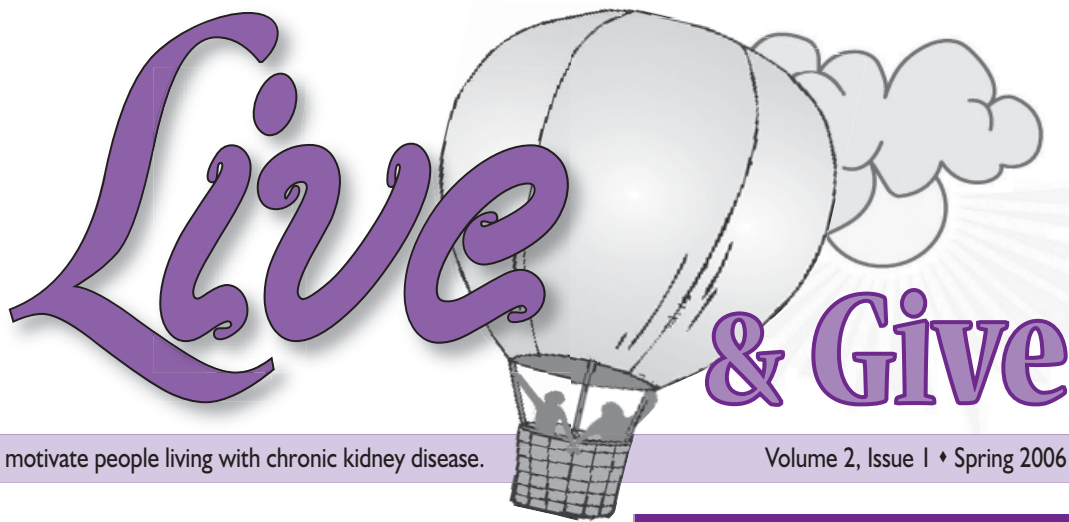




A PROGRAM OF
RSN
Renal Support Network



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

Volume 2, Issue 1 • Spring 2006

Headline News

PEPP: From Patients to Experts

Training in Los Angeles Yields Friends and Trained Speakers

by Tiffany Strohmeier, PharmD, PEPP Speaker

It's been said that people fear public speaking more than anything else. I thought about this while on a plane bound for Los Angeles this past January, where I would spend the next four days learning to become a speaker for RSN's Patients Educating Patients & Professionals (PEPP) program.

At that moment, I didn't know what I should be more afraid of—the possibility that the plane could crash, or the possibility that we'd land safe and sound and I would actually have to speak in front of people!

Okay, so maybe I'm exaggerating just a bit. Actually, I was excited and honored to have been

chosen to take part in the PEPP program, but I *was* nervous. I really



Tiffany Strohmeier, along with other PEPP trainees, awaits the start of a training session.

didn't know what to expect. After all, flying into Los Angeles made me feel a bit like maybe I was going to be in a new reality TV show.

I could almost hear the tag line... "Twenty kidney patients

from around the country—on different modalities and with their own unique stories—are plucked from their dialysis and transplant

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Read the perspective of another PEPP speaker, and see more photos of the PEPP training event too!

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Contact Your Senators and Representatives!

Ask them to cosponsor the *Kidney Care Quality and Improvement Act of 2005*.

In August, please take the opportunity to meet with them when Congress takes a break and members are in their home offices.

You can find information on how to contact them, including sample letters, at

RSNhope.org.

RSN Report

Update on Kidney Care Bill weKAN Patient Activists Again Converge on Capitol Hill

At this time a year ago, 20 weKAN patient activists—representing 16 states—traveled to Washington, DC, to meet with their elected officials. Over the course of only two days, the patients met with 55 members of Congress and/or their aides.

The patients—trained in advance and knowledgeable about the points of the Kidney Care Quality and Im-

provement Act of 2005 (S. 635, H.R. 1298)—educated their lawmakers about the bill and asked each one to become a cosponsor. The results exceeded all expectations! Eight members of Congress became cosponsors of the bipartisan bill that day, and others signed on in the days following.

Due to the great success of last

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KidneyTalk! Arriving in June

by Lori Hartwell, RSN President



Most people who know me would probably say, "Lori likes to talk!" I do enjoy people, and I do enjoy learning new things and shar-

ing the knowledge I have acquired over the years. So I am very excited about Renal Support Net-

work's latest project, "KidneyTalk!" *KidneyTalk!* is an online radio talk

KidneyTalk!
Streaming
Health, Happiness & Hope
over the Internet



tor recently diagnosed with end-stage renal failure and

now on dialysis. We are having so much fun creating these shows and interviewing guests.

Stephen is best known for his roles as Flounder in the movie "Animal House," Dr. Elliot Axelrod in the TV series "St. Elsewhere," and Vir Cotto in the TV series "Babylon 5."

A new half-hour show will be uploaded to the *KidneyTalk!* webpage (located on the RSN website, www.RSNhope.org) every Tuesday at 2:00 p.m. Pacific Time, and will also be accessible as a podcast. Each show will be available online 24 hours a day, seven days a week.

In preparation for the debut of *KidneyTalk!*, interviews have already been conducted with the following:

- **Jodi Picoult**, a best-selling novelist and author of "My Sister's Keeper," the story of a young woman conceived in order to be a blood cell and tissue donor to her older sister, but who resists when asked to donate a kidney.
- **Peter Quaife**, a former member of the British rock group "The Kinks," who began hemodialysis in 1998. To pass the time, Peter began drawing cartoons about what went on at his dialysis clinic. A collection of his cartoons was recently published under the title "The Lighter Side of Dialysis."



- Comedian **Howie Mandel**, host of the TV game show "Deal or No Deal," on finding your sense of humor when living with a chronic illness.

Additional interviews include: two patients who provide real-life advice on dating, a nephrologist who discusses the considerations of pet ownership, and a discussion on how patients benefit by having a fistula placed first and how to care for it.

The goal of this unique undertaking is to convey—in an informal, radio show format—practical advice on living well in spite of chronic kidney disease. You will hear from people who have not let kidney disease stand in their way, and

from others who were inspired to take better control of their lives.

KidneyTalk! is interactive, so if you have an idea for a future show or guest, or just have a general comment about living with chronic kidney disease, we'd love to hear from you.

You can send us an e-mail at kidneytalk@RSNhope.org, or leave us a voicemail at (866) 379-HOPE (4673). This is a toll-free number, and select voicemails will air on upcoming shows. We look forward to hearing from you! ☺

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.

Newsletter Staff

Editor-in-Chief

Lori Hartwell

Managing Editor; Layout & Design

Shari Gilford

Director of Communications

Joseph G. Herman

Editorial Coordinator

Gordon Lore

Distribution

Renal Support Network

Printing

Vindan Print Brokers, Inc., Denver, CO
George Bravdica, owner

Contact Information

Renal Support Network

(818) 543-0896

9 AM-5 PM Pacific Time

Submissions, Newsletter Business

shari@renalnetwork.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

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The World or Bust

by Bill Peckham, weKAN Patient Activist

Why do I travel? I think it comes back to how I deal with kidney disease and life in general.

I live in the moment—which, let me tell you, has its significant drawbacks. I'm never prepared for tax season; in fact, I'm terrible at managing money. As long as I have a couple of bucks in my pocket, I'm good to go. I also lose track of friends.

If I'm with you, or if I see you every day, or if you make it onto my Yahoo calendar, then you have my undivided attention. But change routines or move and I'll not be the one who keeps in contact.

On the other hand, living in the moment does have its advantages. With kidney disease, living in the moment has allowed me to free myself from expectations. I wake up, the legs work, the eyes see, and I'm ready for the day. I generally don't worry about a shortened life span or about what 15 or 30 more years of dialysis may hold.

My expectations are short-term: the morning walk, tonight's dinner, the next trip, because if there's ever a time to be in the moment it's when you're traveling. The greatest moments I've ever had (and some truly dark moments too) have been while traveling. It is while traveling that life seems most real, the most detailed.

Why bother traveling? When I write about my travels, I like to report on the beautiful beaches, the lovely people, the great food.

But, there are other places, and there are other days. Places where you wonder why you ever left home, and days you want only to forget. Marseilles was horrible, but when I

find myself in a Marseilles, I just get on a train and find a Florence.

When I'm traveling, my goals are immediate: food, rest, and (most recently in Cancun) learning Spanish. My expectations are few. Tomorrow I may rendezvous with a friend I've known for over 35 years, a friend who lives in

the opposite corner of the country, but who I see more often than friends who live across town because we both love to travel. Or tomorrow I may be alone, but content. Content to explore an unfamiliar landscape and marvel at the world before my eyes.

Since starting dialysis in 1990, I have been to 29 countries, dialyzing in 19, on five continents. I have an informal goal of getting to 50 countries, so I'm already 60 percent of the way there.

Why do I travel? I travel to live life, the full spectrum. From floating on my back in the dark waters of a magical cenote (an underground natural pool) to holding the hand of an unconscious loved one far from home, it is life, and life is most clear to me when I leave home and see what is over the horizon.

Why do I travel? Because when I leave home I wake up. ☺



Bill Peckham (right) with his brother Charley in 1999 on top of Sydney Harbor Bridge in Australia.



Bill Peckham has undergone dialysis since 1990. In 2002 he was the first person to use the Aksys PHD[®], after its FDA approval, for short daily home hemodialysis. Bill serves on the board of trustees of the Northwest Kidney Centers in Seattle, WA, and recently received NKC's prestigious Clyde Shields Award for making a significant contribution to the welfare of kidney patients.

Kidney Care Bill

Continued from page 1

year's effort, the Renal Support Network is again sending weKAN patient activists to Capitol Hill, in mid-June. This time, the patients will be honing in on key members of Congress who could help assure the bill's passage, as well as legislators from states not visited last year.

The goal is not only to gain more cosponsors, but to build relationships and help lawmakers "put a face" on kidney disease. One of the comments by a legislator heard last June emphasizes the importance of building those relationships: "Patients tell the truth; that's why we listen to them."

The bill's main points include increased patient education, national standardized training for dialysis technicians, reimbursement incentives for placement of fistulas, removal of barriers to providing home dialysis options, and an annual increase to the Medicare composite rate (the payment per treatment provided to dialysis clinics).

We reported in the Fall 2005 issue of *Live & Give* that there



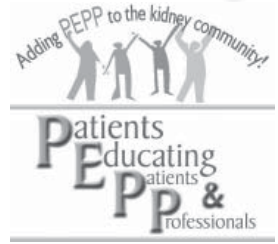
were 120 cosponsors in the House and 19 in the Senate. As of the end of May 2006, those numbers have increased to 146 in the House and 23 in the Senate!

After weKAN patient activists again converge on Capitol Hill this June—building relationships and having fun—you can expect those numbers to increase even further! Look for the report in our next issue of *Live & Give*. Or, for a sneak preview, check out the number of cosponsors on our website, RSNhope.org. ☺

Editor's Note: Read more about Bill's travels around the world at www.globaldialysis.com. Go to "Blogs" and select "Bill" from the Author list.

Adding PEPP to the Kidney Community!

PEPP Speaker Training in Los Angeles, January 2006



LEFT: PEPP speakers on graduation night. (A few missed the photo.)



LEFT: Gail Wick, RN, (standing) shares insights with Tiffany Strohmeier Sanchez (left) and Patricia Sanchez. Gail, a nephrology nurse and recognized speaker at professional conferences, offered input and tips to the PEPP trainees.



PEPP trainees listen intently as they are taught to present complex information.

Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has.

—Margaret Mead, author

Making an Impact on Life

by Jim Dineen, PEPP Speaker

As I wrote this story, two words replayed continuously in my mind—*moving* and *motivational*.



Jim Dineen, from West Chester, OH, 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. They have two married daughters, three grandsons, one new granddaughter, and another grandchild due in August. 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.

These words summed up my

Motivational

experience in Los Angeles while training to become a PEPP speaker. PEPP stands for Patients Educating Patients & Professionals, and is a new program of the Renal Support Network.

Before the word kidney became a part of my everyday vocabulary, I was a trainer and speaker on such “exciting” topics as “Outplacement: How To Find Your

Next Job.” But as my grown daughters reminded me before I left for my PEPP training, now I’ll have something to speak on that actually counts!

As the training began, I sat bewildered over my apparent lack of

knowledge of a disease I thought I understood.

Words like “hyperparathyroidism” and “erythropoietin” just rolled off the lips of some of the other PEPP speakers. We worked with motivational speakers and medical professionals who helped us—a group of mostly novice speakers—become proficient.

Watching and listening to the 20 or so PEPP speakers as they told their stories, and spending time getting to know these new friends, was truly one of my greatest life experiences. But as much as I was moved and stirred to action, I was also motivated.

Many of the PEPP speakers have been on dialysis for more than 20 years, stick themselves with needles every day to control their diabetes, have had more surgeries than I care to count, and still strive to inspire others to overcome their illness.

Moving



Cher Thomas (left) and Roanne Faith Dale spend time chatting over lunch. PEPP trainees came away from Los Angeles with many new friends.

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

PEPP PRESENTATIONS

The goal of PEPP is to improve the outcomes of people who have kidney disease, encouraging involvement and self-management in their own care. Each PEPP presentation runs from 30 to 45 minutes.

FOR PATIENTS AND FAMILY MEMBERS

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

After hearing this presentation, the audience will come away feeling empowered and hopeful despite the complexities of this condition—which are explained in uncommonly clear-cut terms.

Energize Yourself: What you need to know about anemia

This presentation blends the cause of CKD-related anemia with ways to help prevent or manage anemia, highlighted by firsthand stories from the patient-speaker.

FOR PROFESSIONALS

Promoting Patient Participation in the Dialysis Setting

The patient-speaker shares insights on how healthcare professionals can encourage patients to become more actively involved in their treatment plan and reach their full potential.

If you would like to schedule a PEPP speaker at your next event, contact Lori Hartwell at (818) 244-9041 or Lori@RSNhope.org.

I realized I could never again say “I know just how you feel” as I learned of their varied experiences with kidney disease. Each and every one of them motivated me to find new and creative ways to educate people on what this disease does and what it costs in terms of feelings, emotions, families, friendships.... I will forever be ignited, affected, and grateful.

For four enlightening, inspirational, educational, moving, and motivational days, we had fun. At the beginning of his weekly TV show, Jerry Seinfeld would say that the two greatest fears are fear of death and fear of public speaking, and not in that order. In Los Angeles we learned that the latter may not be so frightening after all, and that a small group of people—who have undergone some of life’s most difficult experiences—will truly make an impact! ☞



Bodine Balasco, entertainer and acclaimed motivational speaker, demonstrates his message with slight of hand during his presentation at the PEPP graduation dinner.



From Patients to Experts

Continued from page 1

centers and sent to live together in Los Angeles for four days. Sure, they survived kidney failure, but can they survive Jack Barnard, professional speaking coach?!”

Actually, the idea behind the PEPP program made a lot of sense. Who could be more qualified to talk to people about living with kidney failure than those who actually live with it? We have faced the reality of kidney disease and have something to say.



Jack Barnard, professional speaking coach, energizes PEPP trainees with his interactive presentation style and bold personality.

I have spent over half of my 30 years living with kidney disease. The idea of my teaching patients about things like anemia, secondary hyperparathyroidism, and how to actively participate in their treatment plans made perfect sense. Why? Because those things had major and lasting impacts on my life and generated experiences that I could readily share.

We spent the first morning getting to know each other and sharing our personal stories. Then professionals gave the three presentations, in their entirety, that we were to learn.

What at first seemed to be a daunting task fell into place as we broke each presentation down into small parts and went through them over and over again, practicing in front of the others. We also told and retold our personal stories. At times it was completely exhausting, but somehow we got it done.

In just a few short days we were transformed from ordinary kidney patients into experts on anemia, secondary hyperparathyroidism, and adherence. But even more importantly, we went from being a group of 20 strangers to a group of 20 friends, armed with three fantastic presentations that we can’t wait to share with everyone! ☞



Tiffany Strohmeier, PharmD, first started on peritoneal dialysis (PD) when she was 15. While working on her Doctorate in Pharmacy degree at the University of Kansas, she received a kidney transplant from her mother. In 2005, Tiffany returned to PD and is waiting for a second transplant. She works as a pharmacist and is returning to school to complete a PhD in clinical psychology.



Slip, Slop, Slap

Preventing Harmful Effects of the Sun

by Lori Hartwell

Warnings about the damaging effects of the sun's ultraviolet (UV) rays on the skin have been at the forefront of health advice for years. As a kidney transplant recipient, I know that the chance of getting skin cancer is much higher for me than for the rest of the population.

The body's natural immune system destroys cancer cells every day, but when you take immunosuppressant medication following a transplant, you are at somewhat of a greater risk of developing cancer. If you are on dialysis, your immune system may be weakened

as well, so it is critical to protect your skin too.

Early detection and treatment of skin cancer is key. Remember to conduct self-exams regularly, including on your scalp. It is also a good idea to see a dermatologist periodically.

Slip, Slop, Slap

The American Cancer Society developed a campaign—*Slip! Slop! Slap!*—to encourage everyone to cover up when outside in the summer sun:

Slip on a shirt or other protective clothing.

Slop on a “broad-spectrum” sunscreen (one that protects against both UVA and UVB rays). Apply to all exposed skin at least 20 minutes before venturing out.

Slap on a hat and UV-protected sunglasses, or bring a light-colored umbrella if you're going somewhere where there is no shade (black umbrellas absorb heat).

The sun's rays tend to be strongest between 10 a.m. and 4 p.m., so try to schedule outside events to avoid those times. On cloudy days, be sure to cover up; even if the sun's visible rays aren't getting through the clouds, the UV rays are.

Choosing a Sunscreen

There are many sunscreen products to choose from. A product's “sun protection factor” (SPF) rates the level of sunburn protection that it offers. The higher the SPF, the higher the sunburn protection.

Say you normally get a sunburn in 20 minutes. If you apply an SPF 15 sunscreen, you'll be protected for about 300 minutes (SPF 15 x 20 minutes = 300 minutes).

Sunscreens with an SPF of 15 or higher are generally thought to provide useful protection. Very fair-skinned people probably require an even higher SPF (ask your dermatologist).

Here are a few tips to help choose a sunscreen that's right for you:



Look for a sunscreen that's waterproof if you'll be in the water or sweating a lot.



Skin-care products, such as moisturizers or make-up, that also contain sunscreen (SPF of at least 15) are a real time-saver.



Always check the expiration date on your sunscreen. It will not be effective if it has expired.

LOOK FOR THESE SIGNS OF SKIN CANCER

Any change on the skin, such as a new darkly pigmented growth or spot, but especially in the size or color of a mole.

The spread of pigmentation beyond its border, such as with a mole or freckle.

A spot or growth that continually itches or hurts, becomes crusty, or bleeds.

A sore that does not heal.

On Top of the World

Continued from page 8

wanted to see her ski again. She acknowledges that it took her some time to think about it and feel good enough to get back into skiing. But once again, Lacey isn't one for being left behind.

Lacey chose CAPD as her dialysis modality and began training again. She also continued to write songs, sing, and perform, which is another love of hers. In January of this year, Lacey was invited to perform at RSN's Renal Teen Prom, which is held annually in Southern California.

“The prom was great! I think it's such a fantastic idea,” says Lacey. “I know what it's like to be in their position, when you miss your prom and you miss all your fun



events because you're in the hospital or you're sick. I think the Renal Support Network did a fantastic job putting it all together. I was really honored to be a guest and be a part of it.”

Lacey enjoys being a positive role model: “I think there needs to be good messages out there. We really need to hear something positive, and I think that we are more powerful than we think we are. Having more positive influences, messages, and events in our lives is really going to help us heal.”



Dawn Dungan is a kidney transplant patient who lives with her husband in Billings, MT. Throughout her 20 years with kidney disease she has learned many lessons about life, which she shares through writing and public speaking.



Buy an extra tube of sunscreen and keep it somewhere handy (in your car or purse) for unscheduled activities in the sun.

With a little precaution and common sense, you can enjoy your time in the sun!



Princess For a Day

A Community Event in a Blessed Life

by Martinlow V. Spaulding, MAA, BA, weKAN Patient Activist & PEPP Speaker

Despite having lived the past 14 years with kidney failure, my life has been blessed in countless ways. Because of this, I want to give back to my family, community, and other people with chronic kidney disease. My greatest blessing has been to be a “Daddy” to my six amazing children (one boy and *five* girls!), so I welcome any opportunity to be involved in their activities.

I was diagnosed with kidney failure in 1992 and was started on peritoneal dialysis (PD). The following year, my brother, Paul, gave me the “gift of life,” a kidney. Following that kidney’s rejection 10 years later and another stint on PD (CCPD), my sister, Rita, gave me one of her kidneys. These precious gifts made me aware that family was the greatest gift of all, and I was determined to do all I could to enhance the lives of not only my own family, but the lives of others as well.

Do Dads Club

As a member of my children’s Do Dads Club at Heather Hills Elementary School in Indianapolis, I have the joy of organizing events for the students and their families. My goal is, “Leave them with an experience!”

The Do Dads Club grew out of All Pro Dad, a part of the Family First Foundation led by Tony Dungy, head coach of the Indianapolis Colts football team. Tony wanted to raise



Martinlow V. Spaulding, MAA, BA, has been both a dialysis and kidney transplant patient since 1992. He is a recipient of The Renal Network’s (ESRD Network 9/10’s) Patient Services Award and Felter Patient Memorial Award. He had careers in nonprofit administration since 1990 but currently is an Organizational Behavior Domestic Engineer (“Mr. Mom”). Martinlow, with his wife Elaine (a kidney/cancer nurse) and their six children live in Indianapolis, IN.

awareness about dads who participate in the lives of their children.

As a way of giving back through the Do Dads Club, I organized a “Princess For a Day” gala at the school, allowing dads to show their daughters how very special they are to them. (Not to leave out the sons, “princes” were also welcome to attend.)

Once Upon a Saturday Morning

The school gymnasium was decorated in the style of a fairy tale castle. Following a special breakfast fit for a king (or was it fit for a princess?), each girl—wearing a darling princess outfit and priceless smile—was escorted by her dad into the gym through a brightly lit entrance. The dads wore “king” crowns they had made with their girls, but it was the princesses who ruled the day, and the kings bowed to them and obeyed their royal commands.

Upon entering the castle, every princess received a royal makeover complete with colorful face make-up, beautiful hairdos with bright accessories, shiny fingernail polish with glitter, and sparkling jewelry. It surprised the dads a bit when the princesses “commanded” that the dads should have fingernail polish as well, but all complied and were actually showing off their dazzling nails.

Then a very special moment:

The princesses and kings danced to fairy tale music. Afterwards they received a photo of the royal couple



The princess and her king in royal splendor.

for an everlasting memory. Everyone enjoyed the royal celebration and lived happily ever after.

Giving of Yourself: The Most Priceless Gift of All

“Leave them with an experience” is my philosophy when organizing a community event. Princess For a Day is an awesome experience (and now an annual event). It allows dads who would probably never think of doing something like that a chance to be more loving toward their daughters.

My life is also blessed with other fulfilling “give back” activities. One program I organize is the Child Care Exchange, providing parents with a monthly night off to share special time with each other. The Exchange parents take turns babysitting at the school while they and the kids enjoy dinner and a movie. I also co-chair the school’s Talent Showcase, which encourages dads to perform with their children.

Many dads choose to be a “provider” for their children by giving, giving, and giving *things* to them instead of giving the most priceless gift of all—their *time!* I believe the greatest gift that any dad can leave his

community is not money or items, but legacies... his children.

Live for others!



Dad (Martinlow) applies his nail polish with help from his princess daughter.

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In this issue of Live & Give...
 PEPP Training: Photos and Stories

Spotlight On You

On Top of the World

by Dawn Dungan, weKAN Patient Activist & PEPP Speaker

Wife. Singer. Sister. Teammate.
 Aunt. World Champion monoskier.
 Daughter. Kidney patient. Songwriter.
 Role model.

Lacey Heward wears many hats, both professionally and personally. As a member of the U.S. Disabled Alpine Ski Team, she is competing in the 2006 Paralympic Games in Sestriere (Torino), Italy, as this article is being written. The Paralympics are equivalent to the Olympic Games, except they are for disabled athletes.

Lacey was injured at 16 months old when a 100-pound barbell fell on her back, crushing her spine and leaving her wheelchair-bound. Growing up in an active family, which included four sisters and a brother, Lacey learned early

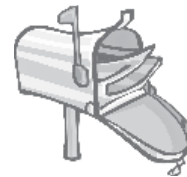
on to keep up with them or risk being left behind. And Lacey isn't one for being left behind.

In 1999, she decided she wanted to take her love of skiing to the next level, so she began racing competitively. By 2002, she had won her way into the Paralympics and a bronze medal. Later, as the number-one-ranked woman monoskier in the world, Lacey was diagnosed with kidney failure.

"It was a huge surprise to me," says Lacey. She was taken completely off guard by the diagnosis. "I thought I was just exhausting myself with the training." She says she found huge support from her family, friends, teammates, and coaches, all of whom



Lacey Heward sings at the 2006 RSN Renal Teen Prom.



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

Calendar

Renal Support Network Patient Lifestyle Meetings

California

- June 25 Tarzana
- July 30 Bakersfield
- August 20 Riverside

3rd Annual RSN National Patient Meeting

Health, Happiness & Hope
 Oct. 5 - Oct. 7, 2006
 Philadelphia, PA

All glory comes from daring to begin.

— William Shakespeare

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