PATIENTS HELPING PATIENTS
wellness & education
WEKAN
KIDNEY ADVOCACY NETWORK

A PROGRAM OF
RSN
Renal Support Network

Live & Give

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

Volume 2, Issue 3 • Fall/Winter 2006

Now...
More Pages!
More Great Articles!

Headline News

Open Enrollment for Medicare Part D

Updated Website Simplifies Process

Medicare has made enhancements to its website, www.medicare.gov, that will provide new help for people with Medicare prescription drug coverage who want to consider changing plans. In addition to 2007 plan-year information, updates to the Medicare Prescription Drug Plan Finder web tool include a cleaner look, increased usability, and reduced page scrolling. It also includes a Monthly Cost Estimator—a personalized chart illustrating 12 months of expected drug spending for each plan.

New features help users compare plans based on price and benefit structure, estimate how their monthly costs may vary over the course of the year, and print clear reports they can refer to later.

"Based on feedback we received from beneficiaries, we have added new features to help beneficiaries get the most out of their Medicare coverage options, build on the high beneficiary satisfaction rates and take advantage of the low costs we've been seeing so far,"

Continued on page 3

Legislative Update

Continue to Contact Your Lawmakers!

by Virna Elly, weKAN Patient Activist, PEPP Speaker

Despite heroic efforts on the part of the renal community, and in light of the recent mid-term elections, the Kidney Care Quality & Improvement Act (H.R. 1298, S. 635) will likely not be voted on in 2006.

Regardless, the need for kidney patients nationwide to reach out to federal and state legislators in order to inform and educate them about chronic kidney disease (CKD) remains vitally important.

Each person affected by CKD has a tremendous opportunity to garner support for laws that affect patients in a positive way. As we saw over the past two years, when patients speak, legislators listen!

To learn more about current legislation affecting kidney patients or how you can contact your legislator, and for more information about RSN's advocacy tools, please visit RSNhope.org and see the section on "Current Legislation."

Look Inside!

Goodness is the only investment that never fails.
– Henry David Thoreau

Lori's Lines

Personal Maintenance Agreement

by Lori Hartwell, RSN President

Recently I was exiting a long flight when I overheard a woman say to her spouse, “I have to go the restroom, my kidneys are killing me!” We all know that her *bladder* was killing her—figuratively speaking.

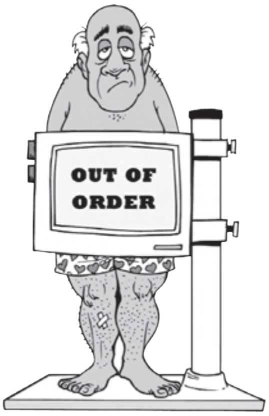
In today’s high-tech healthcare society, I am amazed at how little people know about their bodies and what makes them tick.

Limited awareness leaves people prone to developing serious health problems. The two leading causes of kidney disease are diabetes and high blood pressure. It is estimated that 20 million Americans have chronic kidney disease, which equates to 1 in 9 adults. There are so many people who have no idea that their bodies are in crisis.

During my 38 years of living with chronic kidney disease, I have tried to learn all that I possibly can about kidney disease and my overall well-being. It is important to learn about dialysis adequacy, your medications, vascular access, preventing infection, exercise, transplantation, understanding your lab values... etc. I’ve read everything I could find, I’ve asked questions, and I’ve put all that I learned into practice.

Today’s renal care professionals are in a time crunch. In order to provide optimal care, the renal care team must: meet with each patient, monitor the patient, complete a patient assessment, administer medication, answer questions, and educate the patient on his or her particular condition or care plan. These duties become easier to handle when patients do their part to learn more about how their body functions.

Unfortunately, people are often unaware that their bodies are malfunctioning until the problem has progressed. It’s sort of like owning a computer: Most people (including myself) do not become interested in how the computer works until it crashes. When this happens, we lug our computer off to the shop where the computer technician tells us our computer’s diagnosis in “mumbo-jumbo” computer language. But we don’t care why the computer crashed, we just want it fixed. Right? If we would just read the manual and pick up on a few maintenance tips, we could keep our computers on our desks where they are productive.



In this respect, computers are like the human body. We need to know how the human body works in order to prevent serious damage and costly repairs. If we see our doctor regularly, educate ourselves about how our body works, and pay attention to warning signs, we may be able to prevent a hospital stay and decrease our need for a healthcare professional’s time. If we take steps to maintain our health, we can take some of the pressure off the overburdened healthcare system.

I’m still learning! I owe a great deal of my well-being to the knowledge that I obtained early on. I encourage others to learn as much as they can about their own health so they too can live productive lives. Educating yourself about chronic kidney disease and how your body works could prove to be a priceless endeavor.

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

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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Visit our website:

RSNhope.org

All Kidney Teens and a Guest are Invited!

The Renal Support Network

Presents

The 8th Annual Teen Prom

MIDNIGHT AT THE OASIS

AN EVENING AMONG THE STARS

Sunday, January 14, 2007

6pm - 11pm

Location and Co-Host

Notre Dame High School

13645 Riverside Drive, Sherman Oaks, California

The RSN Renal Teen Prom is FREE for "kidney teens" ages 14 to 24 and one guest.
Registrations received by December 18, 2006, will be entered into a contest to win an iPod Nano!
Call RSN at (818) 543-0896 for more information and to request an invitation.

It's not too late to register!

No-Bake Peanut Butter Balls

By Nikki Gepner, RD

Makes 12 servings, approximately 36 balls
Prep Time: 15 minutes
Chill Time: 1 hour

Ingredients:

⅓ cup unsalted, unsweetened peanut butter
8-ounce package reduced fat cream cheese
1¼ cups graham cracker crumbs
¼ cup mini chocolate chips
1 teaspoon vanilla
½ cup shredded coconut

Directions

1. Using an electric mixer, mix all ingredients except coconut together until well blended.
2. Roll dough into one-inch balls.
3. Spread coconut evenly on a large plate. Roll cookies in the coconut to lightly coat the outside.
4. Refrigerate for at least one hour or until the cookies become firm.
5. Store in the refrigerator for up to one week. These cookies may also be frozen. To enjoy later, remove from freezer and let thaw.

Recipe courtesy of Northwest Kidney Centers, Seattle, Washington.

Nutrition Information

1 serving = 3 balls

Calories: 155	Carbohydrates: 13 g
Protein: 5 g	Sodium: 120 mg
Potassium: 113 mg	Phosphorus: 70 mg

Medicare Part D

Continued from page 1

reports former CMS Administrator Mark B. McClellan, M.D., Ph.D.

The Medicare Prescription Drug Plan Finder allows users to compare their current drug plan to other coverage options for 2007 that may be a good fit. People using the tool will find plans offering lower premiums, price discounts that are larger on average than those available in 2006, coverage of more drugs, and less utilization management. Users will also find more plans offering coverage in the gap for both generics and brand-name drugs.

"If you are satisfied with your current plan and want to stay with it, you don't need to take any further action," Dr. McClellan said. "If you want to consider other options, we have enhanced the tools that make it easier to get the coverage that's right for you."

Open enrollment begins on November 15th and ends on December 31st. During this time, beneficiaries can change their current plan without penalty.

People without web access can get the benefits of all the online personalized plan comparison tools by calling 1-800 MEDICARE (1-800-633-4227), visiting their local State Health Insurance Assistance Program office for free personalized counseling, or attending one of the thousands of local enrollment events taking place across the country from now through December.

Your charitable contributions are the building blocks that support RSN in its efforts to offer many programs that connect and educate those affected by chronic kidney disease.

Thank you for your help!

Perceptions

Images in a House of Mirrors

by Denise Eilers

Growing up in Springfield, the capital of Illinois, it was summer's annual rite of passage—days spent at the state fair. Each visit began and ended at "Happy Hollow," the valley of endless rides, games, and sideshows. The less daring among us always headed straight for the House of Mirrors. There, we took delight in trying to negotiate the endless maze. At every turn, distorted body images, reflected in seemingly miles of mirrors, sent us into girlish fits of side-aching giggles.

In the world of kidney disease and dialysis, however, distorted perceptions are no laughing matter.

From 1980 until 2004, I was care partner to my husband Jerry as he very successfully negotiated that maze of kidney disease and traditional home hemodialysis (five hours, three days per week). An upbeat, hardworking and healthy-looking family man, he was an ideal "poster boy" for dialysis.

Initially, though, friends and family saw things a bit differently. About a year after Jerry began dialysis, we ran into a relative on one of our visits back to Springfield. Obviously flustered, she stammered, "You, uh, uh… you're... here!" Laughing, Jerry patted his body and, purposely misinterpreting what was said, replied, "Well, gosh, you're right! I guess I'm not still in Iowa."

The misconceptions about dialysis can be repetitive, frustrating, and nowhere near reality. So what can we, as patients or family members, do to counter these distorted images? Think **E**ducation, **A**ttitude, **C**ommunication, **H**umor! **"EACH"** of us can reflect an image that will help portray dialysis in a more positive light.

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

Education

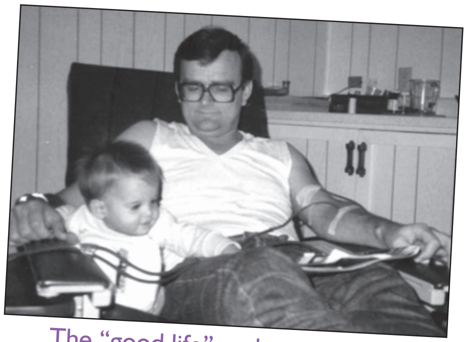
Many of the mistaken ideas surrounding kidney disease are the result of false information or no information. Education is the key! If your unit allows, invite a family member or friend to accompany you to dialysis. If you are on home dialysis, turn treatment night into family time or party night. Jerry and I did, often inviting friends to stop by for pizza and a movie.

> Even as teenagers, Marty's friends would always run downstairs, say hi, and visit with Jerry when he was on the machine. Dialysis didn't faze them—it was just a normal part of life at our house.

Volunteer to speak to a local high school health or science class or at a community college. Nursing and allied health programs would love to have a "real live patient" tell them about the experience of being on dialysis or receiving a transplant. Additionally, keep your legislators at the national and state levels abreast of your concerns.

Attitude

We may not be able to control every aspect of kidney disease, but we can control our attitude. The "Oh, woe is me!" stance evokes a pity we don't want rather than the understanding we crave. The way other people see a patient or spouse is a direct reflection of how we see ourselves.



The "good life" on home hemo: Jerry with his son Marty in 1983. Marty often sat in the dialysis chair with his dad and watched TV, played games, or just cuddled up and took a nap.

Jerry and I heard endlessly, "How do you do it… with work, family and all?" Or, "You both seem so happy!" But Jerry's positive attitude was no public façade; rather, it was an outward expression of the way he really felt. "Everyone has problems," he would tell them. "Kidney disease is mine, but it's not all of me, not by a long shot!" Then he would look at me and tease, "I'm taking you along for the ride!"

Communication

Talk, and then talk some more to anyone interested and willing to listen. If others can climb onto their soapbox, so can we. In the public forum, be attuned to the "negative spin" that the media often puts on chronic disease. Speak up and correct it! Write a letter to the editor about that newspaper story or television show that got it wrong.

Humor

Humor isn't about telling jokes. Humor is a life-affirming outlook of enjoyment and fun even in the midst of difficulty. People were often amazed when they learned that my husband—the dance floor diehard—was on dialysis. He would wink at them and comment, "It's my medications, you know, that give me my energy. But they sure haven't helped my golf game." Humor relaxes people, making them eager to hear more.

"EACH" of us—as patient, care partner, or healthcare professional—must take the initiative to change perceptions, to let the outside world know that kidney disease can co-exist with a full and productive life. Only then will the distorted images become clear. ❧

A Child, A Transplant—No Regrets!

by Debby Kate Stahl Ramsey

“Mommy, your dialysis nurse is on the phone,” my four-year-old son, Kevin, gently said as I was resting. I told my little secretary to let Mike, my nurse, know that I would return his phone call when I felt better. Kevin informed me that “she” (I knew then it wasn’t Mike) was from Northwestern Hospital and really needed to talk to me. Was this the call I had been waiting two and a half years for? Was this the call that might change my life forever? Anxiously I picked up the receiver and said, “Hello?”

> When I see a mountain in front of me, I’ll look for the tunnel through it.

Next thing I knew I was waiting to go into the operating room, lying on a gurney pondering the past and anxiously awaiting the future.

The past entailed discovering at a very early age that I had a type of kidney disease that could be controlled to some extent by regulating my blood pressure and watching my diet. At age 12 I was told that I would never be able to have children. At age 14 my disease was finally given a name—chronic glomerulonephritis.

My doctor told me that this condition would progressively worsen, leading to dialysis or a transplant. This news, as most everything in my life, was taken with the attitude of: *Oh! I see a mountain in front of me… I’ll look for the tunnel through it, the road around it, or the ski lift over it.*

Debby Kate Stahl Ramsey is a single mother of four who owns and operates her family feed business in Zion, Illinois. Since her kidney transplant in 1984 she considers every day a gift. She is the author of “A License to Follow One’s Dream,” featured in Chicken Soup for the Working Woman’s Soul.

Life for me went on as usual. I got married and landed my first “real” job in the Recreation Department at an institution for emotionally disturbed children. My blood pressure was okay, my kidney function was adequate, and I was finally insured!

And then the dizziness began. The nausea. The headaches. My new doctor had changed my medication for hypertension and I felt it wasn’t agreeing with my system. However, it was also at that point—and much to my surprise—that I suspected I might be pregnant! I took a home pregnancy test and was elated when it turned out to be positive.

I phoned the nephrologist’s office and told the nurse the happy news. Unfortunately, she didn’t get quite as excited as I had. She expressed great concern over the dangerous position I was in, even though I still had relatively good kidney function. Her anxiety frightened me regarding the safety of my baby and my own life. Still, I scheduled an appointment and tried to continue with my optimistic attitude.

When I met with my doctor, he *too* spoke to me with apprehensive overtones, and recommended I terminate the pregnancy immediately. I was uneasy, but not enough to go along with his suggestion. Instead, I changed doctors. Eight months later my little boy was born. He had a shaky start, but my miracle baby was that little four-year-old boy who first gave me the joyful news about my “Gift of Life.”

That was over 21 years ago.

Twenty-one years of living life to it’s fullest. Twenty-one years to pursue my dreams. I watched my son graduate from kindergarten, junior high, high school, and college. I became a foster parent with a total of 12 children entrusted to my care over the years. Two precious little ones—twin girls—I adopted, and now they are active teenagers. I didn’t need to be anxious about my future!

After all, there *is* life after transplantation. I have *no* regrets!

Adding PEPP to the kidney community!

Patients Educating Patients & Professionals

PEPP, a program of RSN, trains patient-speakers in how to share life-enhancement knowledge with professionals and fellow patients.

PEPP Presentations

Your Achy Breaky Heart:
What you need to know about secondary hyperparathyroidism
(for patients and family members)

Energize Yourself:
What you need to know about anemia
(for patients and family members)

Promoting Patient Participation in the Dialysis Setting
(for professionals)

To schedule a PEPP speaker, contact Lori Hartwell
(818) 244-9041 ◆ Lori@RSNhope.org.

The PEPP program is sponsored by an educational grant from Amgen.

> *The great thing in the world is not so much where we stand as in what direction we are moving.*
>
> - Oliver Wendell Holmes

Patient Lifestyle Meetings

Sponsored by the Renal Support Network

- Patients Meeting Patients
- Motivating and Educational
- Food and Fun
- Organized by Kidney Patients
- Held Throughout the United States

"Delightful!"

"I enjoyed the chance to meet and talk with other kidney patients."

"I was inspired to become more involved."

RSN-Sponsored Patient Meetings in 2006

May: Anaheim, CA
June: Tarzana, CA
July: Bakersfield, CA
August: Riverside, CA
August: Houston, TX
September: Salt Lake City, UT
October: Philadelphia, PA (National Meeting)
November: Denver, CO
December: Indianapolis, IN

"I was filled with hope for my future after seeing what other patients had overcome and what they were making of their lives."

All RSN-sponsored patient meetings are organized and led by kidney patients (clockwise from top):

Leigh Anne Tanzberger welcomes attendees to the meeting in Houston, TX.

Mandy Trolinger opens the meeting near Denver, CO.

Lori Hartwell, RSN President & Founder, gives a certificate of appreciation to Stephen Furst at the RSN National Patient Meeting in Philadelphia, PA.

Dawn Dungan (left), Chair of the RSN National Patient Meeting with Virna Elly, RSN Project Manager and a speaker at the meeting.

Right: At the National Patient Meeting in Philadelphia, PA, Bettie Hill demonstrates how she hooks up her cycler for peritoneal dialysis. She participated in a patient panel on different dialysis modalities.

Below: At the same meeting, Stephen Furst leads a team of patients in a fun game of "Kidney Outburst."

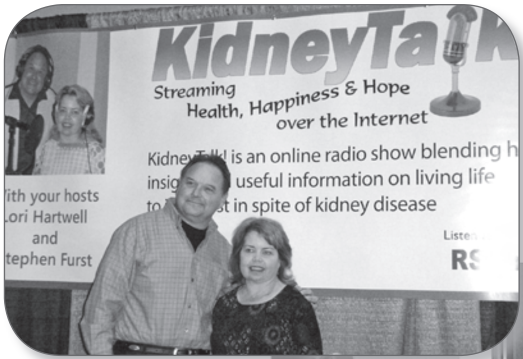
"Very informative speakers who really knew their stuff."

Right Top: Shari Gilford, PEPP speaker and kidney patient, explains the basics of secondary hyperparathyroidism.

Right Center: Life Coach and long-time kidney patient Sharon Pahlka mimics how someone feels before they coach themselves to victory.

Right Bottom: PEPP speaker Dawn Dungan shares her inspiring story with fellow patients at the meeting in Denver, CO.

"I would have compare the meeting to an automobile tune-up. We all need to be 'tuned up' once in a while so we can keep going a few more miles."



KidneyTalk is an online radio show blending h insig useful information on living life to t in spite of kidney disease

Left: Stephen Furst (left) and Lori Hartwell, co-hosts of *KidneyTalk*, pose beneath their photo.

Below: *KidneyTalk* interview with Bill Peckham (left) and Joyce Jackson—on site at the Northwest Kidney Center's Kidney Expo in Seattle, WA. (Aired Nov. 21st. Listen at RSNhope.org.)

"I liked the patient focus and emphasis on becoming your own advocate."

"Very positive."

"I liked learning from people who understand what I have gone through."

Photos at Left: At an RSN patient meeting, patients recieve goody bags full of literature and gifts, and meet other patients like themselves.

Top Left: Patient meeting held near Salt Lake City, UT.

Bottom Left: Patient meeting held in Bakersfield, CA.

More meetings coming in 2007!
Check RSNhope.org for details.

Perspectives

Laughter is Cheap Medicine

by Eddy Sakowicz, weKAN Patient Activist, PEPP Speaker

I dreamed my life was Camelot and my court was filled with laughter. I was only in my late 20's and having the time of my life. My "castle" was almost completed, with good grades and great jobs on the horizon.

Then the sky changed and a shadow fell. The wave of kidney failure came and washed away the walls. Who would have thought that my walls were made of sand? I wondered, who would I dance with at the ball? In the prime of my life, I ended up dancing the minuet with a machine rather than waltzing with a princess.

My friends stopped laughing. When they turned to look at me, they slowly backed away. It's as if I suddenly had become fragile, like I was made of glass. They thought this was no time for me to joke, but a time to grow up and be responsible. Months went by, and no laughter—only pills, doctors, and the harmonious beep-beep of the machines. I *felt* fragile, and worst of all, sick.

Finally the silence became deafening. I needed to hear "normal" people, so I decided to go to a party and live the laughter again. I got there and found friends outside smoking, so I started to give them a hard time. I sarcastically said to one of them, "You know, smoking rots your lungs?" He sarcastically returned with, "You know, nagging rots your kidneys?"

The night air became silent, and everyone's eyes fixed on me. Suddenly, from the center of my deepest sorrows came out the loudest belly laugh. Everyone then realized that it was okay, and they all began to laugh. I realized what it felt like to be alive, to once again laugh and release all that was hurting.

My friends finally understood that my first castle *was* made of sand, and that all we needed to do was start building again. Life began to regain its excitement, and I realized that at "pity parties" you never get good presents. That one good belly laugh made me feel human again.

Not only did I start laughing with my friends, I brought the laughter into my dialysis clinic, making it a happier, more revitalizing place to be. I watched how the laughter changed not only the patients but also the staff. It even trickled all the way to the doctors.

I thought I had developed a new technique! I was about to take a patent out on laughter until I realized that its health benefits had already been studied. I learned that laughter has been shown to lower blood pressure, reduce stress, and boost the immune system. Laughter is a good release of emotion, and it feels ten times better then crying. Doctors actually prescribe having a good time!

So watch a comedy, or go hang out with some friends and do something fun or silly! Allow laughter to come back into your life, and begin to rebuild your Camelot. Fill your life with as much laughter as it can possibly hold, and remember: "Always laugh when you can. It is cheap medicine." *–Lord Byron*

Eddy Sakowicz, now 28 years old, resides in Kentucky. He holds a masters degree in history and a bachelors degree in theatre. In the middle of getting his masters degree, he lost total kidney function, yet completed his degree. He participates in weKAN and PEPP, programs of RSN, and continues to smile while living with kidney disease.

RSN Report

KidneyTalk Recap

Online Radio Show the "Talk of the Town"

Since when has learning about kidney disease been fun? If you think the answer is "never," then you need to listen to *KidneyTalk*, the online radio talk show that made its debut this past June. Co-hosted by Lori Hartwell, RSN president, and Stephen Furst, a TV and movie actor/producer/director who recently began dialysis, *KidneyTalk* looks at the hopeful side of living a full life in spite of kidney disease. Each show blends humor, upbeat songs, and light-hearted "commercials" with motivation and education. The result? A half hour of inspiration!

KidneyTalk!™
Streaming
Health, Happiness & Hope
over the Internet

A new *KidneyTalk* show airs weekly to a listening audience that spans the United States. Guests have included Howie Mandel, host of the TV game show "Deal or No Deal"; Jodi Picoult, a best-selling novelist and author of "My Sister's Keeper"; Sally Satel, a New York Times Op-Ed writer and transplant recipient; and many "or-

KidneyTalk Shows Aired in 2006

November 21st: Creating a Successful Community Event
A patient and a nurse share how they are increasing kidney awareness in their community.

November 14th: Thanksgiving Helpful Eating Tips
A renal dietician shares eating tips and tasty recipes to make your festive meal renal friendly and enjoyable.

November 7th: It's a Hard Knock Life for Kidney Patients
Lori, Stephen, and a dialysis patient of 13 years talk about the pros and cons of dialysis, the emotions that come with dialysis, and the hope you can find when connecting with other kidney patients.

October 30th: Preparing for a Kidney Transplant
A transplant coordinator shares tips on how to prepare for a kidney transplant.

October 23rd: What Scares You about Kidney Disease
On this Halloween Special, Lori and Stephen get goofy and share Halloween stories, offer tips on renal-friendly Halloween treats, and talk about the sides of kidney disease they'd rather do without.

October 17th: How Low Can You Go?
The thought of "crashing" or "cramping" while on dialysis conjures up all kinds of uncomfortable feelings. Learn why low blood pressure happens and steps to prevent it.

October 10th: Education is Key to Living a Better Life with Kidney Disease
Knowledge is power. The more you know about CKD, the more confident you will be with the decisions you make about your care.

October 3rd: Don't Sweat the Kidney Stuff
A dialysis social worker and kidney patient for more than 25 years talks about the patience, support, knowledge, and hope necessary to adjust to life with a chronic illness.

September 26th: Organ Donation—Inspire Someone Today!
Tips are offered on encouraging people in your community to give the "gift of life."

September 19th: Coaching Yourself to Victory
A certified Life Coach and kidney patient for more than 32 years shares strategies for winning at the game of life.

September 12th: Gaining that Winning Smile
A dental hygienist and kidney transplant recipient discusses the relationship between healthy gums and a healthy life.

September 5th: Finding Alternative Solutions for Organ Donation—A Patient's Perspective
Sally Satel, MD—a New York Times Op-Ed writer and kidney transplant recipient—joins the debate on ways to increase organ donation.

August 29th: 100-Plus Years of Kidney Patient Experience
Three longtime kidney patient survivors have a fascinating conversation on living long and well in spite of kidney disease.

August 22nd: Spicing Up Your Renal Diet
A renal dietitian shares tasty tips on eating well while on a renal diet.

August 15th: Take-Home Dialysis
Two nephrologists talk about the convenience and clinical benefits of doing hemodialysis in the comfort of your home.

August 8th: Taking Dialysis on the Road
A dialysis travel specialist shares tips on traveling with dialysis in order to ensure an uneventful trip.

August 1st: Dialysis Success
Roanne Faith Dale has been on dialysis for more than 30 years and has learned the keys to achieving success with dialysis and life.

July 25th: For the Love of Pets
An "animal-assisted therapy" expert discusses the therapeutic benefits that pets can have in helping people with a chronic illness heal.

July 18th: Laughing Through the Illness
Comedian Howie Mandel, host of the TV game show "Deal or No Deal," discusses how humor can help you through a chronic illness.

July 11th: Choosing and Caring for Your Vascular Access
Two nephrology nurses discuss the advantages and disadvantages of the various types of hemodialysis accesses.

July 4th: Independent Living with Home Dialysis
A young woman talks about some of the fears she faced in taking dialysis home and how she overcame those fears.

June 27th: Traveling Around the Globe—Adventures of a Hemodialysis Patient
Bill Peckham has undergone hemodialysis since 1990 and has traveled all over the world, dialyzing in 19 countries on five continents.

June 20th: Peter Quaife—Rock Star
A behind-the-scenes look at the life of famous rock star Peter Quaife, who recently published a collection of cartoons, "The Lighter Side of Dialysis."

June 13th: Dating with Kidney Disease, and When Do You Tell?
A single woman on PD with two prior kidney transplants and a 50-something gentleman enjoying his first transplant reassure listeners that a diagnosis of CKD does not preclude dating and marriage.

June 6th: Jodi Picoult—Best-Selling Author
Jodi discusses her book "My Sister's Keeper," a novel about a girl brought into this world to be an exact donor match for her ailing sister. Jodi provides insight on the personal side of organ donation.

dinary" people, some of whom have lived with kidney disease for over 30 years. Traveling, home dialysis, organ donation, and dating are just a few of the lively topics that have been explored.

All previous *KidneyTalk* shows are archived on our website, RSNhope.org. You can also download podcasts, order a CD (mp3 format) of past shows, and sign up to receive e-mail alerts informing you when a new show is available.

Help us get the word out about *KidneyTalk:* Tell your fellow patients about *KidneyTalk*, encourage your dialysis clinic or transplant center to play *KidneyTalk* in the waiting room (a "How-To" flyer can be found on our website), or suggest that your clinic purchase a few mp3 players along with the *KidneyTalk* CD, Volume 1 (Volume 2 is on the way!) so that patients can listen during their dialysis treatment.

We would love to hear from you! If you have an idea for a show, call 866-379-HOPE (866-379-4673) or e-mail us at info@RSNhope.org.

Keep listening!

Love is a Tender Thing

by Carol James

I think I'm in love. It wasn't that long ago I was introduced to this wonderful friend who has been such an important part of my life. We just hit it off from the very beginning, and now I don't think I could survive without him.

I always thought I'd fall for "tall, dark, and handsome." But here I am with short, stocky, and rather on the plain side. I have a heck of a time getting him to dress up—his favorite color is gray, which he wears all year long. We go round and round about this "distinguished look," but he's terribly stubborn about his attire. It certainly doesn't make him stand out in a crowd, that's for sure!

Speaking of crowds, he's rather shy and very introverted. He definitely prefers a few close friends over large groups. Although his circle of friends is small, they all seem to value their relationship with him and speak very highly of him.

"Baxter" (as I like to call him) is not difficult to please. He's always on a diet, so requires very little time in the kitchen. In fact, he doesn't care for my cooking at all, which pleases me just fine. I've done enough of that in my lifetime!

He would rather just spend time with me. We've gotten so close over these past few months, I can honestly say we share our deepest secrets. There isn't much he doesn't know about me by now. I don't ask him much about the other people in his life—I figure our time together is more important than that.

Like many men, he does have his moods and becomes very impatient when things don't work right. When he's on the job, he expects people to run and jump whenever he shouts. I'm not so sure we would have such a good relationship if I were working for him. He can be very demanding at times.

One of the things I like best about Baxter is that I can remain independent and still be my own self. He's there for me when I need him, but if we're not together every day that's just fine with him. Sometimes he doesn't see me for days, yet he's still as friendly as always when we're together.

On my first anniversary with Baxter, I felt it called for something special. I dressed up in my fanciest dancing dress, bought a bouquet of flowers, and wrote my thoughts in a beautiful anniversary card. When my friends read the card I'd written to my wonderful companion they got choked up. They realized how special Baxter had become to me, even though they had barely paid him much attention before then.

Yes, I'll have to admit I'm a lucky lady. Not everyone has a Baxter Model 1550* in their lives. He's my confidant, my friend, my "significant other," my kidney dialysis machine—the reason I live. ☙

(*Note: The Baxter Model 1550 hemodialysis machine is an earlier model.)

Carol James inherited polycystic kidney disease (PKD) and started dialysis in 1994. After a failed kidney transplant and many years on dialysis, she recently received a second transplant. Her continuous employment at a boat dealership in California has afforded her the ability to maintain a healthy lifestyle and own a home.

Voyage By Sea

Continued from page 12

gales, and just missed a hurricane or two. He crossed the Pacific, Indian, and Atlantic Oceans, rounded the Cape of Good Hope, traversed the Panama Canal, and stopped in Hawaii for a few days of rest.

An excited group gathered at the dock in San Diego, CA, to welcome the Captain home, including many who had sent him off on May 5, 2006. In attendance were Lien's wife and family, his doctors from the Mayo Clinic in Rochester, MN, along with local donor families and organ recipients.

Ardell posted a log on www.lifesharing.org about his travels. He emphasizes, "Awareness is so important to end needless deaths on the waiting list. Unfortunately, some families don't say 'Yes' to donation because they don't know what their loved one wanted. It is so important to register beforehand for your family's sake and to ensure your wishes are followed."

Ardell is an inspiration to us all… there *is* life post-transplant! ☙

Amy Chester is a caregiver to her father, who is currently awaiting a kidney/liver transplant. Amy is a University of California, San Diego (UCSD) alumna and a local REALTOR® in neighboring Rancho Santa Fe. She fills her free time with writing, giving donor awareness presentations to children under age 12, and helping to organize blood drives.

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To Your Health

Hair Today, Gone Tomorrow

by Shari Gilford, weKAN Patient Activist, PEPP Speaker

I was losing it—my hair, that is. My husband tried to convince me that baldness is usually a sign of brilliance, dignity, and wit. After all, look at him! I agreed that he *certainly* merited such a description. As for me, I was just plain discouraged. I didn't feel very brilliant when I couldn't figure out why this was happening to me.

Excessive hair loss in kidney patients sometimes goes undiagnosed and can occur in both men and women. If you notice that you are losing more hair than normal, you need to talk to your doctor about it.

The first time I lost a lot of hair, I had been in the hospital for a few weeks battling a bad infection. My hair loss seemed secondary compared to the severity of my infection, so no one paid much attention to it. To me, however, it was devastating, since my hair had always been long and thick.

I had not eaten well during my illness, and lab tests finally showed an iron deficiency. Once I began IV iron therapy, my hair loss slowed down significantly. Many dialysis patients are deficient in iron, so ask your doctor about your iron levels. Eating a healthful diet that contains adequate protein and nutrients is also essential for hair growth.

Endocrine conditions such as uncontrolled diabetes or thyroid problems can also cause hair loss. And if you lose hair after receiving an organ transplant, it may be a side effect of the immunosuppressants you are taking. Your hair also may be more likely to fall out when you go through a period of severe stress or after you've had surgery.

Your doctor may not think about the relationship of these factors to hair loss unless you ask about it specifically. If you're losing excess hair, be persistent in finding answers because there usually is a very real cause that can be treated.

Once the reason for your hair loss is addressed, your hair should begin to grow back. It may take a few months, so be patient and treat your hair well. Don't wash it more than once a day, lather and dry it gently, try to avoid chemical treatments such as permanents or coloring, use a low heat setting on your blow dryer (or let your hair air-dry), and style it when it is only damp, not dripping wet.

And just between you and me, you can be brilliant, dignified, and witty even *with* a full head of hair!

Shari began dialysis in 1977 at age 11, and received her third kidney transplant in March 2006. Previously, she self-administered her own hemodialysis treatments both in-center and at home (nocturnal home hemodialysis). She designs RSN's graphic materials, and is the managing editor for Live & Give, RSN's quarterly newsletter.

RSN Renal Support Network
Service to those affected by chronic kidney disease

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In this issue of Live & Give...

Patients Meeting Patients: Photo Spread

Over the Top

Voyage By Sea

A Transplant Adventure

by Amy Chester

Ardell Lien returned to San Diego on October 19, 2006, after a 17½-month journey around the world to spread awareness about organ donation. That alone would be a fantastic feat for a 71-year-old!

What is truly remarkable is that Ardell is the first heart and kidney transplant recipient to nautically solo circumnavigate the world. This Minnesotan traveled the 31,310 miles in a small 27-foot sailboat!

Ardell started planning his trip while awaiting his transplant. "He wanted to show the world that a healthy, active life is possible after organ transplant. He certainly has done that and inspired many people along the way," commented his wife Maureen. "Planning for his trip gave him hope—something to hold on to and look forward to while he was on the waiting list and then during recovery after surgery."

At each of the 19 ports where he docked to replenish supplies, Ardell spread awareness about organ donation, proving to the world that there *is* life post-transplant. He met many organ and tissue recipients and spoke with local media about the "Gift of Life," possible only with organ donation.

During his journey, Ardell survived tropical storms and wind

Continued on page 10

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Calendar

Regional Patient Meeting
Dec. 4 & 5, 2006 (Mon. & Tues.)
10 am–2 pm (includes lunch)
Indianapolis, IN

Annual Renal Teen Prom
Sunday, January 14, 2007
6 pm–11 pm
Sherman Oaks, CA

Stay Tuned...
Go to RSNhope.org to check the latest calendar listings. Click "Calendar" on the left navigation bar.

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