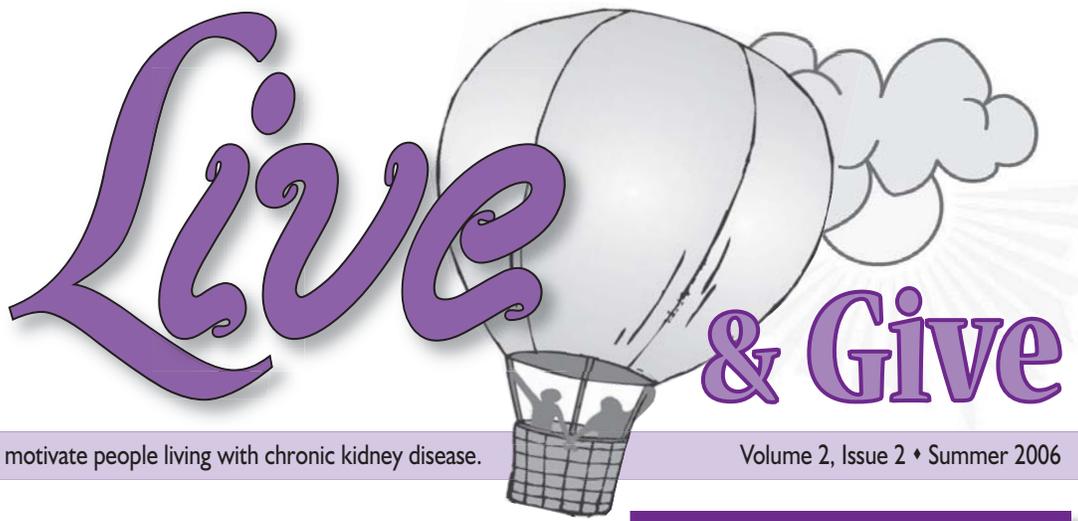




A PROGRAM OF
RSN
Renal Support Network



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

Volume 2, Issue 2 • Summer 2006

Headline News

My New Perspective of Advocacy

A Return to Capitol Hill

by Virna Elly, weKAN Patient Activist, PEPP Speaker

While making my way across the ever-congested roadways of our nation's capital, I soon found myself thinking about the purpose of the day's trip—to share with members of Congress and their staff my experiences and first-hand knowledge of living with chronic kidney disease (CKD).

Unlike the countless times that I have made trips to Capitol Hill throughout my professional career, which has always included an advocacy component, this trip to

“the Hill” would be entirely different.

This time, I would not be accompanying a team of professional lobbyists with professionally crafted messages advocating for someone else's issue.



weKAN patients and family members after an exhilarating day on “The Hill.”

This time, I would be one of 17 members of the Wellness & Education Kidney Advocacy Network (weKAN) who would advocate on behalf of ourselves and the thousands of others across the

United States who live with CKD.

Like many patient organizations, the Renal Support Network (RSN) is

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Can You See Me NOW?!

RSN Report

RSN's National Patient Meeting Connecting Patients from Across the U.S.

RSN announces its 3rd Annual National Patient Meeting—**Health, Happiness & Hope!**—to be held in Philadelphia, October 5–7. Mark your calendars, and get ready to have a lot of fun and meet some great people!

Health, Happiness & Hope! is for pre-dialysis and dialysis patients, transplant recipients, and family members. It is a showcase of RSN's efforts to

educate patients and their families about chronic kidney disease (CKD), providing hope and inspiration in the process. Featured are “patients helping patients” sessions presented by those who have “Been there, done that!” Caring professionals will round out the agenda, providing tips on helping patients live healthier, more joyful lives.

*It's never too late to be
what you might have been.*

— George Elliot

This year, RSN has added a few new features to an already terrific line-up of speakers and activities.

Every attendee will have the opportunity to contribute to a Patient Poster Session by bringing a creative poster with the theme: **“I Can Maintain Health, Happiness & Hope Because Of...”**

The Keynote Address, “From

Continued on page 7



Pay It Forward

by Lori Hartwell, RSN President



My mom and I were shopping. Both of our arms were full with the store's 50%-off sale merchandise. The store was packed and there wasn't a lot of room to move around. The checkout line was long and a man was arguing with the saleslady about a price. The energy in the air was unhappy.

Mom and I looked at each other and mentally asked each other,

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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Web Version (PDF files & archives)

www.RSNhope.org

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EIN#95-4672679

"Is this really worth it?" At that moment, my mom accidentally bumped into the young woman waiting in line in front of her and promptly said, "Excuse me." The woman turned around and asked my mom, "Can I hold something for you?" The woman said this with a big smile and an eagerness to help. Mom was startled; she said, "No, I got it, but thank you for asking."

After we checked out, as we were walking to the car, all we could think about was how nice that woman was and how her kindness really was the highlight of our shopping experience. I often forget that the random act of kindness is the glue that keeps society together and brings a smile to our face.

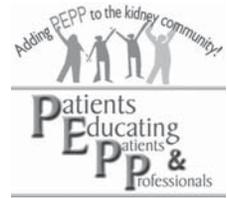
One of my favorite movies is "Pay it Forward." In this movie, a young boy takes on a social studies project to prove that if you help three people in one day, and then they help three people, and so on, the world will be a better place. At the end of two weeks, 4,782,969 people will have experienced a random act of kindness if this progression is followed.

Today, I encourage everyone to "pay it forward." Here are a few ideas: Bake cookies for a homeless shelter. Write a note telling your healthcare professional how much you appreciate him or her. Volunteer to read to children at your local



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

Thank you for your help!



PEPP, a program of RSN, is a group of patient-speakers trained in how to share life-enhancement knowledge with renal 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 renal 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.

library. Organize a toy drive for the holidays. Look for opportunities to open the door for someone.

For those of us who are kidney patients, the opportunities to be kind to fellow patients are virtually endless. And remember... your random act of kindness just might be the difference between someone living in despair or with hope. If you see the need, ask a fellow patient whether you can help out. Say something encouraging to the person sitting next to you at your dialysis unit. Drop off some magazines for your transplant clinic's waiting room. It's not even important that the people you're helping know it was you who helped out.

Helping others makes us happy. To quote the novelist James M. Barrie, "Those who bring sunshine into the lives of others cannot keep it from themselves." ☞

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



Less Wait Time for a Transplant?

By Caroline E. Jennette, MSW

There may be good news in the offing for people who began dialysis before signing up for the kidney transplant waiting list.

Under the guidance of the United Network for Organ Sharing (UNOS), two organ procurement organizations (OPOs)—OneLegacy in Southern California and Gift of Life in Michigan—are testing a new protocol in their areas in which a person's start date of dialysis would now be considered his or her start date of being placed on the transplant waiting list.

For example, if someone began dialysis in 2002 but did not sign up to be placed on the transplant waiting list until 2005, records will now show that person to have been waiting for a new kidney since 2002. In other words, that person will get a three-year jump ahead on the waiting list.

For people who joined the waiting list before starting dialysis, nothing will change. For example,

if someone signed up to be on the waiting list two years ago but started dialysis only one year ago, records will still show his or her time on the waiting list to be two years.

Feelings are mixed about the new protocol. Nonetheless, the hope is that dialysis patients who were not informed of their opportunity to be evaluated for a transplant when they started dialysis will now be on equal footing—in terms of accrued waiting time—with patients who did have their names placed on the waiting list at the time they started dialysis.

The new protocol will be tested for three years. If it proves successful, it may be implemented by other OPOs. 



Caroline Jennette is a macro practice social worker who works at the University of North Carolina Kidney Center in Chapel Hill. Her interests lie in health policy, community outreach for kidney disease prevention and education, and legislative advocacy around issues of health access and patient care.

Return to Capitol Hill

Continued from page 1

intimately familiar with the ins and outs of advocacy, particularly because of the outstanding results that RSN's weKAN volunteer activists produced in a similar trip to Capitol Hill last year.

Training in Advocacy

The idea of patients helping to improve the lot of fellow patients through advocacy is hardly a new one—neither to me nor to many of the other weKAN members. However, this year's trip allowed me to experience something familiar alongside others for whom this was something completely unfamiliar. In essence, I would be turning something old into something new again.

Though never once doubtful of my own dedication to our purpose, I marveled over the enthusiasm and zest of my fellow patients during our months of training, preparation, and hard work. A series of conference calls over the months prior to the trip afforded us opportunities to hone our skills, thereby enabling us to speak with the media, members of Congress, and other patients about our personal experiences with CKD.

Those conference calls—which included presentations by professionals in the renal, media, and legislative communities—provided a forum for us to learn how our experiences could be a vehicle that would not only give a face and voice to CKD, but would also help garner additional congressional support for the Kidney Care Quality & Improvement Act of 2005 (H.R. 1298, S. 635).

This bill is widely supported throughout the kidney community because of provisions that would improve pre-dialysis education, increase access to home dialysis modalities, align incentives for preferred vascular access placement, standardize dialysis technician training and certification, and provide for an annual increase to the composite rate.

Continued on page 5

Legislative Update



New Bill to Study More Frequent Dialysis

A bill that would launch a five-year pilot project to measure the financial impact to Medicare of reimbursing up to seven hemodialysis treatments per week has been introduced in the U.S. House of Representatives.

Under the "Access to Better Choice in Dialysis Act of 2006" (H.R. 5321), the first three weekly treatments would be reimbursed at the standard composite rate (the amount paid to dialysis facilities for providing the dialysis treatment). The additional treatments during that same week would be reimbursed at a lesser amount, ranging from 70%

of the composite rate for the fourth treatment down to 20% for the seventh treatment.

Data obtained from the project would be used by Medicare to evaluate the health status of the patients after receiving daily hemodialysis. Data would include the number of patient hospitalizations during the study period, as well as the usage of erythropoietin (EPO) and iron.

The proposed legislation, which was introduced by Rep. Charles F. Bass (R-NH), would also authorize the government to study the working status of kidney patients. 

A SNAPSHOT OF CAPITOL HILL THROUGH THE EYES OF KIDNEY PATIENTS



weKAN Patient Activists' Visit to Washington, D.C.
To Gain Cosponsors for the Kidney Care Quality & Improvement Act of 2005
June 12 - 14, 2006

Shari Gilford (left) with Representative Peter DeFazio (D-OR).



Shari Gilford of Oregon met with Aaron Davis, health legislative aide to Representative Peter DeFazio (D-OR). Representative DeFazio had not previously been aware of the bill, but became a cosponsor soon after the meeting.

23 States Represented!



Representative Cathy McMorris (R-WA), the only legislator from the state of Washington who had not yet co-sponsored the bill, did so the day after Sharon Pahlka visited her.

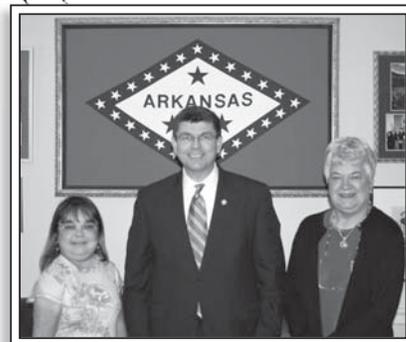


Sharon Pahlka (right) with Representative Cathy McMorris (R-WA).

Leesa Westfall (right) with Representative Jim Leach (R-IA).



Leesa Westfall met with all five representatives and both senators from her state of Iowa. At first she was nervous, being a novice in advocacy, but she quickly became confident and her efforts paid off. Representative Jim Leach (R-IA) became a cosponsor of the bill because of her visit.



Heather Powell (left) and her mother had a memorable appointment with Representative Mike Ross (D-AR). He became a cosponsor of the bill that same day!

Return to Capitol Hill

Continued from page 3

Ready for Action

Our first full day in our nation's capital was comprised of a robust schedule of tailored training, hands-on practice sessions, and productive discussions. We impressed one another while sharing our personal stories, but realized that though our experiences may differ, the voice of CKD patients can, in concert, sound loudly as one.



Tania Michael (left) and Leesa Westfall listen intently during the all-day training on Monday, June 12.

Andrea Budzinsky (right), legislative correspondent to Senator Christopher Bond (R-MO), was thrilled to receive a copy of Paul Rauch's book of poetry.

Throughout the following day on Capitol Hill,



Shari Gilford (left) with Dawn Dungan after they disembarked from the Metro.

I watched with fascination and particular interest as the faces of nervousness and apprehension that I had seen over breakfast and during our commute melted away to reveal poise and polished professionalism. Members of our group who I passed in the halls, who initially had looked harried and lost in Congress' underground passages and winding corridors, had soon transformed into shining examples of people in charge and with purpose.

In just two days' time, we held 106 meetings, received numerous requests from congressional aides wanting to visit dialysis facilities, and secured nearly a dozen new co-sponsors for the bill.



Martinlow Spaulding (left) role-plays as a senator while Sandra Pollock (center) and Leesa Westfall practice articulating the important points of the bill.

At the end of the day on Capitol Hill, Tania Michael enthusiastically reports that she was able to make a few spontaneous appointments with staff of additional New York representatives. Most had not been previously aware of the bill and thanked Tania for the information. Tania also met with legislative aides to Senator Charles Schumer (D-NY)—already a cosponsor of the bill—and to Senator Hillary Clinton (D-NY).



Tania Michael

At the dinner on Tuesday night, Martinlow Spaulding emphasizes the importance of helping those he met on Capitol Hill make a personal connection with dialysis issues.



Recapping Our Experience

During dinner on our last night together in the city, I was humbled and honored to hear that my fellow patients felt, even more poignantly than I did, "energized," "inspired," and "exhilarated" by our common experience.

Jim Dineen of Ohio concluded: "Washington is a big world. It is a big place full of supposedly big people doing big important things. I met nobody that day doing anything more important or more impacting than weKAN. I was very proud to be a part of such a prestigious group of dedicated people. I am honored to be a part of this work."

Malia Langen of Southern California reported that she "came back from D.C. feeling very empowered as both a patient and a citizen. It was a very special experience to be surrounded by so many smart, capable, determined individuals who also happen to be kidney patients." She hopes

"to be able to return next year to make even more connections with our lawmakers and leave an impression on them that only someone with firsthand experience with kidney disease can achieve."

As for me, after having the patina finish on my familiar experiences polished to reveal a shiny new luster, I can only say that though the sound of one patient's voice may be small, the sound of many patients' voices echoing through the halls of Congress is mighty. 



Virna Elly recently celebrated the one-year anniversary of her successful kidney-pancreas transplant. Through writing, speaking, and patient advocacy, Virna addresses issues concerning kidney disease, diabetes, and organ transplantation/donation. She is currently writing a Master's thesis for a degree in Government/Policy at The Johns Hopkins University.

Another Reason for Good Oral Hygiene

by Cheryl Thomas, RDH; PEPP Speaker

You've probably heard how brushing and flossing your teeth daily can help prevent cavities and gum disease, but there might be a new reason to find the energy to clean your teeth. It has to do with the relationship of your teeth and gums to the rest of your body.

For quite a while now, dental professionals have known that gum disease (a chronic bacterial infection of the gums) adversely affects blood sugar levels in patients living with diabetes. But recent research has raised an intriguing question: Can gum disease be related to other diseases and conditions as well? Researchers suspect there is a relationship between gum disease and diabetes, pneumonia, heart disease, low birth weight in pre-term babies, and even kidney disease!

Although the jury is not yet in, there is already compelling evidence of a relationship between gum disease and diabetes, as well as with pneumonia. Think about it... Because your mouth is directly connected to your windpipe (trachea), which is directly connected to your lungs, it makes sense that an overabundance of bacteria in your mouth could travel to your lungs and cause more frequent respiratory infections and possibly pneumonia.

To prevent gum disease, the American Dental Association recommends a yearly dental exam by a dentist, and a professional den-

tal cleaning at least twice a year. People with gum disease or special health conditions, such as chronic kidney disease (CKD), often require more frequent cleanings in order to maintain healthy gums.

Those with CKD (pre-dialysis, on dialysis, or with a transplant) should tell their nephrologist about upcoming dental procedures. To combat possible infection, your nephrologist may prescribe an antibiotic to be taken prior to the procedure. Likewise, your dentist needs to know if you have kidney disease or are on dialysis, as this might influence the type of medications prescribed or procedures performed. For instance, because most hemodialysis patients receive heparin during dialysis, some dental procedures (such as tooth extractions) should be done on a non-dialysis day in order to prevent excessive bleeding. The prevention of cavities and gum disease may have been the motivating factor in how often you cleaned your teeth in the past, but good oral hygiene will likely prove important in reducing your risk for a number of diseases.

Keep smiling! ☺



Cheryl Thomas is a registered dental hygienist and founder of dentalInspirations, Inc., Galveston, TX, specializing in dental management of the kidney transplant patient. She received a kidney transplant in 1999, and was the 2005 recipient of the RDH-Sunstar/RDH Award of Distinction.

Can You See Me NOW?!

Continued from page 8

After 90 Minutes

It's obviously going to be a while, so start ripping advertisements out of the outdated magazines. If you happen to have a Sharpee® marker, add some new style trends to the fashion kings and queens.

After 2 Hours

If you've waited so long that your stomach is starting to growl, put your free cell phone minutes to use and order Chinese food. Have it delivered to the waiting room. The aroma of the food is sure to get you some attention.

After 2½ Hours

By now, you must be feeling somewhat perturbed. Practice the feng shui techniques you've been hearing so much about and rearrange the furniture in the lobby. Your new environment is sure to clear your mind of negative thoughts.

Anything Past 3 Hours

All of that Chinese food, singing, and physical labor sure can be exhausting! Pull out the mini portable tent and your inflatable mattress and nap away. When you wake up, your doctor just may be ready to see you. ☺

Editor's Note: The above-stated suggestions do not imply endorsement either by the author or by RSN. Please use only for the purpose of a hearty laugh!

KidneyTalk!™

Streaming Health, Happiness & Hope over the Internet



A new half-hour show is uploaded to RSNhope.org every Tuesday. Each new show is available online 24/7 for an entire week. (Also available as a podcast. Past shows archived on RSNhope.org.)

Go to RSNhope.org to listen to a few light-hearted commercials previously aired on KidneyTalk!

Past shows include topics such as:

- Taking Dialysis on the Road
- Spicing Up Your Renal Diet
- Laughing Through the Illness

With your hosts
Lori Hartwell
and
Stephen Furst

Listen to **KidneyTalk!** online at:

RSNhope.org



Those Who Go, Those Who Stay

by Jim Dineen, weKAN Patient Activist, PEPP Speaker

I wrote this poem in 1990 when someone asked me about my experiences during the Vietnam war. My daughter Shari then painted a picture for me using my poem as her inspiration. It has the same title and depicts a Vietnam veteran kneeling at "The Wall" memorial in Washington, D.C.

Though originally written with a specific subject in mind, these words also ring true for everyone, and especially for those of us with kidney disease.

(Painting reproduction courtesy of Shari Lacy.)



If time were a day, or a week, or a year,
and friends were the fluid that creates a tear;
Then life for me continues a dream . . .
Bear with me a moment, here's what I mean.

I've lost a few throughout my life,
Some 'cause natural, others 'cause strife;
And through it all some things remain . . .
Life's really not cruel, it just has some pain.

When we rise each morning, sun shining or not,
Don't think of who's gone, but think of who's not;
And give them respect and warmth and love
to get through their day on the wings of a dove,
Or maybe an eagle, an osprey's wing . . .
Give them something to make their hearts sing.

You see, our friends, through life's perils and strains,
are always ours, regardless of pain;
Always seeing the good, forgetting the bad,
that each of us shows whether happy or sad;
Whether times are good or sometimes hard,
they're there for us, they'll deal the card
That's best for us when we're in need . . .
No questions asked, simply planting the seed.

The end of this piece is nowhere to be found,
'cause just like our lives, it flows 'round and 'round;
New friends will come, and old ones will go,
But the ones we know best continue to show
The need for our presence, the need for our trust . . .
Look around you, my friends, those folks are us. ☞



Jim Dineen was diagnosed with kidney failure in 1998. After three years on dialysis, he received a kidney in November 2003 from Joyce, his wife of more than 40 years. In June 2004, their story was featured in Reader's Digest. It focused on how kidney disease dramatically affected their family and brought them closer together. As a speaker for PEPP (Patients Educating Patients & Professionals), Jim educates fellow patients on how best to live with kidney disease.

WANTED

Letters
to the
Editor



We invite letters to the editor. Letters are subject to editing for length and content and should be limited to 100 words. Please include your name, address, daytime phone number, and e-mail address (if applicable).

Thank you!

National Patient Meeting

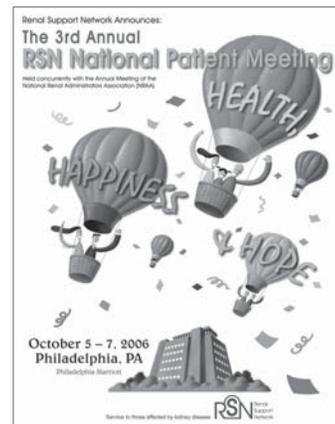
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Sound Stage to End-Stage," will be presented by Stephen Furst, an acclaimed actor/producer/director who starred in movies such as "Animal House" (he played Flounder) and in TV series such as "St. Elsewhere" and "Babylon 5." Along with Lori Hartwell, he is co-host of RSN's *KidneyTalk!* Stephen will be sharing the story of his life and his triumphs over diabetes and now CKD.

RSN will again hold **Health, Happiness & Hope!** in conjunction with the annual meeting of the National Renal Administrators Association (NRAA), making it the only patient-professional meeting of its kind. This allows participants from both meetings to share ideas and socialize in a casual, non-medical setting.

To receive a program or to register for **Health, Happiness & Hope!** contact the Renal Support Network at the number below. We can't wait to see you in Philadelphia! ☞

To download the program for RSN's National Patient Meeting, visit RSNhope.org.
To receive a program in the mail, contact RSN: (818) 543-0896; info@RSNhope.org



We would like to thank those companies that have generously agreed to sponsor RSN's 3rd Annual National Patient Meeting: American Regent, Amgen, Baxter, Fresenius Medical Care, and Roche.

Patience and perseverance have a magical effect before which difficulties disappear and obstacles vanish.

- John Quincy Adams



In this issue of Live & Give...
Washington, D.C.—A New Perspective

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Funny Bones



Can You See Me NOW?!

Waiting Room Tactics to Help You Get Noticed

by Lori Hartwell, RSN President

You rushed to get ready and fought traffic all the way to the doctor's office. You barely made it in time for your appointment and then there you

are, an hour later, and you still haven't seen your doctor.

This can be upsetting.

Yet, it happens time and again. You're thinking, "Hey, my time is valuable too! I wish there was something that I could do to vent my frustrations."

Well... read on, my frustrated friend. The following tips are sure to help you fight back against the "waiting room blues." If not, you will at least get a chuckle out of them!

After 30 Minutes

Bring a fresh pack of Hubba Bubba® bubble gum and challenge yourself to blow the biggest bubble in history. Keep trying. When the gum loses its elasticity, snap it and pop it to the beat of your favorite song.

After 45 Minutes

If no one understands your bubble gum lyrics, sing the song. Be sure to project your voice. You might even want to coordinate a sing-a-long with other patients.

After 60 Minutes

Still waiting? If you have children with you, let them practice their favorite instrument—again and again and again. If you don't have a child, borrow someone else's.



Get your newsletter delivered free to your home!

Contact RSN to Sign Up (contact info on page 2)

Calendar

3rd Annual RSN National Patient Meeting
Health, Happiness & Hope

October 5 - 7, 2006
Philadelphia, PA

Renal Support Network Patient Lifestyle Meetings
Denver, Colorado

November 5, 2006

Annual RSN Renal Teen Prom
Sunday, January 14, 2007
Sherman Oaks, CA

Thanks to our sponsors!



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