



A PROGRAM OF
RSN
Renal Support Network

Live & Give

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

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Headline News

Success on Capitol Hill weKAN Activists' Training Pays Off

by Shari Gilford, weKAN Patient Activist

The bright sun sparkled through the windows of the hotel meeting room where we had gathered for breakfast. The shared sense of anticipation that permeated our thoughts and conversations mirrored the sun's exuberance. Excited chatter filled the air.

This day – Tuesday, June 14, 2005 – marked the culmination of months of preparation. Today, 20 kidney patients, some joined by family and friends, would make a difference on Capitol Hill. Our mission: to convince our senators and representatives to become cosponsors of the Kidney Care Quality and Improvement Act of 2005.

Arriving on Capitol Hill in small groups, we braved the sweltering heat for a moment

before entering the Senate and House buildings. Armed with information packets, gifts, and our knowledge (none of which set off any alarms when we passed through security), we courageously navigated the long, high-ceilinged hallways. The marble floors echoed with our footsteps. This was unfamiliar territory for many of us, but we walked confidently. We were well prepared.

One of the goals of Lori Hartwell, a kidney patient herself and the Founder/President of the Renal Support Network, is to equip patients to advocate for themselves and their fellow patients. She formed weKAN – Wellness and Education

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weKAN members enjoy some social time in the hallway of the Hart Senate building, en route to more meetings.

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RSN Report

RSN Brings "Health, Happiness & Hope" to the Windy City

Take a genuine desire for **Health**, an atmosphere of **Happiness**, and the power of **Hope**, combine it with kidney patients and family members from around the country, and you have the 2nd Annual Renal Support Network (RSN) National Patient Meeting, to be held September 29 to October 1 in Chicago.

With "Health, Happiness & Hope" as the theme, the meeting will emphasize the RSN tradition

of patients helping patients. Speakers include patients who have chosen to view kidney disease as an obstacle rather than a deterrent. Some of the topics they will discuss include returning to work, being a full-time parent while on dialysis, and how to nurture a positive attitude when life is tough.

"An illness is too demanding when you don't have hope," emphasizes Lori Hartwell, President and Founder of RSN. "Our mission is to help provide

that hope and help reassure these people that they are still of great value despite having kidney disease."

Healthcare professionals will also lead sessions on a variety of topics including fad diets (from a renal perspective), connecting with your physician, and new trends in transplantation. An informative panel discussion by patients and

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weKAN and we DID!

by Lori Hartwell, weKAN President



One of my favorite Chinese proverbs is, "Tell me and I'll forget, show me and I may remember, but involve me and I'll understand." This quote is a roadmap to patient involvement.

Mapping out the plan for weKAN "patient activists" to visit Capitol Hill was a first-time experience for Renal Support Network (RSN). Knowing it was imperative to involve these intelligent patients in the process, RSN scheduled interactive conference calls to provide a forum for questions and input. The training materials created from this information would help patients become successful as effective spokespersons and advocates on behalf of fellow kidney patients.

The goal was simple – for each patient to make a personal connection with his or her elected officials and to

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Thank you for your help!

weKAN Live & Give is a publication of the Renal Support Network, a patient-run non-profit 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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enjoy the experience. In addition, we aimed to give the patients the tools they needed to succeed in advocating for the Kidney Care Quality and Improvement Act of 2005 on Capitol Hill. Ultimately, we wanted more members of Congress to cosponsor the bill.

Scheduling an appointment and meeting with members of the U.S. Congress can be intimidating to most, but long-term kidney patients already have the skills to be effective advocates. After all, they have had to learn how to be persistent when talking to busy doctors, or when navigating complex insurance issues.

The weKAN patient activists are a very special group of individuals; many of them took time off from work or left their families to make the trek to DC. They are a volunteer "sales force."

As I reflect back on my days as a sales manager, I remember how imperative it was that I believe in and understand my product. Otherwise, the results could be disastrous. After a difficult sales meeting I would feel defeated, upset that I had not done my best.

It was also imperative that I involve the customer – in this case, the elected official. Real-life demonstrations generate interest. One of the patient activists on peritoneal dialysis explained that there is a special solution in her peritoneal cavity, and she was dialyzing at that moment. Another patient activist showed her dialysis access, a fistula, and informed the legislator that this was her "lifeline."

At the time of this printing, the Kidney Care Quality and Improvement Act of 2005 has 90 cosponsors in the House of

Lori Hartwell looks on as Jennifer Castillo shows her dialysis access to Paul Mitchell, legislative aide to Senator Boxer of California.



Representatives and 11 cosponsors in the Senate. If you want to learn more about H.R. 1298 and S. 635, keep reading this issue of Live & Give! For more information, visit our website at www.renalnetwork.org.

I encourage you to get to know your elected officials so that they can understand the needs of kidney patients by learning about you. If you would like to contact them, either in writing or in person, and need assistance, give us a call. We would be delighted to help you!

Since I began with a quote, it seems appropriate for me to end with a poem that epitomizes our organizational philosophy:

Did is a word of achievement
Won't is a word of retreat
Might is a word of bereavement
Can't is a word of defeat
Ought is a word of duty
Try is a word each hour
Will is a word of beauty
Can is a word of power

– Anonymous

Chronically Yours,

Lori Hartwell

President and Founder of Renal Support Network

Thanks to our sponsors!



Fresenius Medical Care



Do you know a patient who is making a difference in the lives of other patients? Please tell us! We may feature that person in an upcoming issue of Live & Give.

"Health, Happiness & Hope"

Continued from page 1

professionals will explore various home dialysis options now available.

This marks the second consecutive year that the RSN will be holding its annual meeting side by side with the annual conference of the National Renal Administrators Association (NRAA), making it the only concurrent national gathering of kidney patients and professionals in the United States.

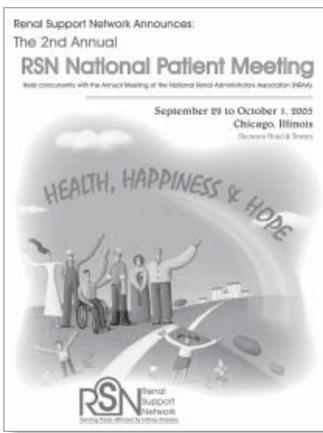
"Sometimes we lose sight of our common objective – quality care in the dialysis facility and a quality life for the patient," explains Lori. "This meeting provides a nice crossover between the patient and healthcare professional."

Joint sessions with the NRAA will focus on topics of mutual interest, and the NRAA vendor exhibit hall will be open to RSN attendees. Friday night entertainment will feature Jamie Gilbert (a.k.a. Jamie-G), a renowned Canadian magician who is currently on dialysis.

"Health, Happiness & Hope" will educate patients and family members about chronic kidney disease (CKD), provide them with hope for a better tomorrow, and inspire them to achieve their goals.

Echoing the sentiments of many of last year's attendees, one patient commented, "Saying goodbye was the hardest part. I had made many new friends who are going through the same things as myself. I hope to stay in touch, and see them all at the next meeting."

Come to this year's meeting and meet these inspiring people yourself! ☞



To download a complete program agenda and registration form, go to www.renalnetwork.org.

To request a meeting brochure by mail, contact RSN at (818) 543-0896, or info@renalnetwork.org.

Success on Capitol Hill

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Kidney Advocacy Network – to meet this goal. A cross-section of weKAN members were about to leave their mark on Capitol Hill.

weKAN "patient activists" learn how to become leaders in the kidney community through monthly conference calls, educational events, involvement in their local area, and relationships with other self-motivated kidney patients across the United States.

"I view the patients in weKAN as leaders, and as future leaders," Lori explains. "Some of them have been successful at taking charge of their own healthcare for 20 or 30 years. But it's no longer about advocating only for their own care, it's about advocating for others. It's about patients helping patients. That's what sets us apart from other organizations."

Our preparation began several months prior to our arrival in Washington, DC. During monthly conference calls we learned how to contact our elected officials and set up face-to-face meetings. A sample script helped us organize what to say. We practiced how to introduce ourselves, tell our story, stay focused on our message, and intelligently articulate the main points of the bill. The results of this excellent training would soon be determined.

Though we did visit with some senators and representatives, the majority of our appointments were with congressional aides specializing in health legislation. Young and intelligent, these aides were eager to hear our stories and understand how the Kidney Care Quality and Improvement Act of 2005 would help us personally.

One key aspect of the bill would guarantee an annual increase to the amount paid by Medicare for each dialysis treatment – the Medicare composite rate. To underline the importance of this aspect of the bill, many of us stated, "I'm living proof that the Medicare program works!" (See a summary of the bill on page 6.)

By the end of that busy Tuesday, 20 kidney patients, representing 16 states, completed a total of 55 appointments. We met in cramped offices, large conference rooms, hallways, and at



Button worn by weKAN patient activists on Capitol Hill. If you would like a button of your own at no charge, please contact RSN.

a table in a noisy cafeteria (while munching on popcorn). The relaxed atmosphere coupled with the genuine interest of those to whom we spoke strengthened our confidence in ourselves and in our message.

Many weKAN members had never previously contacted an elected official. "They discovered how to step out of their comfort zone for the benefit of others," Lori stated proudly.

The results? Eight members of Congress became cosponsors of the bill that day. At least 20 other members of Congress or their aides expressed greater interest in cosponsoring the bill – which was a feat in itself, we were told. The Washington lobbyists who were aware of our visits emphasized their amazement at our accomplishments. Our energy, professionalism, and unusual degree of success had greatly exceeded their expectations! We made a difference! ☞

Many weKAN members had never previously contacted an elected official.

You too can make a difference! Read "It's Your Turn" on page 6.



Shari Gilford was diagnosed with kidney disease in 1977 at age eleven. While she awaits a third transplant, she does her own hemodialysis treatments overnight in her home. She pioneered a newsletter for her local dialysis clinic and was also trained as a dialysis technician.

We must be the change we wish to see in the world.

– Gandhi

June 14, 2005

weKAN Patient Activists Meet with Members of Congress in Washington, DC



Senator Norm Coleman (R-MN) with Keith and Lisa Brandt.

"The most memorable thing about our trip to Washington, DC, was meeting with my senator, Norm Coleman (R-MN). He is very nice, down-to-earth, and cares about people. He allowed us to take a picture with him and wished us good luck. I was so nervous, but there was absolutely nothing to be nervous about. He became a cosponsor!"

- Lisa Brandt

"All our senate and congress folks had young, smart, good people working in their offices. Most were informed about our issues and wanted to take our views to their senator/congressperson. OUR representatives are listening. And I now know what is meant by 'the halls of Congress,' because by the end of the day it had been a long walk!"

- John Derrig

Representative Shelley Berkley (D-NV) receives a certificate of thanks from weKAN members for cosponsoring the Kidney Care Quality and Improvement Act of 2005.

From left: Izabella Khachoyan, Lori Hartwell, Bill Dant, Rep. Berkley,



"The experience of fine, well-organized training, getting to know each other better, and a very productive day of visits on Capitol Hill brought back memories from over 20 years ago when I first began doing this. The big difference: patients with little or no experience in lobbying worked very hard beforehand, arranged their own visits, were well prepared, and accomplished so much. RSN and weKAN showed how commitment, organization, and a light and joyful approach make a huge difference. One congressional staff person told me: 'Patients tell the truth – that's why we listen to them.'"

- John Newmann

"The sheer excitement of walking into our first visit made the trip worthwhile. We were treated very well and welcomed as if we were old friends getting together after a long absence. Representative Walter Jones (R-NC) was patient, warm and understanding. Most surprisingly, he had done his homework and was not only knowledgeable about the legislation, but had also visited a dialysis unit. He was immediately engaged in the visit and empathetic about the existing and future needs of patients. He agreed to sign on as a cosponsor that afternoon, and did so as promised. It is especially exciting to realize I can be more involved in a process that I frequently feel overwhelmed by and removed from."

- Jennifer Castillo



Jennifer Castillo (left) and Dawn Dungan (right) talk to Representative Walter Jones (R-NC) in his office.



Paul Mitchell, legislative aide to Senator Barbara Boxer (D-CA) with weKAN members. Back row from left: Rhonda Brooks, Tim Ryder, Jennifer Castillo, Damue Bagwell, Julie Glennon. Front row from left: Terri Melvin, Paul Mitchell, Lori Hartwell, Izabella Khachoyan.

"When Amy Hackney, my father, and I just happened to walk into the offices of Representative Sessions and Representative Green of Texas to pitch the bill – and then to find later that one of them had immediately signed on as a cosponsor – was so powerful. We did not even have an appointment, but he signed on based on the merits of the bill. Congratulations to everyone who was in DC, and to Lori for planning the trip and believing in us all!"

- Leigh Anne Tanzberger



Monday morning: A review of the important points of the bill, plus arranging schedules and logistics for Tuesday's meetings on Capitol Hill.

Below: Lori hands out buttons for everyone to wear. One favorite: "I'm Chronically Happy!"

"The weKAN trip to DC was wonderful. As a patient I truly felt that I was helping to make a difference in the lives of fellow patients. As a transplant patient, I was excited to be healthy and able to lift my voice to help others. I am very grateful to be a part of an organization that allows me the opportunity as a patient to be heard."

- Amy Hackney



"As a kidney patient I have often been held back from 'just doing' because of a feeling of being less than adequate. This trip proved to me that that is no longer true. Meeting congressmen and their aides gave me a feeling of 'being someone' very capable and knowledgeable. I had such a feeling of empowerment. It gave me peace. The icing on the cake was in knowing that we were making a difference in peoples' lives for the future, which only helped to validate my life a little more. And for that I will be forever grateful."

- Terri Melvin

"Washington, DC, was a truly awesome experience. Talking with our representatives about an issue that is so near and dear to one's heart and feeling like we were making a difference really leaves one feeling empowered. I talked with the aide that works for Senator Pryor (D-AR). We had met before and had toured a dialysis facility in Little Rock. This time, however, our meeting hit a little closer to home – her doctor had told her that if she did not lose weight, she was a prime candidate for diabetes. Our discussion turned toward diabetes and high blood pressure, the leading causes of kidney disease. She acknowledged the need for better education before dialysis becomes necessary, an issue the bill addresses."

- Heather Powell



Above: Nancy Sharp, RN, of the American Nephrology Nurses' Association (ANNA) leads a role-playing session with Bonita Balkcom-Guilford and Terri Melvin.



Left: Bill Dant and Greg Castillo engage in the discussion.

"The legislative aide for Senator Schumer (D-NY) expressed surprise to learn that I not only did my own hemodialysis treatments at home, but had also become a certified dialysis technician in New York State. I think she saw that patients really do want to be involved."

- Shari Gilford

"The aide I was talking to seemed quite disinterested until I told her that my kidneys were knocked out by ibuprofen. Only minutes earlier this woman had taken ibuprofen. She almost broke her arm taking that travel-size packet out of her pocket! While she's trying to read the packet with her fingers shaking, I took the opportunity to explain that one in nine Americans have kidney disease and don't know it, and this is an example of why they should be educated and why we need this bill."

- Rhonda Brooks



weKAN members – clockwise from left: Latrice Bolling, Julie Glennon, Lori Hartwell, Lisa Brandt.



John Anderson, former representative of Illinois and 1980 presidential candidate, had breakfast with weKAN patient activists to let them know that elected officials do listen and that a single person can make a difference.

D.C. Participants

weKAN Patient Activists and Family Members

States listed are those each patient represented. Some patients represented more than one state.

- Damue Bagwell..... CA
- Bonita Balkcom-Guilford GA
- Latrice Bolling MD
- Lisa and Keith Brandt..... MN
- Rhonda Brooks CA
- Jennifer and Greg Castillo CA
- Bill Dant..... UT
- John Derrig WA
- Dawn Dungan MT, NC
- Shari Gilford..... OR, NY
- Julie Glennon..... FL
- Amy Hackney..... TX
- Lori and Dean Hartwell CA
- Terri Melvin..... CA
- Joseph Morton and Pearl Lewis..... MD
- John Newmann VA, NY
- Sharon Pahlka..... WA
- Heather Powell AR
- Leigh Anne Tanzberger and parents.... TX



Talking with Congress: It's Not Really That Scary

Most of us probably think of members of the U.S. Senate and House of Representatives as being out of reach. After all, they are very important people, responsible for passing the laws that govern this land.

As it turns out, members of Congress have great respect for the “everyday” person who approaches them. And when that person is a patient – whose very life may hang in the balance of pending legislation – even more respect is paid. This became clear when 20 weKAN “patient activists” and family members recently visited Washington, DC.

The weKAN members – who arranged each meeting themselves – were there to gain cosponsors for the bipartisan Kidney

Care Quality and Improvement Act of 2005 (see sidebar). Perhaps as important as gaining cosponsors to the bill, the patients made a personal connection with their elected officials.

Members of Congress serve at the pleasure of their constituents, and they want to know your concerns. For that reason, it is important that you contact them regarding the Kidney Care Quality and Improvement Act of 2005 and ask them to cosponsor this bill.

The Renal Support Network (RSN) has made this easy. Simply go to www.renalnetwork.org, and click on “Act Now! - Kidney Care Quality and Improvement Act of 2005.”

You will be led through “Easy Steps to Have Your Voice Be Heard,” consisting of a summary of the bill, identification of your elected officials, ways to contact them in both Washington, DC, and your home state, and a series of sample letters and scripts for phoning, writing, or scheduling visits. If you do not have Internet access, please contact RSN at (818) 546-0893 and we will provide you with any information or materials you may need.

A great time to contact your representative and senators in your home state is during August, when Congress takes a recess. Always remember, you are the key to helping lawmakers understand the realities of kidney disease. You are, in fact, the expert. ☞

The Cookie Lady

Continued from page 8

weeks before she needed the money, Marsha, along with her two daughters and her mom, baked cookies, cookies, and more cookies!

“We started at 6 o’clock in the morning on Saturday and we baked, cooled, and packaged cookies until 1 o’clock in the morning on Sunday both weekends in a row,” Marsha reported.

They made chocolate chip, shortbread, peanut butter, oatmeal raisin, and oatmeal chocolate chip cookies. They sold the cookies by the dozen to family members, friends, and kidney patients.



One fellow patient who doesn’t bake anymore bought 25 dozen and gave them away as gifts. Another bought eight dozen and put them in the freezer for when her grandchildren visited.

Marsha and her family baked 125 dozen cookies each weekend for a grand total of 250 dozen cookies baked and sold! So, how many cookies does it take to get from Hawaii to Denver? 3,000! That’s a lot of cookies!

So, was it worth all the effort? Marsha quickly replied, “Oh, definitely! I will be baking my cookies again this year. I will start in the summer so I don’t have to cram all that baking into two weekends. That was a lot of work.”

Marsha added excitedly, “I look forward to being there every year. I’m just hoping it will be in Hawaii one year.” So do we, Marsha.

And with her perseverance, determination, and enthusiasm, who knows? ☞



Dawn Dungan is a kidney transplant patient. Her 20 years of experience with kidney disease influences her work as the patient activist coordinator for weKAN. She has a degree in English and does freelance writing. As a public speaker, she focuses on kidney disease, diabetes, and death/dying. She and her husband live in Billings, MT.

*We make a living by what we get.
We make a life by what we give.*

– Winston Churchill

Kidney Care Quality and Improvement Act of 2005

Major points include:

- early screening programs and education to help control the onset of kidney disease in those at risk
- standardized training for dialysis patient care technicians
- annual increase in the payment made by Medicare for each dialysis treatment (Medicare composite rate)
- financial incentives promoting placement of fistulas instead of grafts
- education for patients on self-management skills and modality choices
- removal of barriers to the option of home dialysis

The bill is being supported by Kidney Care Partners – an alliance of patient advocates, renal care professionals, and dialysis providers and suppliers (www.kidneycarepartners.org).

Legislative Update



More Frequent Dialysis

by John Derrig, weKAN Patient Activist

A new bill introduced in Congress by Rep. Jim McDermott (D-WA) – the Kidney Patient More Frequent Dialysis Quality Act of 2005 – will increase reimbursement for people who could benefit from more frequent dialysis treatments.

If approved, this bill will allow the Medicare Program to pay for up to five hemodialysis treatments per week for qualifying patients either at home or in a facility, as well as payment for in-facility training for more frequent hemodialysis. It requires the clinical judgment of a physician to determine whether the individual is likely to

achieve better clinical outcomes, quality-of-life outcomes, or both from more frequent hemodialysis. Many patients who dialyze more frequently experience a decrease in medications, a decrease in hospital admissions, and an increase in overall health.

The bill also directs the Secretary of Health and Human Services to periodically review and update quality standards for more frequent hemodialysis, and to collect data and document savings in expenditures due to the improved health of patients.

Write to your representative and ask him or her to cosponsor HR 3096. ☞

Summer Diet Tips From a Pro

by Leigh Anne Tanzberger, weKAN Patient Activist

As a dialysis patient growing up in New Orleans ("Fat City") – where all people do is eat, drink, and go to restaurants – I have learned a few "tricks of the trade" over the past 20 years because, I must confess, I am no different than anybody else . . . I love to eat out!

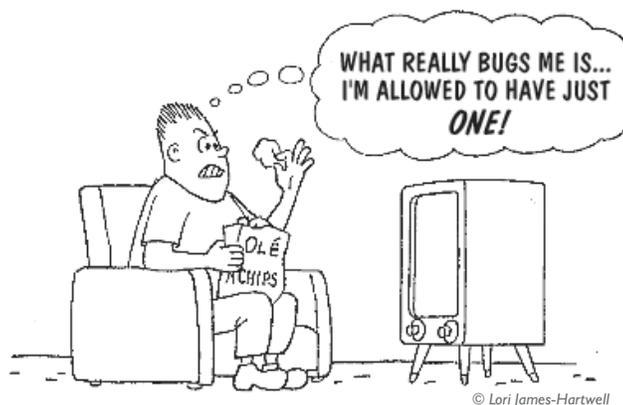
When I go to a restaurant, I always ask for my drink with extra ice. The ice takes up space, so there is less liquid to drink. I also use my straw to drink more slowly. I put the straw in my drink, plug the top of the straw with my finger, and then drink the little bit of liquid inside the straw.

Depending on what I order, I ask for no added salt. You will still get some sodium when you eat in a restaurant, but by eliminating any added salt you can at least decrease your total sodium intake.

Although I really like to eat out, I usually limit it to once a week. If you eat out more often, find places that will give you some good low-sodium options, and remember which menu items would be best to choose.

Some other tricks I've learned:

✓ I stay away from potato chips, Cheetos, nuts, and other salty snacks because they make me more thirsty. And when I drink too much, the fluid I retain causes my next dialysis session to be harder on my body.



- ✓ I do not ADD salt to my food at all! If I want some added flavor, I use spices. Be creative and experiment with new flavors.
- ✓ Frozen grapes are a very refreshing treat that will help quench your thirst.
- ✓ I really enjoy Popsicles on hot days. Each Popsicle stick (the singles, not the doubles) is only 1 to 2 ounces of fluid.
- ✓ Another idea is to fill an ice cube tray with your favorite drink – iced tea, lemonade, Kool-Aid, or Crystal Lite if you're diabetic. You can then suck on one of these flavored ice cubes to quench your thirst rather than drinking a full glass of liquid.
- ✓ Other dialysis patients I've known over the years recommend sucking on some hard candy. Sour balls, Lifesavers, or sugarless hard candy can help quench your thirst.

✓ My personal trick, however, is to drink a small "ICEE". Since it's frozen, you are drinking only about half the amount of fluid that you think.

✓ Finally, if nothing else works, sucking on a lemon wedge will always quench your thirst!

Use my "tricks of the trade" and enjoy these hot summer months without being too restrictive. Experiment with creative ideas and share them with your fellow dialysis patients! ☺



Leigh Anne Tanzberger began dialysis in 1978. A transplant she received in 1981 failed four years later since the disease she has is reoccurring. Since 1985 she has performed various modalities of dialysis. In 1993 she earned a degree in Management and Marketing from Rutgers University – School of Business. Among other accomplishments, she has served as president of the New Orleans Kidney Patient Association. Since moving to Texas, she became the first patient to be invited to sit on the Board of Directors of the Texas Renal Coalition.

It's hard to beat a person who never gives up.

– Babe Ruth

MEDICARE IN PLAIN ENGLISH

The New Medicare Prescription Drug Plan

It's coming soon! Starting January 1, 2006, Medicare will be offering plans to help you pay for prescription drugs. This is the Medicare Prescription Drug Benefit, Part D, that you might have heard about.

The wheels start turning on November 15, 2005. Beginning on that date, anyone covered by Medicare can join a Medicare prescription drug plan. The wheels stop turning on May 15, 2006. After that date, you can still join a plan but it will cost you more.

It is important to know that the upcoming drug plans are not the same

as the drug discount cards that you might currently have. The discount cards were only a temporary measure until Medicare Part D kicked in, and they will expire on May 15, 2006.

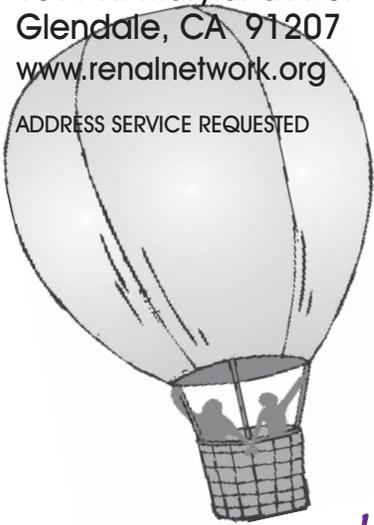
Confused? You're not the only one. The most important thing to remember is that you have to do something, and it would be to your advantage to do it by May 15.

To help ease the confusion (or, possibly, to help add to it), Medicare will be sending you a handbook in the mail this fall – *Medicare & You 2006* – that will list the Medicare prescription drug plans

available in your area.

You also will be able to get free, personalized information at www.medicare.gov, or by calling 1-800-MEDICARE (1-800-633-4227) to help you choose a plan that best meets your needs. Your State Health Insurance Assistance Program (SHIP) also can provide free, personalized counseling about the plans. Call 1-800-MEDICARE to get the telephone number of the SHIP nearest you.

Don't forget to check with your healthcare team. They can help you choose the plan that's right for you. ☺



*YOU can make a difference!
Look inside!*

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trip to Capitol Hill.

Spotlight On You



The "Cookie Lady"

by Dawn Dungan, weKAN Patient Activist

How many cookies does it take to get from Hawaii to Denver, the site of last year's annual Renal Support Network (RSN) National Patient Meeting? To find out the answer, we asked Marsha Hatakeyama, the official "cookie lady" and fellow member of weKAN.

Marsha lives in Kailua-Kona, Hawaii, and is a full-time single mom of two girls – Jennifer (9 years old) and Ashlynn (13 years old). She is a kidney-pancreas transplant recipient. While the pancreas transplant was successful, the kidney rejected and Marsha had to go back on dialysis.

It was during a dialysis treatment in August 2004 that she first heard about RSN's National Patient Meeting (held last September). Lori Hartwell, president of RSN, had visited Marsha's dialysis unit while on vacation. Nearing the end of her visit, Lori met Marsha and handed her a brochure about the meeting. Marsha recounts, "We talked about it for a little while and I said to Lori, 'I don't

know how I'm going to get there, but I'm going."

Marsha kept in touch with Lori by telephone and e-mail about the upcoming patient meeting. These conversations fueled her determination to somehow get to Denver. She shared with friends and family members her desire to attend the conference, which prompted a family friend to generously donate her personal frequent flyer miles to Marsha.

Marsha still needed money for other costs such as the registration fee, hotel reservation, and food. "Unless a bundle of money fell from the sky, my trip just wasn't going to happen because of the time frame," Marsha said with a laugh. "I knew I had to do something."

That was when the cookie idea was born. Marsha's mom likes to bake cookies, so Marsha asked if she would help bake cookies to raise money for the trip. With a time frame of only two



Marsha Hatakeyama, the "Cookie Lady."

How wonderful it is that nobody need wait a single minute before starting to improve the world.

– Anne Frank

Calendar

2nd Annual RSN National Patient Meeting

Health, Happiness & Hope
Sept. 29 - Oct. 1, 2005
Chicago, IL

Annual Renal Teen Prom

Music, Music, Music
Sunday, Jan. 15, 2006
Sherman Oaks, CA

ATTENTION

Did you pick up this newsletter in your dialysis center or transplant facility?
Sign up to receive your next issue at your home address.
Contact the Renal Support Network today!
(see page 2 for contact information)

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