

A PROGRAM OF  
**RSN**  
Renal Support Network

# Live & Give

Volume 6, Issue 2 ♦  
Fall/ Winter 2010

The bi-annual update helping educate and motivate people living with chronic kidney disease.

## KidneyTimes Essay Winner

### You Never Know What You're Gonna Get First Place *(Theme-Book, Movie, or Song That Inspires You)* by Amanda Ratz

As a teenager, you think terrible things happen only in the movies and would never happen to you. In our minds we already have our life and our future planned out. But, what happens when the wind blows something in your direction, something which you have no control over? At the age of 16, I learned Tom Hanks' quote was so true, "Life is like a box of chocolates, you never know what you're gonna get."

I was diagnosed with an autoimmune disease.

A week after my diagnosis, I experienced my first admission into

the hospital, followed by a kidney biopsy. My physicians entered my room and explained the bad news, stating "your disease is extremely active. We need to start an aggressive course of treatment immediately. We will try everything possible, but there could be a chance your kidneys will fail and you will need a transplant in order to survive."



Suddenly, my future was a huge question mark. My disease was attacking my joints and my blood vessels and causing excruciating pain. Mariah Carey's lyrics became my inspiration. Every day I listened to her song There Can Be Miracles, When You Believe. I felt as if I was on a roller coaster ride, dangling off the back end, holding on for dear life by only my pinky finger. The disease was in charge and there was nothing we could do to stop it. My faith was

*1st Place Essay; Continued on page 5*

## Headline News

### Medicare Changes Dialysis Payments; How will this Affect Patients?

Starting January 2011, Medicare is implementing a new way to pay dialysis providers for dialysis treatments. Currently, providers are paid for each dialysis treatment itself. Then they are paid extra for such items as laboratory tests, injections of EPO, Iron, and other IV medications.

Medicare is changing their payment policy by paying providers one lump sum for most dialysis related costs (the dialysis treatment, supplies, lab tests, IV medications, and some oral drugs). Medicare refers to this as

bundling payment of care. Medicare has determined a preset price per treatment based on past cost data.

Dialysis providers have until November 1st 2010, to decide if they want to start having all services reimbursed starting in 2011 under the new system or gradually transitioning to the new payment system over four years.

In addition, Congress has mandated that Medicare develop quality measures to ensure that providers are delivering quality care and not

*Medicare Changes; Continued on page 4*

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# Buttons are Helping Me Keep it Together

by Lori Hartwell



As you may know, I have a number of health challenges. When I started back on dialysis last March, after a 20 year run with my kidney transplant,

I needed to again adjust to living on dialysis. At times I felt a bit down and frustrated. Although I had been on dialysis before, I again had to learn to adapt to this major lifestyle change.

As individuals with a chronic disease, how can we deal with the bumps in the road that seems to continually appear before us? One of the strategies I use to cope with challenges in my health status is to engage in the creative process.

When I am creating something or watching someone create, it helps me relax and get my mind off my health issues. It also helps me stay distracted so I don't eat or drink out of boredom. And let's face it, we are usually not tempted to eat or drink the things that are good for us!

Your route to the creative process can follow many roads, and many of them can be found without leaving your home. I love to watch the Food Channel with Bobby Flay. When he is throwing down his cooking skills and using all kinds of colorful ingredients, I am inspired to try to come up with some new combinations of healthy foods that are appropriate for my diet. Similarly, when I watch the HGTV channel, I often see them redecorate and transform a home just by moving around things that are already there. These shows often inspire me to do a few simple things around my home to give it a fresh or different look. This inevitably brings a smile to my face and gives me a feeling of accomplishment. Even if I can't do all the things I see on TV, the act of watching someone else create something is often inspiring.

But there are many artistic things that you can do without having the

talents of a Bobby Flay or a master carpenter. I have always believed that if you take the body the mind will follow, so I often look for art therapy projects to get my mind in a chronically happy place!

An art project may sound daunting if you think you are a person with no artistic talent—but they don't have to be. For example, a friend of mine turned me on to buttons. She made these beautiful button bracelets



and each one looks like a piece of art. I wanted to learn how to make them, so she showed me how. I was off and running with my newfound fun. Even more important, I found that even the most inept artist can design something beautiful and have fun doing it.

The more I learned about buttons and the history behind them, the more intrigued I became. There are so many different types of buttons: silver, gold, ivory, bone, mother-of-pearl, glass, stone, wood, horn, ceramic, Bakelite, plastic, and polymer clay. Some of them date as far back as the 18th Century. It became like a treasure hunt for me. I often search for that perfect button that will complete my bracelet. I scavenge garage sales, vintage stores, and Ebay.

At first I wondered why I was so attracted to finding old buttons and using them to create something new and interesting. Then I realized that most of the buttons I receive have been sitting in an old jar and may

have been thrown away. I realized that I am giving the buttons a new life!

Buttons also are known for keeping things together. On several occasions my girlfriends have come over and we sort buttons into color piles, design a bracelet, or just chit-chat. Buttons became a new source of interesting conversation with my friends. And once they knew about my new artistic hobby, they started to send me buttons that they had lying around the house or had found in their own travels. Buttons have become a way of helping me connect and keep me connected with my friends.

Button art and other forms of art therapy offer many stress reduction benefits. In addition to the pure enjoyment of creativity, it is rewarding when you master a new task that requires problem-solving skills and an artistic eye (even if it is only artistic to your eye). Art and emotions are closely linked,

so art-making can help to positively alter one's mood. Engaging in the creative process can provide you with hours of enjoyment that take your mind off the other challenges that you may be facing. I always feel better when I am working on my button art, and am very satisfied whenever I finish a bracelet.

I realize that button art is not the pathway that everyone will take to release their inner artist. But with thousands of activities to pick from, I encourage you to engage in a creative activity. I believe that it will offer you many moments of happiness that will help you get through the tough times. ☺



# Salt is Not My Friend

by Wendy Rodgers

As I prepared for in-center hemodialysis, I'll never forget the first moment I read through the Renal Diet Manual that came home with me from the hospital. I cringed, as most patients probably do, when I heard the word "diet". But I was determined to be open to change and willing to do what was best for my health. While turning the pages, I was surprised to learn that some healthy foods such as tomatoes, cantaloupe, and green leafy vegetables were foods that I needed to avoid or modify as a dialysis patient.

Some foods to avoid weren't surprising at all. One of the most obvious was salt (Sodium). Reducing and/or avoiding sodium intake is something that everyone should aim for whether or not they are living with chronic kidney disease (CKD). Who would have thought that something so obvious and something I viewed as an easy change would be so hard!

I would have to say I realized the depth of my friendship with salt while in the grocery store. The moment I walked through the door, my positive, willing-to-change spirit began to wither when I saw the display of chips

that seemed to welcome me. I rolled my cart by those items as fast as possible and tried not to look as I thought, "how am I going to replace my crunchy snack that goes great with sandwiches?" I decided to start at the opposite side of the store where I usually don't begin. I selected meat without any problem. However, I soon had to mourn the loss of purchasing my favorite quick and easy frozen meals and snacks when I read the labels--they were filled with sodium. I decided to not feel defeated and moved on to look

for a crunchy alternative to chips. I chose tortilla chips without salt despite the fact that



Doritos were calling my name. I also decided to try some "low sodium" snack crackers so I would feel like I had another crunchy snack in case the tortilla chips didn't work out. The seasoning aisle was the place I almost crumbled because I saw that almost everything I used in cooking was not beneficial to my health. I did not want to give up the Creole

## How much sodium is that really?

<b>Sodium Free, Salt Free, No Sodium</b>	Less than 5mg sodium per serving. Check the ingredients list for possible phosphorus additives or salt substitutes.
<b>Very Low Sodium</b>	35mg of sodium or less per serving.
<b>Low in Sodium, Less Sodium,</b>	140mg sodium or less per serving.
<b>Light in Sodium, Lightly Salted</b>	At least 50% less sodium than the original product.
<b>Reduced Sodium, Less Sodium</b>	At least 25% less sodium than the original item.
<b>No Salt Added, Unsalted</b>	No additional salt was added to the product during processing. This does not mean it is low in sodium. The product must declare "This is Not A Sodium Free Food" on information panel if food is not "Sodium Free".

seasonings and flavorings that I absolutely love and grew up eating. Although Mrs. Dash offered so many flavors, I just wasn't thrilled about using them. By the time I made it to the other side of the grocery store all I could feel was a

.....  
Salt: Continued on page 9

**weKAN Live & Give** is a publication of the Renal Support Network, a patient-run nonprofit organization whose mission is to identify and meet the non-medical needs of those affected by chronic kidney disease.

**weKAN Patient Activists** serve to mobilize, educate, motivate, and empower fellow chronic kidney disease survivors to advocate for themselves and for one another. Together we can make a difference.

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# History of Medicare Payment for ESRD

**1965**

Medicare and Medicaid are established

**1972**

Medicare End-Stage Renal Disease (ESRD) program is established

**1978**

ESRD Networks are developed to oversee Quality Improvement in dialysis centers  
Congress mandates CMS to develop a Prospective Payment System (PPS) for dialysis services

**1983**

Composite rate reimbursement for dialysis is implemented, the first “prospective payment” in Medicare.

**1989+**

Medications such as EPO, Iron and Vitamin D are introduced and billed separately from the dialysis services.

**1993**

Medicare extends coverage of immunosuppressant drugs for kidney transplant recipients to 36 months

**2003**

Medicare Modernization Act was passed that included Medicare Part D

**2008**

Medicare Improvement for Patients and Providers Act mandates Medicare to bundle all dialysis services into a prospective payment, including oral drugs that are the equivalent of separately billable injectable medications, effective January 1, 2011. The law also required the establishment of a Quality Incentive Program related to dialysis reimbursement, the first of its kind in Medicare.

**2011**

ESRD PPS begins, with some facilities phasing in. All facilities will be paid under the PPS system beginning January 1, 2014.

**2012**

Quality Incentive Program implemented January 1 with three initial measures.

## Medicare Changes

Continued from page 1

skipping on the services that you are currently receiving.

Medicare has developed three quality measures and promises that more will be developed to ensure that you receive quality care. Two measures are for anemia (hemoglobin) and one measure is for dialysis adequacy.

The proposed rule for how the bundle itself would work was submitted to the kidney community two years ago for comment and improvement. Patient advocates from weKAN, the RSN education and advocacy program, were very active in proposing improvements. Many comments from weKAN were incorporated into the final payment rules Medicare published.

So you are probably asking yourself, “How will this change affect people on dialysis?”

If your dialysis clinic chooses to opt-in to the new payment system they will be required to provide your dialysis medications, including some oral medications (e.g., oral vitamin D). This will be a change for some patients on how they receive their medications.


The dialysis providers will be required to furnish the medications to you via a pharmacy.

Medicare developed a standard list of dialysis lab tests that will be included in the bundled payment. Co-payments may rise slightly due to the fact that lab tests, which historically had no co-payment, are now included in the bundled payment.

However, non-dialysis lab tests can be drawn in the clinic and the provider will bill your insurance directly and reimbursement will be paid separately.

Whenever a payment system is changed there are always questions or issues that arise that may not have been anticipated. Medicare has agreed to monitor this reimbursement system change closely and correct it if problems arise.

It is important for all patients to ask their dialysis clinic if they are changing payment systems, and to speak to your health care professionals and legislators if you feel your quality of care is being compromised.

If you would like to be involved in providing feedback on legislative and regulatory issues, visit RSN’s weKAN webpage or email us at [weKAN@RSNhope.org](mailto:weKAN@RSNhope.org). Become a weKAN patient advocate and make your voice heard. 

### Reporting from Bill Dant and Kathe LeBeau.

**Bill** lives in Salt Lake City, UT. He dialyzed for 18 years beginning in 1977 before he received a transplant in 1995. Bill has a Masters degree in counseling and has worked for kidney patients with the ESRD networks, NKF, and RSN for many years.



**Kathe** began home hemodialysis in April of 2007 after being diagnosed in 2004. She is the Project Manager for RSN’s weKAN group, and is also a PEPP speaker and HOPEline operator. Kathe lives in the Capital Region of New York State.

shattered, my hope seemed dim, and my courage was tested but my strength kept me alive. Each day that song gave me the little bit of strength I needed to get through the next day. That year, I spent more nights in my hospital room than I did in my own bedroom. St. Louis Children's Hospital had become my home. But I never stopped believing and my miracle finally arrived December 11, 2000! A perfect matched kidney and a second chance at life! My older brother Matt risked his life to save mine.

After the transplant, I made a promise to myself to better the lives of those affected with kidney disease and to increase the availability of all organs for transplantation. I know that to Pay it Forward would help so many individuals and one day it might even grant me my third chance at life. Becoming involved after transplant was the wisest thing I have ever done. Sometimes helping those in need or cheering someone else up becomes the best medicine.

Currently, I'm no expert on living with a chronic disease, even after

11 years. Life is still like a box of chocolates and each day I do not know what I am going to get. I do struggle at times and life isn't easy. I search everyday to find that perfect balance where physically, emotionally, spiritually and mentally I'll be at one. My goal is to find that perfect harmony! I try to remain positive every day. Over the years, I've learned your attitude makes the difference in whether or not you sink or swim when dealing with an illness. If I wake up and feel like I do not have enough strength to continue-- that's a bad day. I quickly remind myself of this gift of life I was given, keep my head held high, smile and remember the promise I made to myself.

I am a registered nurse, a sister, a friend, a daughter, a volunteer and an advocate for chronic kidney disease (CKD). I am not my disease! This disease is just a part of me. It is the best yet, the worst thing that has ever happened to me.

I've realized the plans for our life can be changed in an hour, a minute,

or even a second. You can wake up one day and your life could be changed forever. So what happens when the wind blows something in your direction that you can't control? Well, there isn't one thing that helps me survive CKD. Everything does! My family, friends, nurses, physicians, books, movies, and songs have taught me to "bend when the wind blows," to "pay it forward", and that "there can be miracles when you believe." Keep your head held high if the wind knocks you down. You weren't born to break, so pick yourself up, have faith, find your strength, and search for harmony. You're not your disease! Always remember to smile.

Life is like a box of chocolates, but what you get might be exactly what you need!

My name is Mandy Ratz and I am a kidney transplant survivor! ☺



Mandy Ratz, 27, began her struggle with Kidney Disease at the age of 16. After spending one year on dialysis, she received her brother's kidney shortly after her 18th birthday. Currently, Ratz resides in St. Louis, Missouri working as a Registered Nurse and is actively involved in charitable organizations.

## What's New Online

# RSNhope.org KidneySpeak Launched



**KidneySpeak, RSN's new speaker program, is designed to provide the tools and resources to help patient presenters become as effective as possible in educating their community about organ donation and chronic kidney disease (CKD).**

**KidneySpeak will connect speakers with meeting/event organizers across the country. "We get requests for speaking engagements from all over the country and don't always have a speaker in their area," says Lori Hartwell, RSN President and Founder. Through KidneySpeak, RSN will be able to serve as a match-maker between the organizers and the speakers; both will be submitting applications online. RSN is encouraging the kidney community to share KidneySpeak with local service clubs and meeting planners to help spread awareness.**

**If you are interested in joining the list of speakers or requesting a speaker for a meeting please visit our website and fill out the online application and an RSN team member will contact you.**

JOIN  
speaker list

REQUEST  
a speaker

KidneySpeak was made possible by support from Amgen, Fresenius Medical Care and Abbott.

# The Anatomy of a Food Label

**Serving Size** – Although serving size is a government standard per gram that doesn't mean it's an accurate serving size for you. Keep that in mind when you are reading the rest of the label. Also check servings per container. A container might look like a perfect serving for one person but there might be 2 or 3 servings in that one container. That means you have to multiply all of the following totals by 2 or 3 if you plan to consume the entire contents.

**Sodium** – This is an important item for patients to keep track of. Look at the *mg* rather than the percentage. People on dialysis want to control sodium due to thirst and risk of high blood pressure. Transplant recipients should control sodium to avoid swelling as well as high blood pressure. People with kidney disease are advised to limit sodium to less than 2000mg a day.

**Potassium** – It is not required by FDA to list potassium but more food manufacturers are beginning to include it on the label; normally it would be found between Sodium and Total Carbohydrates. If it is not listed, look at the ingredient list for potassium sources. Avoid products with potassium chloride if you are on a low potassium diet.

**Each of these nutrients is also a lab value. Review your lab tests with your doctor to be sure you are getting optimal nutrition.**

**Albumin (protein)  
Phosphorus  
Potassium  
Sodium**

## Nutrition Facts

Serving Size 29 crackers (30g)  
Servings Per Container about 10

### Amount Per Serving

**Calories** 130      **Calories from Fat** 40

		<b>% Daily Value*</b>
<b>Total Fat</b>	4.5g	7%
Saturated Fat	1g	5%
<i>Trans</i> Fat	0g	
Polyunsaturated Fat	2g	
Monounsaturated Fat	1g	
<b>Cholesterol</b>	0mg	0%
<b>Sodium</b>	320mg	13%
<b>Total Carbohydrate</b>	20g	7%
Dietary Fiber	less than 1g	3%
Sugars	0g	
<b>Protein</b>	4g	

Vitamin A 2% • Vitamin C 0% • Calcium 4% • Iron 6%

\* Percent Daily Values are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs:

		Calories	2,000	2,500
Total Fat	Less than	65g	80g	
Sat. Fat	Less than	20g	25g	
Cholesterol	Less than	300mg	300mg	
Sodium	Less than	2,400mg	2,400mg	
Total Carbohydrate		300g	375g	
Dietary Fiber		25g	30g	
Calories per gram: Fat 9 • Carbohydrate 4 • Protein 4				

**INGREDIENTS:** ENRICHED FLOUR (WHEAT FLOUR, NIACIN, REDUCED IRON THIAMIN MONONITRATE [VITAMIN B1], RIBOFLAVIN [VITAMIN B2], FOLIC ACID), SOYBEAN AND PALM OIL WITH TBHQ FOR FRESHNESS, SKIM MILK CHEESE (SKIM MILK, WHEY PROTEIN, CHEESE CULTURES, SALT ENZYMES, ANNATTO EXTRACT FOR COLOR), SALT, CONTAINS TWO PERCENT OR LESS OF YEAST EXTRACT, PAPRIKA, YEAST, PAPRIKA OLEORESIN FOR COLOR, SOY LECITHIN.

**CONTAINS WHEAT, MILK AND SOY INGREDIENTS.**

Example Nutrition Facts from reduced fat Cheez-It®

# Food Label

**Daily Value** – The daily value percentages are based on a 2,000 calorie diet which is not appropriate for everybody. Talk to your dietitian or doctor to find out what is right for you and adjust the percentages based on that total. Also keep in mind that certain diets may require less of certain things like sodium, cholesterol, or sugars or more of others, like protein.

**Protein** – Naturally, the higher the amount of protein the better, but keep in mind other factors like sodium, potassium and phosphorus. Consuming adequate amounts of high quality protein is important whether you are on a specialized diet or not. However, dialysis patients require more protein.

**Phosphorus** – This mineral is rarely shown on food labels but when it is you can find it listed among the other nutrients. If it does not show phosphorus in milligrams or as a percent Daily Value on the nutrition label, check the ingredients for “phos,” for example: monocalcium **phosphate** or **phosphoric acid**. These are used as preservatives, flavor enhancers or non-caking agents and are forms of phosphorus.

**Everyone is different, consult your renal dietitian (RD) on how much of each nutrient is right for you.**

# Protein

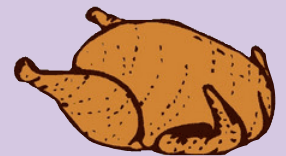


## Why is Protein Important?

Each time a patient dialyzes, they lose some protein. For this reason, their protein needs are higher than a person not on dialysis. People on dialysis need to consume enough protein to keep their albumin level at 4.0 or above.

## What is Albumin?

Albumin is a type of protein that helps with growth and maintenance of body tissue, prevention of anemia, and prevents loss of muscle mass.



## How Much Protein do I Need?

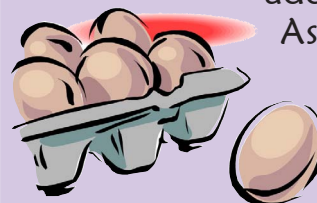
People on hemodialysis should consume 0.8-1.0 grams of protein per kilogram of weight. Peritoneal dialysis patients should consume 1-1.2 grams of protein per kilo. Therefore, a person on hemodialysis who weighs 70kg would need to consume 56-70 grams of protein each day.



## How can I add protein to my diet?

Egg whites are a good source of high quality protein, add them to your food when ever possible. Protein powders are another good way to add protein to a meal.

Ask your dietitian for recipes that include adding protein powder to foods.



# HOPEline

If you have chronic kidney disease  
and don't know what to expect call

English

1-800-579-1970

Support from someone  
who's been there.

Monday-Friday 10am-8pm (PST)

 Renal  
Support  
Network  
RSNhope.org



Si tiene enfermedad renal crónica  
y no sabe que le espera

Español

1-800-780-4238

alguien que ya estuvo ahí  
le ofrece su apoyo.

Lunes-Viernes 10am-8pm (hora del Pacífico)

## It's Your Turn



## Garden Delights

by Shari Gilford

As I stand in the newly green grass I envision juicy red tomatoes, carrot fronds dancing in the breeze, and pole beans clambering up to the sky. The warm sunshine is coaxing every living thing to raise its sleepy head after the cold winter. Spring urges me to get busy and plant my vegetable seeds!

My mother instilled in me a love for fresh vegetables. Her yearly garden provided an abundance of taste sensations, and I was allowed to eagerly nibble at whim. Nothing is better than a fresh-picked green bean or snow pea, or the sensation of a sun-warmed cherry tomato on my tongue.

In January of 1977 I began dialysis. I was 11 years old. I cried when I found out my garden smorgasbord was now off-limits. My mother found it strange that I couldn't have all those vitamin-packed vegetables anymore. Isn't that what keeps a child healthy?

I wasn't deprived for long. Just as summer arrived, my brother gave me his kidney—the gift of life... and the gift of vegetables! On my first day home after too many days of Jell-O and hospital food, my mother fixed my favorite


meal. With great delight, I delved into my plate of freshly-dug potatoes baked on the grill and just-picked tomatoes, cucumbers, and green beans. It was the best-tasting meal I'd had in a long time.

As an adult, I now understand the reasons why some foods are restricted. However, a dialysis diet doesn't stop

me from planting my favorite high-potassium vegetables—tomatoes, potatoes, and butternut squash. I've learned to eat them in moderation, carefully keeping track of my potassium intake. Fortunately, not all vegetables are taboo. I can quickly devour large portions of green beans and cabbage!

Basil is the most treasured plant in my garden. For me, summer equals basil... and fresh pesto. Pesto perks up the flavor of steamed vegetables, and on pasta it's a lower-potassium choice than tomato sauce. I could eat it every day!

My garden provides more than just good food. Digging, bending, reaching, squatting, lifting, and numerous trips back and forth to the garage are all great calorie-burners and muscle-strengtheners. After a few hours, I know I've given my body a good workout! I'm tired but invigorated.

In my garden, all my senses wake up—as I feel the warmth of the sun and hear the birds singing, as I smell the fragrance of damp grass and as my fingers touch the cool, soft earth. Every part of me pulses with life and exhilaration. My garden sprouts the miracle of life in my heart. 



*With over 30 years of combined dialysis and transplant experience, Shari's passion is to help fellow patients live well. She received her third kidney transplant in March 2006. In the near future, she and her husband have plans to live in India for a year. Shari is active in a kidney support group in her community and has been involved in RSN's programs for many years.*



**"A fruit is a vegetable with looks and money. Plus, if you let fruit rot, it turns into wine, something Brussels sprouts never do." ~P.J. O'Rourke**



## “Who would have thought that something so obvious... would be so hard!”

series of losses. I wanted to just leave my cart and walk out because my perception of CKD was changed by my salt restriction. And at that moment, I truly saw that salt was NOT my friend.

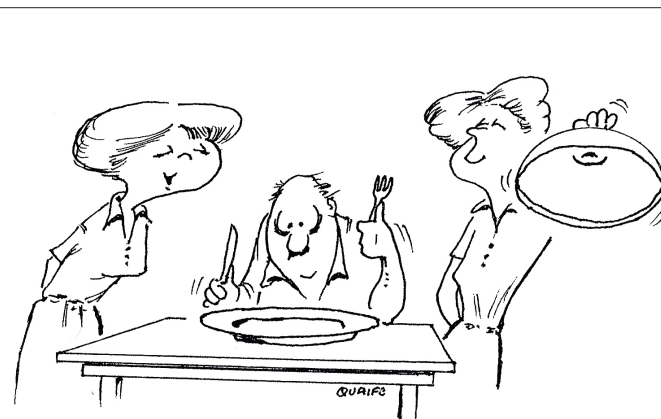
I dialyzed for 9 years and discovered a few tips that helped me enjoy food that was not filled with sodium. I also learned that consuming more sodium made me thirstier which, in turn, caused me to retain more fluid. My dietitian gave me a list of all the foods I could eat, which helped when I made my grocery list. I began to see that my losses weren't so great and that I actually liked most of the foods I had to choose from. This tool alone helped me walk through the doors of a grocery store with more confidence. I talked to others and learned that I could use things like lemon, lime, pepper, herbs, onions, and even oil-based salad dressings to season or marinate my food. I also have found great seasonings that contain no salt to season food. My need to “crunch” could be satisfied by carrots and tortilla chips without salt. Most surprisingly, I learned that after I reduced my salt intake, my salty favorites were less appealing! Salt is no longer my enemy, we have worked out our relationship and are now just acquaintances. ☺



Wendy Rodgers was diagnosed with systemic lupus in 2000. A former Math & Science teacher, she currently resides in Torrance, CA. Wendy holds a B.S. in Biology and a Masters' in Education which she completed while on dialysis. As a member of the Renal Support Network, Wendy is a PEPP speaker and weKAN patient activist.

**A**s a member of the rock band The Kinks, who made memorable songs such as *Lola* and *You Really Got Me*, Peter Quaife was much better known as their original bass guitarist than for his dialysis cartoons. Quaife was diagnosed with renal failure in 1998. “During those long, boring, sessions, I found that drawing cartoons was an amusing outlet for all of my frustrations with the condition, the hospital and even at times, the professionals that were treating me,” stated Quaife in a message that appears on the website for his book of cartoons, *The Lighter Side of Dialysis* of which there are two volumes.

Sadly the world lost Peter Quaife on June 23rd 2010. He will be remembered through great music and playful cartoons.



...and this dish is totally potassium-free!

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# Programs & Services

## HOPEline

A toll-free call-in line offering patient-to-patient encouragement and support from operators who have lived successfully with chronic kidney disease.

English **1-800-579-1970** Spanish **1-800-780-4238**  
Monday - Friday, 10:00 a.m. - 8:00 p.m. (Pacific Time).

## KidneyTalk

Online radio talk show hosted by Lori Hartwell & Stephen Furst, covering a wide variety of kidney-related topics. Listen at **RSNhope.org** or download podcasts from **iTunes**.

## RSN Renal Teen Prom

Annual prom held in the Southern California area each January for teenage kidney patients. Young people with CKD ages 14 to 24 come from across the United States to enjoy a night of glamour.

## Regional Patient Lifestyle Meetings

Based on the theme of "Health, Happiness, & Hope," meetings held nationwide offer a setting where people with kidney disease and their families can learn about issues related to their illness in a relaxed, friendly atmosphere.

## KidneySpace

An online discussion forum to air your questions, thoughts, and opinions on lifestyle issues related to transplant and kidney disease. Go to **KidneySpace.com** to join the conversation!

## KidneySpeak

This program provides tools, resources and presentations to inform people on chronic kidney disease and organ donation. Developed patient speakers through the PEPP (Patient Educating Patients and Professionals) program can also be requested for healthcare and patient meetings.

## Chronically Happy: Joyful Living in Spite of Chronic Illness

Written by Lori Hartwell, *Chronically Happy: Joyful Living in Spite of Chronic Illness* is an upbeat, motivational book that helps people living with chronic illness create joyful, fulfilling lives. **Available on Amazon.com for Kindle or in paper back. Also available from RSN in audio.**

## weKAN: Wellness & Education Kidney Advocacy Network

A national group of people with kidney disease who advocate on behalf of fellow patients. *Live & Give*—weKAN's biannual newsletter for patients—inform, inspires, and educates patients, family members, and healthcare professionals.

## KidneyTimes

An online resource with articles written by kidney patients and professionals on medical, social, nutritional, and lifestyle issues. Home of the annual "KidneyTimes Essay Contest."  
**KidneyTimes.com**

## Renal Recipe



## Renal Rookie Cooking Challenge

Prepared by Ed Robinson

When I was asked to prepare a renal friendly meal for a friend on dialysis, I thought, "Sure, no problem. I cook healthy all the time. I just have to make sure to provide plenty of whole grain breads, wild rice, fruits, and plenty of water. Easy, right?" I couldn't have been more wrong.

The Renal Diet is so tricky because it is so counter-intuitive. Every other restrictive diet I can think of is just an extreme version of regular healthy eating: low carb, low sugar, low sodium, low mercury, and high in nutrients. I learned that cooking properly for a person with kidney disease, I have to throw these pre-conceived ideas out the window. While it's easy to learn that someone on dialysis needs to have very minimal fluids, what is less easy is keeping meals low in phosphorus, potassium and sodium while providing high

protein. It is especially difficult when many food labels do not include either phosphorus or potassium.

All is not lost, however, because once you get used to the renal diet, there are plenty of delicious foods left to include. As a result, I created a few recipes that are tasty and meet the suggested guidelines. The Imperial Indian Chicken (recipe on page 12) uses large bone-in chicken breasts for plenty of protein seasoned with a flavorful salt-free dry rub. The glaze also has a good amount of lemon juice, which is another great way to add flavor without sodium. It is served with white rice, which is lower in phosphorus than either brown or wild rice.

And of course, everyone has a bit of a sweet tooth, but with chocolate and peanut butter being high in phosphorus and potassium, how do I prepare a cookie that is tasty without using these key ingredients? The

answer, I found, is butterscotch and/or caramel. The Crispy Butterscotch Cookies made with cream of wheat makes the perfect cookie for the renal diet. And, for an even more decadent, but still renal-friendly treat, I made a caramel-filled butterscotch chip cookie, both pictured to the right.

While it was a challenge to learn how to cook renal-friendly, it is mostly because of the large learning curve. Once I discovered what foods and seasonings I had to work with, there was no reason I couldn't create great tasting meals for my friend.



Ed Robinson has been a self-taught home chef since he was tall enough to reach the counter. He recently hosted and created the cooking show "Five \$ Feasts." Ed caters low-budget film/video shoots and is a food stylist for the cooking show "Fed-up!"

## Sign up to receive Live & Give

- Yes!** I would like to receive a free subscription to the weKAN Live & Give newsletter.  
 **Yes!** E-mail me renALERT, RSN's electronic update! (Please provide your e-mail address.)  
 **Yes!** Please send me \_\_\_\_\_ additional copies of weKAN Live & Give to distribute.

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**Renal Support Network** 1311 N. Maryland Ave. • Glendale, CA 91207 toll free 866-903-1728 • 818-244-9540 fax \_\_\_\_\_

## Give back to Renal Support Network

- YES!** I would like to help RSN continue the programs that help educate and motivate those affected by chronic kidney disease.

Enclosed is my gift of:

\$ \_\_\_\_\_

### Method of Payment for contributions:

- Check or Money Order (payable to Renal Support Network)

*"An illness is too demanding when you don't have hope."  
 ~Lori Hartwell*

### Crispy Butterscotch Cookies



Photos by Jodie Younse

- ½ cup margarine
- ½ cup packed brown sugar
- ½ cup sugar
- 3 Tbsp egg alternative (1 egg)
- 1 tablespoon milk
- 1 teaspoon vanilla extract
- 1 cup + 3Tbsp all-purpose flour
- 1 teaspoon baking powder
- ½ teaspoon ground cinnamon
- 1 cup Cream of Wheat
- 1 cup butterscotch chips

Preheat oven to 350°F. Grease cookie sheet. Beat butter and sugars until creamy. Add egg, milk and vanilla. Beat until fluffy. Stir together flour, baking powder and cinnamon. Add to butter mixture; mix well. Stir in cereal & butterscotch chips. Drop by level tablespoons onto prepared cookie sheet. Bake 9 to 12 minutes or until lightly browned. Let stand on cookie sheet 1 minute before removing to racks to cool. Makes 3 dozen.

**Calories 100** | **Protein 0.7g** | **Potassium 32mg** | **Fat 4.5g** | **Carbohydrates 14g** | **Sodium 46mg** | **Phosphorus 22mg**

Find the recipe for the **Goey Caramel-Filled Butterscotch Cookies** and many other renal-friendly recipes at [KidneyTimes.com/recipes.php](http://KidneyTimes.com/recipes.php)



*In this issue of Live & Give...  
Renal Friendly Eating*

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Photo by Jodie Younse

### Imperial Indian Chicken with White Rice

**Dry Rub:**

- 1 tsp. curry powder
- ½ tsp. paprika
- ½ tsp. onion powder
- 1 tsp. garlic powder
- ½ tsp. ground ginger
- ½ tsp. cumin

2. Prepare the dry rub by combining all of the dry ingredients
3. Rub the chicken breasts with the dry rub and olive oil, making sure to get the rub underneath the skin of the chicken breast
4. Cook 1 cup of white rice in a rice cooker. After the rice is done cooking, add 1 tbsp of chutney and half of the chopped green onions.
5. Place the chicken in a roasting pan and roast at 450°F for 25 minutes.
6. Meanwhile, prepare the glaze by melting the butter into the remaining chutney in a small saucepan. After the butter has melted and the chutney has heated through (about 5 minutes,) add the lemon juice and remove from heat.
7. After 25 minutes, spoon half of the prepared glaze onto the chicken breasts. Return to the oven and roast for 5 more minutes or until an instant read thermometer reads an internal temperature of 160°F.
8. Remove the Chicken from the oven and spoon remaining glaze over the chicken.
9. Serve the chicken over the rice, and enjoy.

- 1 jar Trader Joe's Mango Ginger Chutney\*
  - 2 Tbsp unsalted I can't believe it's not butter
  - 1 Tbsp lemon juice
  - 2 bone-in split chicken breasts
  - 1 Tbsp olive oil
  - ½ cup green onions, chopped, including the green stems. (optional)
  - 1 cup white rice
- (\*If Trader Joes is not available in your area choose another low sodium chutney. The sodium content should be 100mg per serving or less.)
1. Preheat the oven to 450°F.

**Calories 705 | Protein 37g | Potassium 582mg | Fat 28g | Carbohydrates 73g | Sodium 543mg | Phosphorus 325mg**

**More recipes on reverse and on [KidneyTimes.com/recipes.php](http://KidneyTimes.com/recipes.php)**