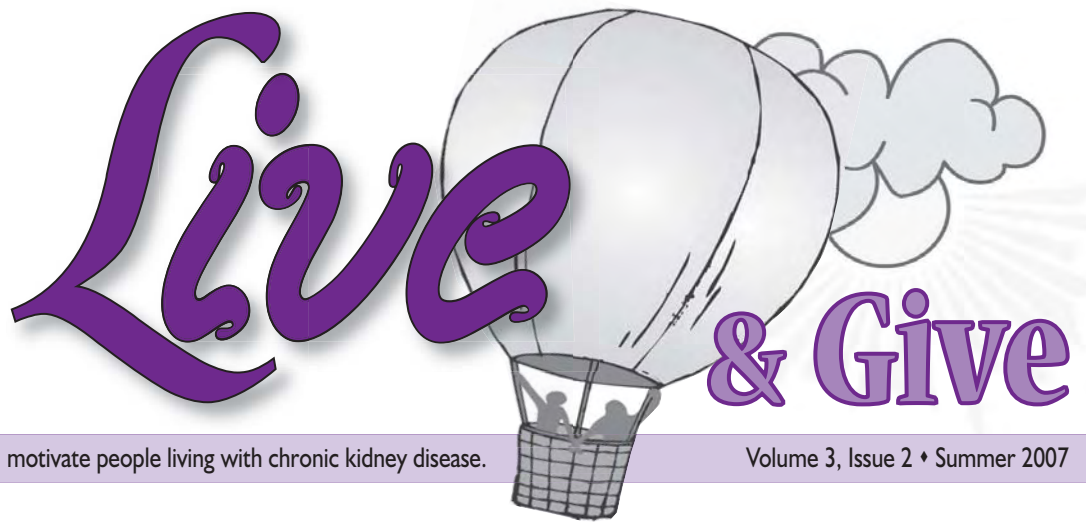




A PROGRAM OF
RSN

Renal Support Network



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

Volume 3, Issue 2 • Summer 2007

Headline News

Expanded Transplant Opportunity

by M. Jill McMaster, PEPP Speaker

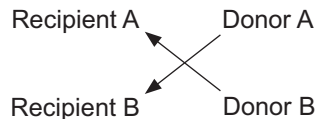
We've all heard it before from our friends on the waiting list. Maybe you've even said it yourself. "My (husband, wife, child, cousin, friend... pick one) volunteered to give me a kidney, but we weren't compatible."

That statement will soon be relegated to the history books by living donor paired kidney exchanges.

According to www.transplantliving.org, "A paired exchange donation consists of two kidney donor/recipient pairs whose blood types are not compatible. The two recipients trade donors so that each recipient can receive a kidney with

a compatible blood type. Once the evaluations of all donors and recipients are completed, the two kidney transplant operations are scheduled to occur simultaneously."

Living Donor Paired Kidney Exchange



In other words, if Donor A is not compatible with Recipient A, and Donor B is not compatible with Recipient B, then Donor A can be

matched with Recipient B and Donor B can be matched with Recipient A.

Research indicates that an organ from a living donor is preferable to one from a deceased donor. The practice of matching pairs has been successfully tested in a small number of transplant centers and has been

Continued on page 3

Look Inside!

- 2 **LORI'S LINES**
Aspirations for the Future
- 4 **OVER THE TOP**
Who's Your Caregiver?
- 6 **PHOTO SPREAD**
Dream and Live!
Inspiration from Long-Time
Dialysis Heroes
- 8 **SPOTLIGHT ON YOU**
Expanding Myself
- 9 **TIPS TO REMEMBER**
It's Hot: Drink Not!
- 11 **LEGISLATIVE UPDATE**
Make an Appointment
- 12 **RSN REPORT**
RSN Regional Patient
Lifestyle Meetings

Thanks to our sponsors!



Professional Points

Do You Have Anemia?

by Susan Vogel, MHA, RN, CNN

Are you feeling tired or depressed? Or are you cold when everyone else in your family is sweating, especially after you turn up the heat? You could have anemia.

What Is Anemia?

Anemia is a condition in which the body doesn't have enough red blood

cells. As a result, your tissues don't get enough oxygen, and your energy level and quality of life can suffer.

So what causes anemia? Normal kidneys produce a hormone called erythropoietin (EPO), which stimulates the bone marrow to make new red blood cells. When your kidneys don't work properly, they don't

Continued on page 5



Aspirations for the Future

by Lori Hartwell, RSN President



When I was diagnosed with chronic kidney disease in 1968, no one really talked about my future because back in those days, they

didn't think I had one! But there was one person who finally gave me hope.

I was trying hard to overcome yet another medical hurdle during one of my many hospital stays when my doctor said, "Lori, someday you're going to write a book and call it *I Can*." He went on to tell me how

important my attitude and strong will were to my recovery. That was the first time I started to believe I had a future, and it gave me the will to fight the many battles that lay ahead.

I never thought of myself as a writer, but I knew I had a story to tell. So I began to write about my life, just small snippets of experiences and random thoughts. Eventually, these short stories ended up in a book called *Chronically Happy*, which fulfilled my doctor's prediction.

Untapped Talent

They say that we all have a book in us waiting to be born. I believe that there's a huge,

untapped reservoir of literary talent among those with kidney disease: not only talent, but an innovative perspective that goes beyond the mundane and into the

profound and spiritual. This fresh insight can bring a joyful laugh, a grateful tear, or food for thought as the reader comprehends the overwhelming challenges that those who are chronically ill face every day.

I want to challenge you to start writing your story. All of us have something important to share with someone else. Just look at



the many excellent contributions to this newsletter from people who have kidney disease.

Essay Contest

Do you have an aspiration for the future? To motivate you to start writing, the Renal Support Network is holding an essay contest (see opposite page for details). The theme of the contest is "Aspirations for the Future: What Gives You Hope."

Have you defied the odds to pursue a personal goal or developed a plan to reach your dream? How have you held on to hope despite difficult circumstances? Describe a person who challenged you to go beyond your limitations or tell a story about a pet or a hobby that keeps

a smile on your face. Write about hope!

This essay contest is a forum for you to share your experiences with others, as well as an opportunity to be recognized publicly for your writing. You're

the thought leaders in the kidney community; you provide the most inspiration to fellow patients. Your essay can inspire others, give them hope, and help them realize that they're not alone.

Words live forever. I look forward to hearing *your* story!

Chronically Yours,

Lori Hartwell

President & Founder
of the 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.

Newsletter Staff

Editor-in-Chief

Lori Hartwell

Managing Editor; Layout & Design

Shari Gilford

Editorial Coordinator

Gordon Lore

Distribution

Renal Support Network

Contact Information

Renal Support Network

818-543-0896 or 866-903-1728

9 AM-5 PM Pacific Time

Submissions, Newsletter Business

shari@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

Web Version (PDF files & archives)

www.RSNhope.org

© 2007 by Renal Support Network
All Rights Reserved
EIN#95-4672679

Visit our website:

RSNhope.org

Announcing:

RSN's Annual Essay Contest "Aspirations for the Future: What Gives You Hope"

AWARDS

1st place—\$500

2nd place—\$300

3rd place—\$100

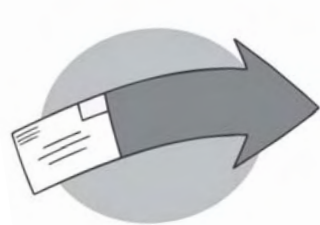
Contest Guidelines

The author must be diagnosed with chronic kidney disease to participate.

Essays must be no longer than 750 words, must be typed, and must include the author's complete name, address, phone number(s), and e-mail address (if applicable). All essays will be judged on responsiveness to the theme, originality and creativity, and technical expertise. Visit KidneyTimes.com for complete contest guidelines.

Entries must be received by August 31, 2007.

Winners will be announced on RSNhope.com and KidneyTimes.com.



E-mail, fax, or mail entries to the following address:

KidneyTimes Essay Contest
c/o Renal Support Network
1311 N. Maryland Ave.
Glendale, CA 91207
Fax: 818-244-9540
essay@rsnhope.org



KidneyTimes.com is a new website launched by RSN that provides "Health Information Beyond the Ordinary" for those coping with kidney disease. Patient profiles, medical information, examination of real-life issues, recipes, and many articles written by patients are just a sample of what this new website offers. It also features "Easy-Link Access," allowing professionals to "prescribe" articles to their patients. Truly an extraordinary website!

Made possible with support from Roche.

Visit today and take the quick poll!

Expanded Transplant

Continued from page 1


shown to work well. As a result of paired donation exchange, more people are being transplanted with good kidneys in a timely manner.

New legislation and a U.S. Department of Justice opinion in April of this year have paved the way for the future development of a national network, and www.transplantliving.org will continue to report on its progress.

In the meantime, with legal issues resolved, additional transplant centers will likely begin living donor paired kidney exchanges and even cooperate with other centers in their region. As everyone knows, the larger the pool of donor/recipient pairs, the greater the opportunity for matches.

Everyone wins with living donor paired kidney exchanges:

- ◆ The living donor has the satisfaction of giving the gift of life.
- ◆ More transplant candidates receive organs.
- ◆ Recipients are removed from the waiting list for deceased donors, thus benefiting those who remain on the list.
- ◆ Medicare saves money since more people with end-stage renal disease receive transplants instead of continuing with dialysis.

Those who are interested in living donor paired kidney exchanges should consult with their transplant teams. There are 72,000 people waiting for a kidney transplant. Suppose a significant percentage of those waiting had a willing donor, compatible or not. For the first time, we could actually see the waiting list shrink. Wouldn't that be nice? 



M. Jill McMaster is a General Public Member of the Board of Directors of the United Network for Organ Sharing. A recipient of a kidney transplant, Jill retired after successful careers in the federal government and the U.S. Navy Reserve. She enjoys spending time at her home on the Tennessee River and volunteering for kidney research and organ donation organizations.



Who's Your Caregiver?

by John D. Garcia, weKAN Patient Activist

Let me introduce myself. My name is John D. Garcia, and I acquired end-stage renal disease rather suddenly in October 2004. I'm married and have a 34-year-old son who lives at home, and a 30-year-old daughter.

My wife is a public school superintendent who puts in many nights a week at work. The task of being my caregiver fell to my son. At first he just kept watch over me to make sure that I was all right. He

also made sure I took my medications and that I had enough to eat.

You may not think this is unusual, but let me explain. My son's name is John Christopher, and he has Down's syndrome. He's on disability and has a part-time job at a nearby convenience store. John worried about me and took excellent care of me. I was very fortunate that he could accompany me wherever I went, even to the Renal Support Network conference in Philadelphia last October.



John (left) with his son John Christopher at the RSN National Patient Meeting in Philadelphia, October 2006.

So when I started home hemodialysis with the NxStage system in August 2006, there was no question in my mind as to who would be my caregiver. But there *were* questions in the minds of the healthcare

professionals who were going to train us. John began training with me, and his attention to detail astounded the trainers.

They realized that having him as my caregiver wouldn't be a problem at all.

Some people say you don't need a caregiver and can

do home hemodialysis by yourself. To them, I say go right ahead. As for me, on two occasions I had a sudden drop in blood pressure and passed out while on dialysis. John immediately put his training to work and successfully revived me. This is one of the main reasons that I would never attempt dialysis alone.

John's attention to detail

and his dedication to caring for me have allowed me to better cope with kidney failure. I've always been a very active person, and it's been hard for me to accept that I can't do everything I used to do. John is really more than just my caregiver and son—he's also my friend and companion. He accompanied me on a dialysis-at-sea cruise when I



John puts in his needles to prepare for his dialysis treatment.

was doing in-center dialysis, and he and I recently took our new portable dialysis machine for a week's vacation to Disney World.

With the help of John and his sister Karen, my quality of life continues to be excellent. On January 30, 2007, Karen donated one of her kidneys to me. Both she and I are doing very well. I'm truly a lucky man to have such a caring family. ☞



John D. Garcia is a former Chief of Emergency Services for a major university. He holds a BS in Fire Science and an MS in Public Service Administration. His kidneys failed in October 2004 and he received a transplant from his daughter in January 2007.



John Christopher diligently checks to make sure everything is running correctly during his father's dialysis treatment.



The people who make a difference in your life are not the ones with the most credentials, the most money, or the most awards.

They are the ones that care.

— author unknown

Do You Have Anemia?

Continued from page 1

produce enough EPO, causing a decline in the production of new red blood cells.

Other factors can also contribute to anemia. For example, your iron levels could be low. To form red blood cells, you need both EPO and iron, as well as vitamins and folic acid. Other medical conditions—such as infection or inflammation—can cause anemia too. It's important to get a complete checkup by your physician to rule out other causes.

When your tissues don't get enough oxygen, you may feel tired, depressed, or cold. Sometimes you may have difficulty breathing. You might not sleep well or think very clearly. Your skin could look pale, and you might have problems with sexual function. All of these are possible symptoms of anemia.

How Is Anemia Measured?

Two laboratory tests—hemoglobin and hematocrit—specifically test for anemia. Hemoglobin provides a direct measure of the amount of oxygen that can be carried by the blood and is the most accurate test for anemia. The goal is to keep your hemoglobin between 11 and 12 g/dL (grams per deciliter). Hematocrit, which measures the percentage of the blood that is made up of red blood cells, should be between 33 and 36 percent.

The target values for hemoglobin and hematocrit are part of

the guidelines put out by the National Kidney Foundation's Kidney Disease Outcomes Quality Initiative™ (see the sidebar) as optimal for those with chronic kidney disease.

KDOQI™

The Kidney Disease Outcomes Quality Initiative (abbreviated KDOQI™) is a program developed by the National Kidney Foundation to provide standardized clinical guidelines for the treatment of those with chronic kidney disease. One of these guidelines focuses on anemia.

Benefits of Treating Anemia

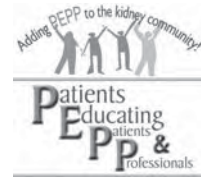
Maintaining hemoglobin within the target range allows many people to lead a more active life, with an enhanced ability to exercise or perform the activities of daily living. Those who assessed their quality of life reported that when their hemoglobin increased, their quality of life improved as well. However, anemia is only one of the factors that can contribute to these improved outcomes—each individual may or may not realize all of these benefits.

What You Can Do

You can be an advocate for your own care by knowing your lab numbers and by working closely with your kidney care team to manage your anemia. Following your dialysis schedule and not cutting treatments short can significantly affect how well your anemia is managed.

It is important to know when you're at an increased risk for lower hemoglobin levels. The following factors may affect your hemoglobin level:

- ◆ **Predialysis:** If you've been diagnosed with chronic kidney disease but aren't on dialysis yet, check with your kidney care team to see whether your hemoglobin is low and treatment is warranted.
- ◆ **New to dialysis:** After you start dialysis and are being treated for anemia, it sometimes takes many months before hemoglobin levels reach the target range.
- ◆ **Recent hospitalization:** Hospitalization for any reason often leads to low hemoglobin levels that can persist for months. Be aware of your levels



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

PEPP Presentations

For Patients & Families

Your Achy Breaky Heart:
What you need to know about secondary hyperparathyroidism

Energize Yourself:
What you need to know about anemia

NEW! **Taking Charge and Adding Life to Your Years**

For Professionals

Promoting Patient Participation in the Dialysis Setting

NEW! **Empowering Patients to Be Their Own Advocate**

To schedule a PEPP speaker, contact RSN.

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

during and after hospitalization. Check with your kidney care team to see whether any change in medications is necessary.

- ◆ **Infection or inflammation:** If you find that you have an infection or inflammation, notify your kidney care team immediately.

Remember: Knowing your numbers and what they mean will help you take better care of yourself. And just maybe you won't need to turn on the heat when the rest of your family wants the air conditioning!



Sue Vogel has over 30 years of experience as a nephrology nurse and is just starting a new position as Manager of Chronic Therapies, Western Region, for NxStage Medical. She is a member of the board of directors for the Renal Support Network.

Dream and Live!

Inspiration from Long-Term Dialysis Heroes

Heather Powell



"I know it is not my strength that gets me through, but my faith in Christ, my loving and supportive family, sheer determination, and a positive attitude. Attitude is half the battle."

At age eight, Heather began hemodialysis treatments, switching to peritoneal dialysis shortly thereafter. Maintaining a positive attitude, she went to camp with other children on dialysis and kept up with her schoolwork. She received a transplant in 1987 during her sophomore year in high school.

While Heather was attending college, the transplant failed. Though she dropped out twice due to her poor health, she finally graduated with a BS in psychology. With the support of her parents she began doing hemodialysis at home. This enabled her to complete a masters in social work and then work full time with the National Kidney Foundation of Arkansas as Program Director.

In 2004, after 13 years on dialysis, Heather received a kidney from her mother. The transplant was only possible because of a therapy that reduced Heather's antibody level.

Heather now works full time as a clinical therapist and volunteers for ESRD Network 13 and the Renal Support Network. "For me," she says, "helping others takes the focus off my own pain."



Roanne Faith Dale

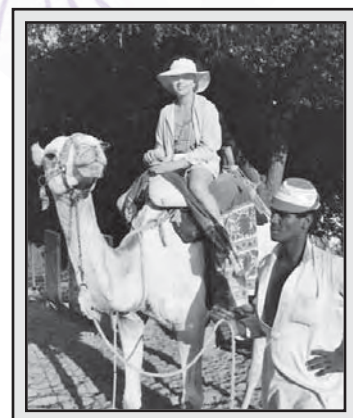
"It's important to develop a passion in life, to find something that gives meaning and purpose to your existence."

In 1972, three weeks after donating a kidney to her sister, Roanne's remaining kidney began to fail. Initially she underwent acute dialysis, but by 1978 she needed dialysis permanently. Deciding to not blame anyone for her kidney failure, she instead found faith in her ability to overcome all the challenges.

She completed a course as a nail technician in 1979 and then started a salon business with her partner Jim. Fulfilling a life-long dream, Roanne has traveled twice to France, and also to Egypt.

During the many hours she has spent dialyzing throughout the last three decades, Roanne has made use of her extra time by reading, making jewelry, crocheting, learning to use a laptop computer, studying French, learning Egyptian hieroglyphs, and investigating metaphysics, astronomy, and astrology.

In 2004, she authored the book *Dialysis Success* to help people with kidney disease realize that life is not over. "It's not enough to just live with kidney failure, I want us to thrive!"



Sharon Pahlka

"I believe we need to live our dreams. That will give us hope and remind us that we can continue to meet the challenges that will inevitably come. I am still alive and loving life!"

Sharon started dialysis in the late 70's at age 23. During her many years on dialysis she not only raised her son, but also attended college. After



graduating from the University of Washington with a degree in social work, she began speaking in the community and in schools, educating others about kidney disease.

In the early days there were no medications available to treat anemia, so Sharon's hemoglobin was severely low.

Though she had little energy, she still waterskied competitively alongside contestants who were much healthier. She dreamed of someday waterskiing in a championship competition.

After 19 years, Sharon received a kidney from her brother that has continued working for 14 years. Soon after her transplant she finally realized her dream and was strong enough to compete in the 1998 Regional Waterski Championships. She was even seeded fifth in seven states!

She recently started a new career as a life coach, speaker, and writer. Her passion is to help people make good choices. Her motto: "Life is a gift."



Your living is determined not so much by what life brings you as by the attitude you bring to life; not so much by what happens to you as by the way your mind looks at what happens.

— Lewis L. Dunnington, author



Bill Dant

"Take counsel from your hopes and not from your fears."

Bill began hemodialysis in 1977 when dialysis meant cellophane coils and recirculated dialysate. He took this clunky equipment home two months later and continued doing hemodialysis at home for almost 18 years. This allowed him to work full time and raise a family.

As a private pilot, Bill was able to travel extensively with his family while on treatment. Sometimes these trips included taking a "wearable artificial kidney" with him. This experimental device was worn on the chest, had no safety alarms, and looked like scuba gear with blood tubing. It wheezed and moaned—each treatment that ended with the patient still alive was a success.

Bill received a transplant in 1995 and returned to school for four years of training as an editorial photographer. He feels very blessed and grateful to retain the gift of life in his 30th year since kidney failure.

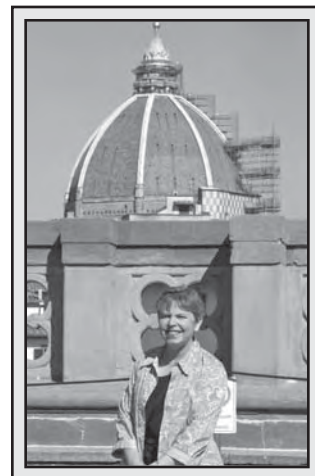


Jennifer Castillo

"Dialysis has slowed me down, but I have not missed out on anything."

Jennifer started hemodialysis in 1979 at the age of 18. Not daunted by this hurdle, Jennifer completed college and a masters program. While working full time in New York, she traveled three times a year to San Francisco to complete a graduate program. She finally moved to San Francisco where she met her husband at a ball-room dancing class.

She has had two transplants. The first lasted only three months, and the second only gave her a 13-month reprieve from dialysis.



Jennifer has always worked full time while on dialysis. She also volunteers her time speaking and writing about dialysis issues. Two years ago she and her husband traveled to Paris, and last year they visited Rome and Florence.

A trusted nephrologist once told her that anything and everything is possible on dialysis. She believed him!

Expanding Myself

by Mary Rubino, PEPP Speaker

Until recently, I never realized how small my world really was. I was raised in a small town and never thought much about what was going on elsewhere. Having kidney disease changed all that.

Suddenly I was in the big city of Boston, Massachusetts,
 being tested for a transplant,
 hoping for a place on the waiting list,
 enduring surgery to have a fistula placed,
 learning all I could about dialysis,
 all things I knew nothing about.

My world was expanding.

Years went by, and something inside me changed. The more I was affected and the more I saw how it affected others, the more I understood that somehow I had to help.

Working full-time while on dialysis didn't leave me a lot of room for much else.

But I started

by putting out donor information at work,
 by talking to other patients about what helps,
 by writing down how I felt about everything I was going through,
 about everything I was learning, and, most important,
 about what worked.



This past March, 30 PEPP speakers, all having kidney disease, attended four days of speaker training in Los Angeles, CA.

For information on how to book a PEPP speaker, see the ad on page 5 or fill out a request form at RSNhope.org.



Mary Rubino was diagnosed with polycystic kidney disease and lithium toxicity in 2002. After over two years of in-center hemodialysis she received a successful cadaveric transplant. She continues to work full time and looks forward to helping others through the PEPP program. She enjoys gardening with her grandson Jared.



Mary Rubino gives a short, unrehearsed speech at the PEPP training.

Research and plain dumb luck led me to Lori Hartwell's book *Chronically Happy*, led me to the Renal Support Network (RSN).

Even though I had no experience giving speeches, I applied to the Patients Educating Patients & Professionals (PEPP) program.

I was choosing to go beyond all that I knew and was comfortable with. I was growing and changing.

My world was expanding.


In the middle of the application process, the call for my transplant came. It was successful, and I'm so grateful. When I got home a week later I sent in the application, but wasn't chosen. Instead, I received a recommendation to join Toastmasters International.

A month after my transplant, I went back to work but couldn't let go of my vision to give back.

My world had expanded.

So I joined Toastmasters, became involved in my club, spoke as much as I could, and applied for the PEPP program again a year later.

Recently, I was lucky enough to go through training and join this amazing group of speakers, all of whom have experienced kidney disease.

My world has changed so much. Becoming involved has been empowering. I'm so glad that I stepped outside my little world. I highly recommend it! 



It's Hot: Drink Not!

Ideas to Quench Your Thirst

by Shari Gilford, weKAN Patient Activist, PEPP Speaker

Ahh... summer's here! Does it make you long for a tall glass of tea or lemonade with lots of ice cubes? You envision the condensation on the outside of the glass, and you can almost hear the ice cubes clink as you head for the refrigerator.

Whoa! Stop right there! What about your fluid restriction? *Just this one glass*, you tell yourself.

If you are on hemodialysis, your recommended fluid intake may only be a few cups per day. That's not much, especially when it's hot and everyone else is drinking continually. And don't forget—that bowl of ice cream counts too!

Are thirst-quenching cold drinks just a fantasy now that you're on dialysis? Maybe. But there are many creative ways to assuage your thirst. The first is

to drastically limit sodium intake. Less salt equals less thirst. See the accompanying list for other simple suggestions that might help you too.



Remember that not all fluid comes in

the form of something to drink. Beware of hidden liquids: ice cream, milkshakes, Jell-O, whipped cream, gravy, soups, sauces, and the liquid naturally found in fruits and vegetables. Ask your dietician for specific guidelines on how much you can eat of these foods, and remember to count them toward your fluid allotment.

Learn what works for you and try to keep everything in perspective. After all, life isn't enjoyable if there are too many restrictions. Begin by making small changes in your fluid intake, and learn to practice moderation. You'll feel better during dialysis as well as in between. Then you can *really* enjoy life, even without all that liquid! ✂



Shari Gilford 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.



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!

Thirst-Quenching Tips

- ◆ Freeze low-potassium fruit—grapes, cranberries, pineapple, blueberries, apples, raspberries—and munch on them instead of drinking.
- ◆ Stay away from Popsicles® or sugary drinks, which can actually increase thirst.
- ◆ Reach for an ice cube instead of a drink. Stock up on pre-made ice cubes from a convenience store. They won't be as hard on your teeth as the ones you make in a tray. Don't eat too many because they still count as fluid.
- ◆ Freeze fruit juice or herbal tea in ice cube trays. Or add lemon juice to ice cubes made with water.
- ◆ Buy those plastic balls that you freeze to put in drinks. Run water over them before freezing to add a thin layer of ice. When you're thirsty, take one out of the freezer and suck on it.
- ◆ Suck on a lemon. But don't get a sour attitude!
- ◆ Suck on hard candy (sugar-free).
- ◆ Chew gum.
- ◆ Brush your teeth and rinse well. Or just rinse your mouth repeatedly with cold water. Your mouth thinks it had something to drink even though you didn't swallow.
- ◆ When you take pills, wash them down with something you enjoy.
- ◆ In restaurants, ask for a glass of ice cubes instead of water. A straw lets you drink the melted ice in small amounts.
- ◆ Instead of opening a whole bottle of juice, open a can of frozen concentrate and mix just a tablespoonful with water to make a small amount. Cover the opened can with plastic wrap and a rubber band and refreeze. The effort makes you less likely to indulge.
- ◆ If you know you're going to a cookout or party where everyone will be sipping drinks, fill an insulated cup with ice cubes, attach a secure lid, and bring it with you.
- ◆ If you want to drink a little extra of your favorite beverage, do it when there is only one day—instead of two—between dialysis treatments.
- ◆ If you've been really good at keeping your fluid intake down for the day, reward yourself with a small (4-oz.) glass of your favorite liquid. Savor it; you deserve it!



Regional Patient Meetings

Continued from page 12

table, and pick up your registration bag loaded with materials.

As you make your way to the buffet, you'll pass exhibits and pick up some free literature and samples. While you eat, you can visit with other patients, family members, and exhibitors. Not only will you get to know other members of the kidney community in your area, you might just find a new friend!

Now it's time to increase your knowledge and be inspired. The organizer of the meeting—someone who also has kidney disease—will provide a brief



Registration

introduction. Then the speakers, who include both patients and professionals, will give informative presentations on such topics as anemia, secondary hyperparathyroidism, life coaching, transplantation, different methods of dialysis, and exercise. After a few presentations, there will be a short break so you can stretch your legs,

and then the presentations will continue. In between, you might even win a raffle prize!

Still not convinced that you should attend? Well, see what past attendees had to say:



Delicious Buffet

"I was inspired to become more involved."

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

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

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

"I would 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."



Informative Exhibits

Registration is free for patients, who can bring one guest, also at no charge. You'll get a free meal and invaluable education that can add "life" to your years!

See the calendar on page 12 for a list of upcoming meetings. For more information and to register online, go to RSNhope.org or call 866-903-1728 (toll free).

We hope to see you there! 

KidneyTalk!™

Streaming Health, Happiness & Hope over the Internet



A new half-hour show is uploaded weekly. All shows are available online 24/7. Also available as a podcast on iTunes.

Listen to *KidneyTalk* online at:

RSNhope.org



With your hosts
Lori Hartwell
and
Stephen Furst

Order CDs
of *KidneyTalk*
at RSNhope.org!



Mandy Trolinger, MS, RD, currently works both as a project coordinator for RSN and as a renal dietitian. She has been on hemodialysis, and is a two-time kidney transplant recipient. In her spare time she volunteers, exercises, and spends time with her husband and pets. She resides in Highlands Ranch, CO.

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 _____

City _____ State _____ Zip _____

E-mail _____

Phone _____ home work cell

METHOD OF PAYMENT FOR CONTRIBUTIONS:

Check or Money Order (payable to Renal Support Network)

Credit Card: MasterCard Visa American Express

Total billed to credit card \$ _____ Billing Zip _____

Card #: _____ Exp. Date: _____ / _____

Cardholder Name (as on card): _____

Signature _____ Date _____

All donations are tax-deductible. EIN#95-4672679

- 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:

\$ _____

Please check all that apply:

- Patient—I have experienced:
 - transplant PD hemo
- Family Member Administrator
- Physician Nurse
- Dietitian Social Worker
- Technician Company Rep
- Other _____

Cut form on dotted line and mail or fax to the Renal Support Network. Thank you!

Renal Support Network

1311 N. Maryland Ave.

Glendale, CA 91207

866-903-1728 • 818-244-9540 fax

Legislative Update



Make an Appointment

Patient activists involved in the Renal Support Network's Wellness & Education Kidney Advocacy Network (*weKAN*) recently traveled to Washington, DC, in order to educate lawmakers on the importance of voting for bills that help people with kidney disease. Exceeding all expectations, 30 patient activists completed 167 appointments, garnering many new cosponsors for the Kidney Care Quality and Education Act of 2007 (S. 691 and H.R. 1193).

However, we all know that advocacy doesn't begin in Washington, DC, nor does it end there. Advocacy begins with each one of us.

Sharing our knowledge of kidney disease with our elected representatives and letting them know that their votes affect our lives is vitally important, whether we do it on Capitol Hill or in our own neighborhoods. You and I can influence the course of history. And this summer provides us with an opportunity to do just that.

This August, lawmakers will be back in their home districts. You can

use this opportunity to "put a face on kidney disease" so they have a real-life example to remember when they're back on Capitol Hill, wading through the text of a bill. When they read the words "kidney disease," they'll see *your* face!

Meeting members of Congress is an awesome and invigorating experience. All you need to do is be yourself. After all, you have a unique perspective on kidney disease.

Tell them about the goals you've accomplished while on dialysis, the process of getting a transplant, or the family you raised during your illness. Inform them of the facts, such as how many people are awaiting a kidney transplant, how many people are at risk for kidney disease, and that the two leading causes of kidney failure are diabetes and high blood pressure. (Go to RSNhope.org to learn the facts about kidney disease.)

Let them know that you care about legislation that affects you and your fellow patients. You may find that the person you meet knows someone

who has kidney disease. That personal connection could be the basis for building a relationship.

You can find out who your elected officials are by visiting RSNhope.org and clicking on "Advocacy." Then click on "Contact Congress" in the Action Center.

The website also has other tips on how to contact your representatives, including sample letters, sample scripts for scheduling an appointment, and information about current bills and hot topics. If you need further help, feel free to call the Renal Support Network at 866-903-1728 (toll free). And please inform us if you've made a visit to your representative.

Take time this August to reach out to your elected officials. They would love to meet you, and you'll come away feeling empowered in knowing that you helped make a difference. Besides, it's a great experience. That's a win-win situation!

Together, we *can* make a difference!



In this issue of Live & Give...
Inspiration from Long-Term Dialysis Heroes

NON-PROFIT ORGANIZATION
U.S. POSTAGE
PAID
GLENDALE, CA
PERMIT NO. 94

RSN Report

Coming to a Location Near You!

RSN Regional Patient Lifestyle Meetings

by Mandy Trolinger, weKAN Patient Activist, PEPP Speaker

Do you ever feel that you're living with kidney disease by yourself, or wonder whether anyone else

shares the same concerns? Do you want to know more about what your lab values mean, how to live an active life,

or how to prevent complications? Well, you don't have to look any further! The Renal Support Network (RSN) is expanding its patient lifestyle meetings across the nation, bringing "Health, Happiness & Hope" to a city or town near you!



So why should you attend an RSN Patient Lifestyle Meeting?

You'll meet other patients and professionals, gain knowledge that could add years to your life, have a chance to win great raffle prizes, and get a kidney-friendly meal—all for

FREE! Come and enjoy a fun-filled day learning from other patients and professionals.

Still not sure whether to attend? Well, let me walk you through a meeting. You'll arrive about 10 a.m., check in at the registration

Continued on page 10

Calendar

RSN Regional Patient Lifestyle Meetings

July 15 (Sunday)
Las Vegas, NV

July 22 (Sunday)
Tarzana, CA

August 26 (Sunday)
Houston, TX
Riverside, CA

September 9 (Sunday)
Torrance, CA

September 16 (Sunday)
Oklahoma City, OK

September 29 (Saturday)
Huntington Beach, CA

October 6 (Saturday)
Salt Lake City, UT

RSN National Patient Leadership Meeting

September 27-29
Huntington Beach, CA

Go to RSNhope.org to register online for a meeting, check the latest calendar listings, or download a meeting flyer.