

Renal Support Network

The quarterly update helping educate and motivate people living with chronic kidney disease.

Volume 4, Issue 3 + Fall 2008

Look Inside!

Headline News

Congress Passes Kidney Legislation

CONGRESSIONA

by Kathe LeBeau

I have to admit that this summer I officially became a C-SPAN junkie.

I was glued to the coverage of the Senate debate, vote, and veto override on the proposed Medicare legislation that contained positive provisions for the kidney dialysis program. I listened as the

Senators spoke out in support of this bill which would make a great deal

of difference in kidney patient's lives. On our annual weKAN trip

to Washington, DC in May, we had met and discussed with the Senators and Representatives these same issues regarding kidney disease.

After a great deal of debate, a promised Presidential veto, and an overwhelmingly sup-

portive override vote, H.R. 6331, the Medicare Improvements for *Continued on page 3*

SPOTLIGHT ON YOU Swept Away by a Tornado: Lori Hartwell's Vision LORI'S LINES Excuse Me! What Am I Ordering? PHOTO SPREAD **RSN 15th Anniversary RSN** Programs 10th Anniversay Renal Prom **PROFESSIONAL POINTS** Medication Safety—Get It **RIGHT!** BOOK REVIEW 'The One Hour Activist" TO YOUR HEALTH Time... Just a Little More Time... Please

Spotlight On You

Swept Away by a Tornado: Lori Hartwell's Vision

Diagnosed with kidney disease at age two, in and out of peritoneal dialysis and hemodialysis, and hospitalized for three transplants the last still going strong after 18 years—Lori Hartwell is something of a medical and human marvel.

When she first saw "Wizard of Oz," Lori immediately recognized her own story in Dorothy's. "After

being swept away by a tornado, Dorothy was seeking a place of comfort—home. When you are swept away by the tornado of a chronic illness you are not comfortable in your own body; you seek security, comfort, a home. You need courage, wisdom, and heart to deal with all the emotions you go through in order to find that place of comfort."

For forty years, Lori has experienced, listened, learned, talked, and pondered the challenges of being a person with chronic kidney disease. When Lori started to embark on her career as a renal care professional traveling and selling equipment, she told her story as part of the sales pitch. Pretty soon Lori's Lines

Excuse Me! What Am I Ordering?

by Lori Hartwell



Eating out is one of life's little pleasures. All the over-hyped food on the menu is designed to tempt you, right? When you

are on a special diet, eating out can be challenging—that is, if you are aiming to stay on your diet!

The tempting titles that adorn the menus turn your willpower to Jello! Like Tony Roma's special barbecue ribs boasting that tantalizing famous barbecue sauce of theirs. Or an Olive Garden culinary special, Chicken Scampi. Yum! I can

weKAN Live & Give is a publication of the Renal Support Network, a patientrun nonprofit organization whose mission is to identify and meet the nonmedical 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.

Newsletter Staff

Editor-in-Chief Lori Hartwell Managing Editor; Layout & Design

Jodie Younse Editorial Coordinator Kathe LeBeau

Distribution Renal Support Network

Contact Information

Renal Support Network 866-903-1728 Toll Free 9 AM–5 PM Pacific Time

Submissions, Newsletter Business info@RSNhope.org, or mail to RSN

Address Changes & Distribution

Live & Give Distribution Dept. Renal Support Network 1311 N. Maryland Ave. Glendale, CA 91207 *info@RSNhope.org*

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© 2008 by Renal Support Network All Rights Reserved EIN#95-4672679 just taste the chicken breast tenderloins sautéed with bell peppers, roasted garlic, and onions in a garlic cream sauce served over angel hair pasta. And then they fill you up with all that hot bread and butter they bring to your table before your meal even arrives.

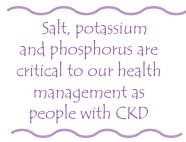
But wait! Salt, potassium, and phosphorus are critical to our health management as people with CKD, and we need to be mindful of what is in our food or we pay a big price. Calories, trans fat, cholesterol, and carbohydrates are hiding everywhere, and we have to know what we are actually eating.

When I eat out, I have a set of standard questions that I ask my server. One of my favorite questions is "what is one of your

favorite items on the menu?" Immediately, I can tell if the server knows anything about the food they are serving. Their answer will guide me—if I trust their opinion. I can further my interrogation by asking them how the food is prepared. How much salt does the chef or cook add and do they marinate the meat or vegetable in any type of sauce?

Once I make my selection I am not afraid to ask for substitutions or for dressings or sauces on the side. I am a stickler for my meat being well done.

For many years, I was afraid to send a meal back. After all, I didn't want to be a bother. Does that sound familiar? One of my good friends who is a vegetarian



taught me that this was not only not good for my health but it was also not good for the restaurant! Restaurants rely on repeat business and if my meal is not a savory experience, I may not return or recommend them to a friend. That is bad for business.

I remember the first time I sent a meal back. It was so salty that I chugged a glass of water to quench my thirst after just one bite. I summoned the server with an "Excuse



me!" As she approached the table I politely asked her if she would mind changing my order to something less salty. Of course I had to explain that it was because I have kidney disease and my ankles swell up like water balloons.

She responded that her Mom had the same problem with several diet restric-

tions of her own. She was happy to help me get a meal that would not cause me discomfort.

So next time you are dining out, don't be afraid to say, "Excuse me. What am I ordering?"

Chronically Yours, Lori Hartwell President & Founder of the Renal Support Network

Changes for Quality

Continued from page 1

Patient and Providers Act of 2008 was enacted by a significant majority as Public Law No. 110-275. The Senate's vote was 70-26, more than the two-thirds needed to override President Bush's veto of the Medicare legislation, and the House voted 383-41 to do the same.

Provisions of the Bill

The part of the bill that addresses chronic kidney disease and is most important to people

Hear what concerned patients have to say about bundling.

To watch the video "Bundling of Dialysis Services" go to RSNhope.org and click on Advocacy

To discuss bundling and other issues check out KidneySpace.com

living with chronic kidney disease (CKD) includes establishing pilot educational projects to increase public and medical community awareness of and screening for CKD as well as improving the **monitoring systems** to determine the prevalence of CKD. The terms also extend Medicare coverage to kidney disease patient education services, providing for six education sessions for people who are in Stage IV of their renal disease and are already on medicare.

Bundling

The bill revises requirements for payments for renal dialysis services and directs the implementation of a bundled payment system under which a single payment is made to a service provider or a renal dialysis facility for renal dialysis services, including labs and certain medications. The bill requires regular and public reporting to Congress on the implementation of the ESRD bundling payment system and quality initiative, focused on quality measures of patient care including vascular access, anemia management, iron management, bone and mineral metabolism, and patient satisfaction.

One of the major provisions of the new law side-stepped a 10.6% planned cut in Medicare payments to physicians. This cut was to have taken effect on July 1, 2008, which would likely have resulted in fewer Medicare patients having access to care. Instead, physicians will now

> receive a 1.1% increase for 2009. It was exciting to be part of this

advocacy initiative. We should celebrate the importance of patient advocacy and the opportunities to speak up and speak out on issues people living with CKD face every day. If you talked with your Congressman, sent a letter or an email, or made a phone call to their office through this process, you have helped create history-making legislation that will impact kidney patients for years to come.

And if you didn't, it's never too late to let your voice be heard for kidney patients. Follow the activist priorities on our web pages under "Advocacy" at RSNhope.org and join our weKAN group of kidney patient activists. Who knows, you could find yourself glued to C-SPAN one day! 🗠



Diagnosed with kidney disease in 2004, Kathe LeBeau began home hemodialysis in April of 2007, and is presently on the kidney transplant waiting list. 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 with her husband of 11 years, Loren Fadding.

What do you wish your family and friends understood about kidney disease?

- I wish they would understand • that the exhaustion isn't just physical, it's mental too.
- That I can't have cheese on • my hamburgers!!!... How many times do I have to say it?
- I think sometimes people forget that just because I have CKD (chronic kidney disease), doesn't mean I can't still go out and have fun sometimes. We are not dying!
- I was so SICK of hearing, "So when is your transplant???" I remember when my brotherin-law asked I said, "Are you **VOLUNTEERING?**"
- I wish they would realize that • I can still function and be a mom, I just need more breaks than I used to...
- I would like my family to understand the seriousness of the disease even though I have had a transplant. I am not cured and they think I am.
- I wish my family could understand how lonely it is.

(Excerpted from a recent forum discussion on ihatedialysis.com. Posts used with permission from forum members. Submitted by Karol Franks, administrator, ihatedialysis.com)



You'd think I'd be used to it by now, wouldn't you? The heads turning, the funny looks, the whispers. I know what they're thinking, what they're wondering. It's the very reason

I used to never do it in public. I would wait until I was at home before I would do it. Of course, waiting caused me a lot of trouble.

Just what is it that I'm doing in public, you're wondering? I'm

managing my diabetes, including checking blood sugars and taking insulin injections. It's not a big deal to me any longer, but the number one question most people ask me when I'm doing this is, "Are you shooting up?"

When you pull out needles from your little black kit, people are fascinated. I think they also want to make sure you're not going to come after them with the needles! Managing diabetes isn't always easy, but it is necessary for optimal health.

I've been a Type I diabetic for thirty-five years and I've learned through the years that the number one thing I need to do is to take care of myself—no matter what's happening or who's looking.

Because I used to worry about what people would think if they saw me taking an injection, I would

> wait until I got home. But by then, my blood glucose would be 300 or higher. A normal blood sugar ranges from 80-120.

I had to make some changes and I knew it. If I kept doing it this way, I knew I'd have a lot

of complications that were my own doing. I had to swallow my pride, confess that I wasn't as healthy as everyone else, and that I needed to do some extra things to be as healthy as I could while living with a chronic illness.

The first time I decided to check my glucose and take my insulin in public I was at a restaurant. I chose an area that was private, where not too many people were sitting. Almost as soon as I sat down, a large family came in and chose the table across from me. "Oh great," I thought. I was nervous because I didn't want to be turned in for taking drugs (that's another story). Knowing what I had to do, I pulled out my kit anyway and went through the whole process while the entire family watched and whispered to each other.

I'll never forget what happened next. When the family left, the mother and one of the children walked over to my table. The mother reached for my hand and said to me, "Thank you for checking your blood glucose and taking your insulin in public. This is my daughter, Amy, who is four years old and she is a diabetic too. But she doesn't want anyone to know. She doesn't want to take her shots in public. When she saw you do it, she said she could do it, too. Thank you for helping her see that she needs to take care of herself."

Managing diabetes comes in many disguises, like the incident above. I've learned in taking care of myself that sometimes I'm teaching others to take care of themselves too. May the head turning, funny looks, and whispers continue!



Dawn Dungan is a kidney transplant recipient. Her 20 years of experience with kidney disease influences her work as RSN's patient activist coordinator for

weKAN. She has a degree in English and does freelance writing. As a PEPP speaker, she focuses on kidney disease, diabetes, blindness, and death/dying. She lives in Billings, MT.

Did you hear the one about the hospital that banned the wearing of Crocs shoes?

According to the American Free Press, hospitals in Vienna, Austria have forbidden everyone from wearing these popular shoes because they "could interfere with the proper functioning of precision electronic equipment, or even cause explosions." Strangely, there have been no reported problems of the shoes causing harm to anyone.

The hospitals state they are taking a "necessary preventive measure." Tests have apparently shown that Crocs are not antistatic, and in operating rooms, dialysis facilities, intensive care units and other sensitive areas, people must wear antistatic clothing.

It sounds plausible... or is it a Croc?

Swept Away by a Tornado: Lori Hartwell's Vision

Continued from page 1

she was being asked just to tell her story and at times found her clients were more interested in her story than the product. As a result, she has spoken all over the country for the kidney community as a motivational speaker and has authored "Chronically Happy: Joyful Living in Spite of Chronic Illness."

As she said, "At some point I realized I had a choice—to continue with my communications company and keep writing or to leave a different legacy by focusing on developing the Renal Support Network (RSN)."

RSN is now celebrating its 15th Anniversary. Lori's strong vision has guided RSN, its staff and constituents, and the messages she brought 15 years ago ring just as true today: One friend can make a difference: An illness is too demanding when you don't have hope; Instilling health, happiness and hope through education, advocacy, and awareness... one person at a time.

She remembers, though, "There were no expectations for patients, that we could be productive, could help others, or had talents and intellect. I just knew that it's impossible to feel unhappy if you feel appreciated. I wanted to help other patients learn what I knew from my experience."

Her thoughts and memories of the first years are filled with words like "tools," "resources," "confidence," which she knew were necessary to take people with

Lori celebrates the third anniversary of her third transplant, the same year she started RSN.



CKD to the first level of leadership in their own health care. All RSN programs are designed to bring out the best in patients, making them part of the process and helping them to understand the purpose.

Lori felt that the key to creating community and alleviating loneliness was in "patients helping patients," but where was the structure to enable that most

healing of activities? Drawing on her experience as a communicator, and knowing her own needs as a patient, Lori was ready to share what she knew. "I think RSN continually enlarges the canvas because as patients learn to

> advocate for themselves. they advocate for the larger community."

Asked about her future vision she said. "I see a future with many more 'Loris,' people who understand the RSN vision of what one-on-one can do, what a true network can accomplish. It's hard work, takes time and dedication, and people have to have the stamina and drive to continue it." She continues, "Over the next vears, we have to nurture an environment of acceptance and understanding with tools, resources and confidencebuilding to get through the emotions of an illness. You can't help another if you are not ready to understand and accept your illness."

Lori is in good health and she says, "There are always little tornadoes that enter my life, but with heart, brain, and courage you face what has to be done, have the wisdom to know which battles to fight and what you need. Then you get to that sense of comfort that is Kansas and home. I think Kansas

is making the most of the things you've learned and not letting talents and gifts go unexplored and shared with the world. That's what RSN is here for."



Heidi Lesemann is the program marketing manager for the Renal Support Network. She has a passion for playing the piano and loves to prepare gourmet foods for friends, family, and co-workers.





Regional Patient Meetings began in Southern California as local educational meetings. Organized by patient leaders within their local communities, the meetings are now held across the country to inform, educate, and enlighten patients and family members.

Lori Hartwell had an idea to hold a prom just for teens with chronic kidney disease. The first RSN Renal Teen Prom was held January 13, 2000, and it has been going strong for nine years. Next year, RSN will celebrate its 10th Renal Teen Prom!

FOUNDED IN 1993

Baile & Boogie

"Prom"

e Dame High School herman Oaks, CA

1day, January 16, 2000 5:00 - 10:00pm

903

Renal Support Network with hite

LORI RSN

DIRECTORY The Renal Support Network published its first Directory in 1993. The Directory contained the phone numbers of willing patients and family members who could give strength and hope to fel-low patients in the kidney community.

In 2002 Lori Hartwell published her book, "Chronically Happy: Joyful Living in Spite of Chronic Illness," an upbeat, motivational book that helps people living with chronic illness create joyful, fulfilling lives.



KidneyTimes was launched in 2007 as an online publication for kidneyrelated updates, patient profiles, and important health topics. It is also the home of the annual Essay Contest.

The PEPP Patient-Speaker Program, initiated in 2006, sends patient speakers nationwide to educate their peers and provide the patient's perspective to healthcare professionals. Below, Shari Gilford gives a presentation during the annual PEPP speaker training.

RSI

Kidneyspace.com

RSN's most recent child is the fastgrowing KidneySpace, an exciting online dialogue and message board that connects kidney patients to share their experience and stories. It includes a live chat support group on Tuesdays and Thursdays.

Renal Support Network

The HOPEline was born in 2007 to provide patient-to-patient encouragement and support by offering experience, strength and hope from one person who has lived successfully with CKD to another. Call (800) 579-1970, available M-F 10am-8pm PT. Sandra Pollock (left) and Lorraine Edmond practice their listening techniques during HOPEline

KidneyTalk is a biweekly podcast that began in June 2006. KidneyTalk emphasizes the hopeful side of living a full and active life despite kidney disease, blending humor and guest interviews with motivation and education. Co-hosts Lori Hartwell and Stephen Furst have interviewed an array of healthcare professionals and patients on the half-hour show.

Created in 2004, weKAN provides patient activists from across the country with tools needed to become actively involved in the medical, regulatory, and legislative decisions affecting their lives as patients. Once a year, members make their way to Washington, DC. Pictured, Montana Senators Jon Tester and Max Baucus bookend weKAN advocates Dawn Dungan, Sharon Pahlka and Diana Headlee-Bell.

Live & Give, the quarterly newsletter of RSN, is written and published mostly by patients to educate, inform and inspire fellow patients, family members and healthcare professionals.

& Give

Coming soon! "Somewhere Over the Rainbow" The 10th Annual RSN Renal Teen Prom January 18, 2009

This year, RSN and about 350 guests will celebrate the 10th Anniversary of the RSN Renal Teen Prom, a nationally known event. There are limo rides, glamour photos, a DJ, celebrities, appetizers and dinner all held in a dazzling setting. Free prom dresses are available in advance of the prom, and transportation to the prom can be arranged. The theme is "Somewhere Over the Rainbow" and the Prom will be held Saturday, January 18, 2009 in Sherman Oaks, CA (Los Angeles).

To make sure you receive an invitation, write RSN at info@rsnhope.org, subject line: Prom, and give us your name, address, phone, and email (if you have one). Or check the website rsnhope.org. You don't want to miss this one!

Dialysis clinics may request as many invitations as they have teens. The age limits are from 14 to 24.



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 quarterly newsletter for patients-informs, inspires, and educates patients, family members, and healthcare professionals.

PEPP: Patients Educating Patients & Professionals

PEPP patient-speakers are trained to give educational presentations about kidney-related issues to patients and professionals. To learn about the presentations offered or to schedule a PEPP speaker for a meeting of patients or professionals, go to RSNhope.org and click on Programs, then PEPP.



KidneySpace: Live Chat

Introducing Flash Chat on KidneySpace. Live chat for members to connect in real time with other members.

Join the online support group every Tuesday and Thursday night. Chat with fellow patients, caregivers, friends, and family members of CKD, LIVE!

See KidneySpace.com for schedule

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 both in Southern California and the Washington, DC, area for young kidney patients. Open to teens ages 14 to 24 from throughout the United States.



HOPEline

A toll-free call-in line offering patient-to-patient encouragement and support from operators who have lived successfully with chronic kidney disease. Call 800-579-1970 Monday - Friday, 10:00 a.m. - 8:00 p.m. (Pacific Time).

Regional Patient Lifestyle Meetings

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



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."

KidneySpace

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

For more information about RSN and **RSN's programs, visit our website:**



Medication Safety—Get It RIGHT!

by Denise Eilers, RN, BSN

Last November, the accidental overdose of Dennis Quaid's twins was major news. More recently, contaminated heparin and its recall left us wondering about the safety of our drugs.

Medication mistakes can happen, but minimizing those errors is crucial to your good health. There are many commonsense measures you can take to be safe. Every patient should become familiar with the Six Rights of Medication Administration: the **RIGHT PERSON** must receive the **RIGHT MEDICATION** in the **RIGHT DOSE** at the **RIGHT TIME** in the RIGHT WAY with the RIGHT DOCUMENTATION.

Right Person

Make sure you always receive your own medications. When picking up prescriptions, verify that you receive only those prescribed for vou.

Never share medication. Having the same symptoms doesn't necessarily indicate the same problem. No two people are alike, and their health problems are likewise unique.

Right Medication

Never substitute one drug for another simply because both are used to treat the same condition. With a new medication, read the product information and the label carefully; they explain what the

medication is for and it's possible side effects. Keep medication in the original container and never mix pills together.

Know the name and dosage of each drug and why Having the same symptoms you're taking it. It doesn't necessarily indicate isn't enough to just the same problem. say, "Well, I take the little round yellow pill twice a day and the white pain pill when I need it." When you're hospitalized, ask the name of each medication the nurses bring you and find out why you're getting it—each and every time.

Never take medication in the dark; turn on a light so you don't grab the wrong bottle. If the printing on a label isn't clear, don't guess-confirm what it is with your pharmacist first. If the lettering is too small to read, ask for larger print. Labels include a detailed description of the medication and any identifying numbers and letters stamped on the pills. Use this safeguard!

If possible, fill all your prescriptions at one pharmacy. That way, the pharmacist can check for possible harmful drug/ drug and drug/food interactions. Tell every healthcare provider about every medication you take, including over-the-counter drugs, herbal remedies, vitamins, and

How can your everyday shopping benefit **Renal Support Network?**



At www.iGive.com/RSN, you can buy everyday items at over 650 stores at the Mall at iGive.com, like Barnes & Noble, Lands' End, Best Buy, and Neiman Marcus. It's FREE, no invisible costs or tricky obligations. A percentage of each purchase is donated to the Renal Support Network.

Join now at www.iGive.com/RSN Information is subject to change. Visit www.iGive.com for current details. © iGive.com Holdings, LLC nutritional supplements. Alert providers to any allergies you have to foods, drugs, or dyes used in medical tests.

Right Dose

You may have heard, "If a little is good, a lot is better." Nothing could be farther from the truth. The right dose

means taking the correct amount of any medication. When you're hospitalized, check the number of pills you're given. If you take one pill at home and a nurse gives you two, ask why.

Right Time (and Frequency)

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Take medication at the right time and as often as directed. Certain drugs are given at a specific time of day or should be taken before or after meals. Some must not be taken together because of possible interactions. Check with your physician or pharmacist to be sure you're taking your medications correctly.

Don't stop taking a medication just because your symptoms subside. For a condition to resolve completely, you need to take medication for the duration prescribed. There are also certain medications that shouldn't be discontinued "cold turkey."

It's easy to miss a dose. Use a watch or cell phone alarm, or a "pop-up" message on your computer as a reminder. More sophisticated reminder systems can be set to alarm at the correct time and have a "lockout" feature to prevent an accidental overdose. Find out what do to if you miss a dose. It's usually unwise to take it with the next dose.

Continued on page 11

"The One Hour Activist"

Reviewed by Julie Glennon "THE ONE HOUR ACTIVIST - THE 15 MOST POWERFUL ACTIONS YOU CAN TAKE TO FIGHT FOR THE ISSUES AND CANDIDATES YOU CARE ABOUT"

By Christopher Kush JOSSEY-BASS A Wiley Imprint 211 pages Available at Amazon.com and other stores

Some of us have been touched by an issue that has dramatically affected our lives, like an illness. This illness has changed who we are and how we live. Because of this change we become passionate about getting involved—helping ourselves and others. We learn through experiences that laws do not always benefit patients and things need to change. Because of this, advocacy becomes our goal.

"The One Hour Activist" by Christopher Kush, to me, is the ABC's of advocating. If you have never contemplated getting involved with your legislators, this book will take you through the important steps of becoming an effective advocate for your cause including letter writing, phone calls, actual legislative meetings, and many other grassroots actions that will help you be a persuasive voice.

Kush does a wonderful job of keeping things somewhat simple. Throughout the book he includes helpful one hour rules as well as advocating dos and don'ts. An especially helpful rule is to keep an up-to-date list of your representatives at every level of government and how to contact them. In that way, you are always ready to communicate with the people who have the authority and the incentive to act on your behalf.

As for a don't—never send a "Robot" letter or an "electronic petition." Rather, make your letter personal—put a face on your issue. Explaining to your legislator how your issue will play out in the real world is so important. However, where you live is probably the most important thing to your legislator. That is why getting involved locally is very valuable. Sharing our story and building relationships with our legislators is crucial. We all have a unique story to share. Legislators can always read statistics, so our job is to grab their attention—draw them in and make them sit up and listen and hopefully take action to improve our cause.

So, if there is an issue that is important to you, get involved. Legislators are real people just like you and me. They want to make their constituents happy. Don't stay quiet, make a phone call or write a letter—share your thoughts and advocate for change for yourself and for those that do not have a voice. \bigcirc



Julie Glennon received a successful kidney transplant in 1999 after being diagnosed with both lupus and chronic kidney disease in 1988. She

keeps active by volunteering with The Kidney Association of South Florida. She is also a weKAN patient activist and HOPEline operator with the Renal Support Network. Julie and her husband live in Florida.

Support from someone who has been there is only a phone call away



Patients helping patients

Monday – Friday 10:00 am – 8:00 pm (Pacific Time)

For kidney patients, their families, and concerned health care providers.

Time... Just a Little More Time... Please Continued from page 12

that is gaining interest—the interest for us that helps us to stay alive! Let dialysis work for you. Work with it! We can't be our own worst enemies. We are soldiers in the battle for life. Who knows? You could get blessed with a kidney or restored kidney function. No one knows if that can happen. But, one thing is for sure, shortening and skipping treatments may have a negative impact on your selection for transplantation.

So, please, don't make withdrawals from your CD ("Course of Dialysis"). Instead, allow it to gain interest for you. We can do dialysis and we can do it right. We didn't get this far by giving up. Don't cheat yourself. You deserve all you can give. Don't give up on Numero Uno. Stay in the chair for your entire treatment and come on your designated days. What do you have to lose? Nothing but toxins and fluid. Isn't that enough? Think about it. And, then act upon it. It's a small price to pay for LIFE! Thank you for your time!



Celeste Compton, now 68, retired from her position as Office Manager at Mount Sinai Hospital Medical Center of Chicago in 2000 after a diagnosis of kidney failure and subsequent kidney transplant. Since the rejection of her kidney she has been on dialysis for three years, enjoying an excellent quality of life. She is marwith five children, seven grandchildren, and one great-grandchild.

Give the gift of health, happiness & hope!

| 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. Name Address | 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: |
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| CityStateZip | Please check all that apply: |
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| Phone | Family Member Administrator |
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often a consideration. However,

it's wise to jot down the time "as

needed" prescriptions are taken and

to keep a record of your daily

RSNhope.org Visit our website:

Medication Safety—Get it Right!

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Right Way

Getting medication the right way is critical, especially in

healthcare facilities. Medications can be given orally, injected into subcutaneous tissue or muscle, or infused into a vein. Most fall into only one or two of

regimen. Keep a list of medications, updating it each time there's any change. Remember to take this, as well as a health history, along when you travel.

The "File of Life," a form on which you can list health history, allergies, emergency contact information, and medications, is available online (www.folife.org). One copy, inserted into a bright red plastic magnetic envelope, can be placed on the refrigerator. A smaller version fits easily into a wallet. Emergency personnel are trained to look for both. Get It Right

In the real world, mistakes happen. Nobody's perfect. Getting it right takes informed and knowledgeable patients. After all, it's a matter of your health and safety. Could anything be more important?



Denise Eilers is both a healthcare professional and family member. Her husband Jerry was on traditional (three days per week) home hemodialysis from 1980

until his death in October 2004. Denise is a volunteer with Genesis VNA Hospice in Davenport, IA, where she resides. She also teaches nursing fundamentals at United Township Area Career Center in East Moline, IL.

these categories. When you receive any medication, ask questions to make sure you know what you're being given.

Right Documentation

At home, documentation isn't



1311 N. Maryland Ave. Glendale, CA 91207



In this issue of Live & Give... RSN Celebrates Its 15th Anniversary

To Your Health

Time... Just a Little More Time... Please

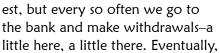
by Celeste Compton

How ironic that once we have to rely on dialysis to live we know how precious time is, but we often

don't want to spend more time on the dialysis machine! But it is more time on dialysis that allows us more time to live. What a contradiction. If you think about it, we only cheat ourselves when we skip or shorten our treatments. Of course, we

can justify the behavior: sometimes legitimately on occasion and other times we may just "not feel like it."

It's sort of like having some money in the bank that's drawing inter-



there will be no more. Try to think of your treatments like that. The dialysis treatments are deposits into our health bank. Similar to a CD (Certificate of Deposit), there should be no withdrawals. The penalty is the ultimate... our lives.

Let's be good to ourselves and let our bodies reap the benefits of the deposits into our health account that dialysis contributes. Why work against ourselves? Why fight the very process

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Patient Lifestyle Meetings October 19 (Sunday) Pittsburg, PA November 2 (Sunday) Albany, NY RSN Renal Teen Prom January 18, 2009 (Sunday) Sherman Oaks, CA 10th Anniversary Theme: Somewhere over the Rainbow Go to RSNhope.org to check the latest calendar listings, download a

meeting flyer, or register online.

RSN 2008 Regional

