throughout her ordeal, she took her daughters to Six Flags amusement park on a regular basis. And recently, she and Jason reserved an entire day to create a backyard play space for the girls. Afterward, her scheduled date with Awsom-O ran late into the evening. It's important to her that she doesn't miss a beat.

"I know this isn't the end for me. I can keep going because I know this is just temporary." Life is about living, enjoying the good times while meeting everyday challenges, and taking advantage of new opportunities as they come along. Rachel is now working toward losing weight to prepare for the possibility of a kidney transplant.

Rachel encourages others with a life well-lived. "Anyone who needs dialysis can look at me and see that you can still live your life."

**Mary Nesfield** has enjoyed a long career in magazine publishing. She is a freelance writer and editor for Renal Support Network and works from her home in Columbia, South Carolina.





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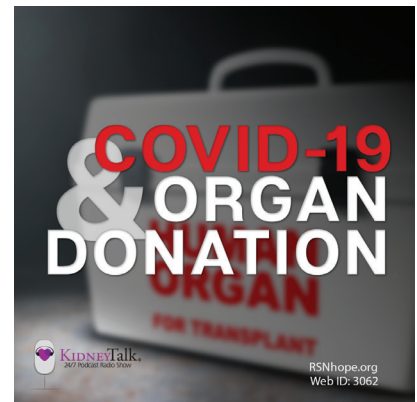
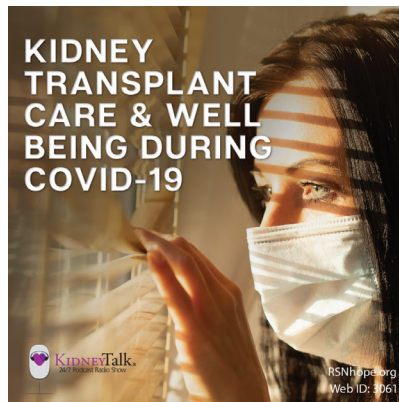


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In addition to federal websites and healthcare professional information, browse these and RSN KidneyTalk™ podcasts and blog posts about how people who have kidney disease or kidney transplants can cope and stay safe during the Covid-19 outbreak.







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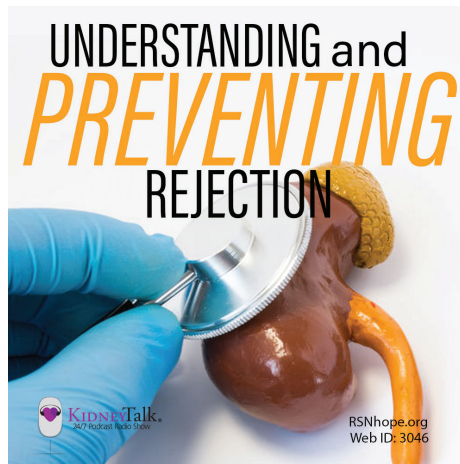
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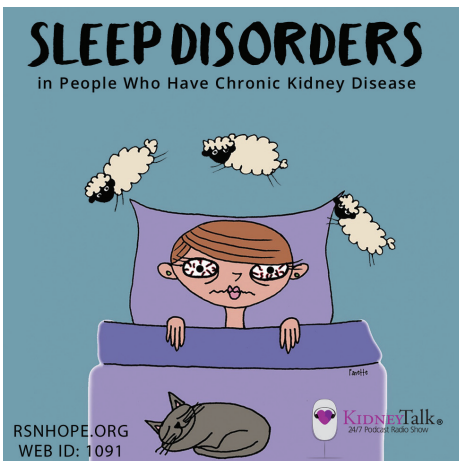
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Lori Hartwell founded Renal Support Network (RSN) in 1993 to empower people who have kidney disease to become knowledgeable about their illness, proactive in their care, hopeful about their future and to make friendships that last a lifetime.

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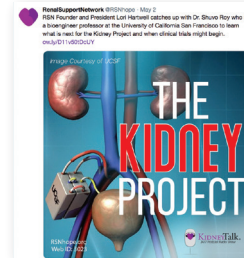
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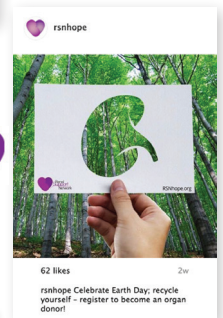
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