**New Bill Introduced in Congress**

*by* Lori Hartwell and Virna Elly

During the final few weeks of 2006 and the 109th Congress, the “Tax Relief and Healthcare Act of 2006” (H.R. 6111) was passed.

At first glance, it may seem that this bill has nothing to do with chronic kidney disease (CKD). In truth however, it does. At the last minute, key Medicare provisions benefiting the kidney community and kidney patients were added. These provisions include a one-time 1.6% increase to the composite rate beginning April 1, 2007, as well as a requirement that the Government Accounting Office (GAO) submit a report about the payment rates for home dialysis to Congress by January 1, 2009.

**New Bill Introduced**

On February 27, 2007, Senator Kent Conrad (D-ND) along with Representatives Dave Camp (R-MI) and John Lewis (D-GA) introduced a new bill called the “Kidney Care Quality and Education Act of 2007” (KCQEA 2007), bill numbers S. 691 and H.R. 1193 respectively.

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**RSN Report**

**NASCAR Angels Help a Prom Volunteer**

*by* Tim Ryder, RSN Staff

It all started with the Renal Teen Prom, held on January 15 at Notre Dame High School in Sherman Oaks, California. Organized by the Renal Support Network (RSN), the Renal Teen Prom usually garners a lot of publicity, and this year an article that appeared in the *Los Angeles Times* caught the attention of the NASCAR Angels.

Who are the NASCAR Angels? That’s the same question Lori Hartwell, president of RSN, asked when she received a call from a representative of the organization, which had decided to do a car makeover for one of RSN’s prom volunteers.

Hosted by Rusty Wallace (former NASCAR champion) and Shannon Wiseman, the NASCAR Angels television show airs across the country on Sunday afternoons. Shannon first films an interview with the chosen person or organization on location. Over the next few days, the process of repairing the vehicle—both mechanically and cosmetically—is also filmed. The show ends with a grand finale: the revealing of a like-new car in front of a live audience of family and friends. It’s a very positive show that features and...
Anyone who has ever gotten anywhere in life will tell you that they exercised a lot of stiff-lipped persistence. When recalling the early days of their career, few successful entrepreneurs can forget the rejections they endured, along with plenty of nail-biting and toe-tapping.

Likewise, every person who is living well despite chronic kidney disease is doing so because of stubborn persistence. It is that refusal to give up despite some very rough going—along with hope that things will get better—that characterizes the achiever.

The area of personal strength in which I take the most pride is my persistence. In managing my chronic illness, I’ve found persistence to be key in allowing me to feel a sense of control over my destiny. As my healthcare workers will tell you, I never quit! When I have a question, I don’t give up until I get an answer. If one doctor doesn’t give me the information I need, I go to another one, or I’ll look something up on the Internet, or I’ll find a nurse or some expert who is willing to help me.

I am also unyielding where my dreams are concerned. I learned early on that if I did not nurture the hope that I would fulfill my dreams, I would not want to take care of myself.

Just as winners must exercise persistence, in most cases they must also wade through a sea of negative feedback. The world has no shortage of people who will try to convince you that your dreams are silly. They might not say it in so many words, but they imply it by saying, “Are you sure that’s realistic?” or “Gee, that seems like an awfully big challenge!”

My dream was to find a way to provide hope to those who have kidney disease and those who care for them. I have certainly encountered many obstacles over the years, but I just kept pursuing my dream anyway! Now I can proudly see the tangible results of my persistence.

After more than 12 years, the Renal Support Network (RSN) continues to serve the kidney community by instilling health, happiness, and hope through education, advocacy, and awareness... one person at a time. RSN fulfills this mission by offering many unique programs such as KidneyTalk, KidneyTimes.com (RSN’s new health information website), PEPP, weKAN, the Renal Teen Prom, and Patient Lifestyle Meetings. You are holding one of the dreams—this newsletter!

Fred Astaire was told he couldn’t dance. Walt Disney was admonished for lacking creative talent. The next time someone tells you that your ideas are silly, unrealistic, or overly optimistic, use that feedback to fuel your determination. Then put your nose to the grindstone and start chipping away at the obstacles.

Whether the issues involve daily choices related to your illness, lifestyle decisions, your career, or your relationship with your family or friends, remember the vital keys to success—persistence and hope.

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

Visit our website:
RSNhope.org
Starting out as a volunteer driver for the Renal Teen Prom, Tim Ryder has now been part of the Renal Support Network staff for two years. He assists with program coordination and finances. He has a bachelor’s degree in Economics & Statistics from Cal. State Los Angeles, and previously worked as a production coordinator for Baxter Healthcare in Glendale, CA.

The door of the garage opened, and as everyone watched in amazement, a shiny Ford Econoline passenger van rolled out. It even had RSN’s purple logo freshly painted on the doors.

Lori was stunned! Everyone clapped and cheered as one of the NASCAR Angels opened the van door and invited Lori to sit in the captain’s seat. This was truly a grand finale to an already exciting day!

If you live in Southern California and happen to see a white van with RSN’s logo on it heading to a patient lifestyle meeting or taking visitors to dialysis, honk and wave!

RSN sincerely thanks Goodyear Tires and the NASCAR Angels organization for making this a magical day that we’ll never forget.

To learn more about the NASCAR Angels and when the show airs in your community, visit www.nascar.com/auto/angels. RSN will post an announcement on RSNhope.org when our show is due to air.

One friend can make a difference!

NASCAR Angels
Continued from page 1

helps people who are making a difference in the community.

Since the NASCAR Angels wanted to help a prom volunteer, Lori chose Rhonda Brooks, a long-time RSN volunteer who chauffeured teens to this year’s prom. Rhonda donated her spunky little Honda for a long-overdue makeover.

During the few days that the NASCAR Angels mechanics worked on Rhonda’s car, Shannon interviewed Lori and learned more about RSN. To accurately portray RSN’s contribution to the community, she asked Lori to take her to a dialysis clinic. The film crew accompanied Shannon as she met patients and learned about dialysis.

Then, at 10 a.m. on Wednesday, February 21, a small crowd gathered at the Mountain View Tire Center in Burbank, California, but unfortunately Rhonda had become ill a few days before and could not attend. In the hope that they could interview her after she recovered, film crews set up their equipment to document the unveiling, and the show went on.

A group of RSN staff, volunteers, and board members, as well as Donate Life representatives, came to take part in the festivities. To begin the program, Shannon interviewed Lori Hartwell. Then, the moment everyone was waiting for arrived: Rhonda’s made-over Honda was revealed.

Shannon pointed out all the things that had been done to the car, and then she said to Lori, “We have a surprise for you too!”

“We have a surprise for you too!” Shannon Wiseman (left) tells Lori Hartwell.

2007 Renal Teen Prom
Held January 14, 2007 at Notre Dame High School Sherman Oaks, CA

Watch a video, listen to interviews on KidneyTalk, and read more about it at RSNhope.org!
Although we don’t know exactly why, pregnancy in women on dialysis is relatively rare. One of the many factors contributing to infertility in women on dialysis is the failure to ovulate due to hormonal changes caused by chronic kidney disease (CKD). The chance of a woman with CKD becoming pregnant is more likely if she has just recently started dialysis and still has a fair amount of her own kidney function.

Though unusual, a successful pregnancy can occur in women on dialysis. There are few documented statistics in the United States, but a recent report from Europe described five women on dialysis who all delivered successfully (although prematurely).

Risks
However, the risk of miscarriage or spontaneous abortion is high (as many as 20% of such pregnancies end in the second trimester). Reasons for the high rate of miscarriage are varied and not completely known, though contributing factors can include high blood pressure and kidney disease.

If a miscarriage does not occur and the pregnancy continues, there is a high rate of neonatal death, with about 25% of infants dying just before or shortly after birth. Also, as was true with the European cases mentioned above, most infants born to women on dialysis will be born prematurely (at an average of 32 weeks compared with usual term pregnancies of 40 weeks).

Most of these infants will also be small for their gestational age, and many surviving infants will have to spend some time in a neonatal intensive care unit. One of the reasons these infants are small and born prematurely is that most women on dialysis who become pregnant have high blood pressure (hypertension), which can become aggravated by the pregnancy.

More Dialysis Necessary
If a woman on dialysis becomes pregnant, significant changes to her dialysis treatments will need to be made during her pregnancy. These changes help maximize the chance that her infant will be born alive.

Longer, more frequent treatments (usually 5-6 days a week) can reduce the risk of low blood pressure during dialysis due to less fluid buildup between treatments and more gradual removal of fluid during the longer treatment time. Low blood pressure during dialysis should be avoided since it can result in low blood flow from the placenta to the infant. More dialysis also minimizes fetal exposure to excessive amounts of toxic substances in the blood—such as BUN (blood urea nitrogen)—that are removed during dialysis.

Steps to Take
To increase the probability of delivering a healthy baby, pregnant women on dialysis need to commit themselves to dialyzing at least 5 days a week, taking additional vitamins, eating a diet higher in protein, and, as with any pregnancy, avoiding alcohol and tobacco. The woman, her partner and family, her obstetrician, her nephrologist, and the members of her dialysis healthcare team will all need to work together to increase the chances for a successful pregnancy.

Pregnancy is not without risk for women on dialysis, but it is possible—and the outcome can be a healthy baby—if precautions are taken. If you are considering becoming pregnant, the journey will not be easy. Therefore, the decision cannot be made lightly. But with the help of your family and healthcare team, it can be a positive experience.

Jean L. Holley, MD is Professor of Medicine at the University of Virginia Health System. She has published on the topic of dialysis during pregnancy and recently edited an issue of the journal Advances in Chronic Kidney Disease that was devoted to the topic of pregnancy and chronic kidney disease.
Tania Michael was diagnosed with polycystic kidney disease in 1985, and already had two young children when she began dialysis ten years later. After three years on peritoneal dialysis (PD), she found out she was pregnant. “I was shocked,” she remembers.

Though they supported her decision to continue the pregnancy, her husband, family, and doctor were concerned about her health. Tania had read that pregnancy outcomes in women with end-stage renal failure were considered to be poor, so to ensure that her baby would survive, she decided to learn as much as she could.

She consulted with several hospitals and doctors to find the obstetrician who could provide her the best care for her situation, and devoured any articles she could find about women who became pregnant while on dialysis. Discovering quickly that such information was scarce, Tania asked her PD staff to help. They found the results of a study for her to read.

“The statistics in the study were not very encouraging. Out of 14 women, no one delivered a full-term baby. Some of the mothers miscarried, and others had a stillborn or deformed baby,” recounts Tania.

She knew these were tough odds and wanted to protect her own life as well as that of her unborn child. She followed her doctor’s instructions to the letter, monitored her diet carefully, and took all of her medications. Her PD exchanges were increased to six times a day to remove added toxins. She also had to visit the PD clinic more often than once a month.

Despite all these precautions, Tania still encountered many difficulties during her pregnancy. She struggled with chronic anemia, extremely high blood pressure, and bouts of severe vomiting. She lost 29 pounds and had to be hospitalized.

She gratefully acknowledges the support—especially the emotional support—she received from her family. They were a constant presence in her life, taking her back and forth to doctor appointments, the hospital, and the emergency room. During this trying time, she stayed positive and put her faith in God.

“What kept me going was my faith in God’s abilities and any extra help that could only come from above,” she acknowledged.

Following medical advice and staying positive paid off. Thirty-one weeks into the pregnancy, Tania delivered a healthy baby girl weighing 2 pounds 6 ounces. Just four weeks later, her daughter had gained enough weight to go home.

“I’m very proud of my daughter because I realize that not only did I have to have strength, but she had to have her own strength while she was inside me. It wasn’t only me. I believe that it had a great deal to do with her. When she born, and also as she grew, she was—and still is—a fighter.

She’s not very big in stature, but she’s very big within herself.”

In February 2001, Tania received a kidney transplant. To educate others about kidney disease, she shares her story and original songs at concerts throughout New York City. She also uses her degree in social work to educate patients like herself who are on dialysis.

Tania and her husband recently celebrated 20 years of marriage. This baby, their third child, has grown into a happy, healthy seven-year-old girl. Tania sums it up this way: “I’m very proud of my little fighter.”

Rhonda Brooks has lived with kidney disease for more than 17 years. She serves as both a board member and treasurer for RSN. As a PEPP speaker and through her community involvement she educates patients and healthcare professionals on various aspects of kidney disease.

Whatever course you decide upon, there is always someone to tell you that you are wrong.

There are always difficulties arising which tempt you to believe that your critics are right.

To map out a course of action and follow it to an end requires courage.

— Ralph Waldo Emerson
Revealing of Made-over Car and a Surprise for RSN
FEBRUARY 21, 2007

LEFT: Everyone claps during the revealing of Rhonda Brooks’ made-over car.
RIGHT: The NASCAR Angels mechanics explain what they did under the hood.
LEFT: The new van, complete with the RSN logo.

BELOW: NASCAR Angels mechanics applaud Lori Hartwell as she articulates her gratitude for this generous gift.

RIGHT: Lori Hartwell’s face clearly expresses her surprise and delight over seeing the RSN logo emblazoned on the side of the van.

BELOW: The sign painters with Lori and Shannon Wiseman.

ABOVE: Lori Hartwell (left) visits the California Speedway with Shannon Wiseman and Ed Rensi, former CEO of McDonald’s.

FAR LEFT: Shannon takes a tour of a dialysis clinic with Lori to learn about dialysis and talk with patients.

LEFT: Frank Volpe with Shannon and Lori.

Photos courtesy of Marlene Klotz-Collins (NASCAR), Izabella Khachoyan, and Shushan Khachoyan.
Once in a while, someone comes along for whom the phrase “She’s a star!” is truly meaningful—not just a casual description applied to celebrities. Rosalyn Moss is just such a person. She would never describe herself that way, mind you. An unassuming though spirited woman with quiet strength, Rosalyn has done something so many of us only wish we could: She tackled the weight loss issue and she won.

The doctors told Rosalyn that to be eligible for a kidney transplant, she would have to lose a significant amount of weight. Not an easy task. But Rosalyn made up her mind, and you get the impression that once she did, success was inevitable.

“I was scared,” she admits. “I was more scared than I had ever been before, and I cried, not knowing what would happen. I felt sorry for myself.” But with what she says was a combination of a strong faith in God, sheer willpower, determination, and support from both her family and her fellow patients and friends, Rosalyn has lost more than 127 pounds in the past year, and she’s still losing. She’s simply amazing.

Rosalyn truly is a star—a shining example of how determination can overcome this all too common obstacle for someone needing a transplant. But a celebrity? Well, when executives at a large pharmaceutical company heard about Rosalyn and her incredible accomplishment, they decided to capture her story on film.

You can tell that although she’s enjoying it, Rosalyn is still astounded that anyone is paying so much attention to her and what she did. Having a film crew follow her around for two days as she went through her normal activities was quite an experience for her and probably for the film crew as well. It isn’t hard to imagine them running to try and keep up with her.

“I feel so much better since I lost the weight; I hardly get tired anymore, like I used to,” she says. “I go to a dance exercise program now, and I really enjoy it.”

Any transplant surgeon will tell you that the long-term prognosis is significantly better if the person receiving a transplant is not overweight. With weight loss, a person’s overall health can improve as well, and Rosalyn can attest to how that translates into a more active lifestyle. She keeps a schedule anyone would envy, let alone those of us who often lead a more sedentary life because of the fatigue associated with kidney disease.

There were other benefits to her weight loss as well. “My husband gave me a long leather coat for Christmas,” she said. “And I had to take it back—it was too big! That never happened before.”

So how did she do it? You can practically hear her shrug her shoulders as she makes it sound simple: “I just followed the renal diet, and I was very careful. I just completely cut out anything that was even the slightest bit in question.” As her body adjusted over time to less protein and fewer carbohydrates, watching her diet became easier. And she also discovered that as she ate less, she felt full faster, making it easier to stick to her eating plan.

But for Rosalyn, the diet was just the mechanics. The real reasons for her success are her spirituality, her strength, and her positive outlook. “Live and let live” is her motto. She tells everyone, “Try to love everyone and everything—the trees, the birds, the flowers... just love life itself, love your family and your friends. Most of all, try to love yourself.” That’s hard to forget when you’re around Rosalyn. She really is a star.

Diagnosed with kidney disease in 2004, Kathleen LeBeau is hoping to receive a transplant prior to needing dialysis. She has primarily spent her career in health and human service programs, doing administrative work as well as direct service. Utilizing her degree in psychology, she currently volunteers her time as a counselor and mentor to fellow patients. Kathleen lives in the Capital Region of New York State with her husband of 11 years, Loren Fadding.
Tips to Remember
The “Fab Five”
Tips for Healthy Weight Loss and Maintenance
by Mandy Trolinger, MS, RD; weKAN Patient Activist, PEPP Speaker

Have you ever lost 10 pounds, only to realize all too soon that you had gained it all back, plus some? Short-term diets might be good for losing weight quickly, but if you do not change your habits there is a strong probability you will gain the weight back. Lifestyle changes not only help you lose weight, they also help you maintain that weight loss for life.

The following tips are lifestyle changes and therefore take time to establish. If you add a new healthy habit gradually—every one or two weeks—you will soon realize that these changes have become part of your everyday life.

Don’t Forget the Fiber
Fiber has been shown to protect against colon cancer, lower cholesterol, regulate blood sugar levels, and help with appetite control by providing a feeling of fullness. High-fiber foods include fruits and vegetables (with the skin when it’s edible), dry beans, bran, barley, peas, and raspberries, to name a few. It’s best to get your fiber from food, but a fiber supplement can help as well. Ask your dietitian whether you get enough fiber and whether a supplement is right for you.

Dine Out Sensibly
At a restaurant, order a half-size portion or split a meal with a friend or family member. You can also ask for a “to-go” box when you place your order. When your meal arrives, immediately put half of it in the box and set it aside to take home. Not only will you decrease your calorie intake, you will also get two meals for the price of one!

Manage the Munchies
Always be prepared for those moments when you get the munchies by keeping healthy snacks on hand. Pick one day during the week to cut up fresh vegetables and make a low sodium dip. Keep them in the refrigerator so you can easily grab a healthy, convenient snack. For an “on-the-go” snack, try a low-calorie protein bar (less than 150 calories). The protein will help diminish your hunger pangs.

Use the Buddy System
Team up with a family member, friend, or fellow patient to encourage each other to make healthy food choices. You and your buddy can also set up times to exercise together and to discuss progress toward your health goals. If competing with others motivates you, organize a contest to see who can lose the largest percentage of weight in a certain amount of time, or who can meet predetermined exercise goals.

Calculate How Much
People often misjudge what one serving should look like. Go to your kitchen and get the dishes you eat from most often. Measure out one cup of cereal and pour it into a bowl. Does it seem like more or less than you usually eat? Another trick is to use small plates and bowls. This will help you to fill your plate with less food, causing you to think you are eating a larger portion.

And remember: Take the time to savor every bite. You deserve it!

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New Bill Introduced
Continued from page 1

During the 109th Congress, a similar sounding bill called the “Kidney Care Quality and Improvement Act of 2005” had been introduced. Although there were 223 co-sponsors for both the House bill (H.R. 1298) and Senate bill (S. 635) combined, because the bill was not passed before the end of the 109th Congressional session, the bill language was updated and introduced under its new name and bill numbers.

What Patients Should Know
The KCQEA 2007 contains provisions that are of importance to patients. A simple way for patients and patient advocates to remember these provisions is: HEART.

Home Dialysis: seeking to understand the barriers to the adoption of different treatment modalities by patients.

Education: providing educational sessions for Medicare beneficiaries with Stage IV CKD to teach them how to slow the progression of the disease.

Awareness: creating public and patient education initiatives to increase awareness about CKD and to help patients learn self-management skills that prevent and control CKD.

Reimbursement: establishing a three-year Continuous Quality Improvement Initiative that would reward providers for quality improvement and outcomes. If the provider meets these goals, they receive a bonus.

Technicians: establishing a uniform training for patient-care dialysis technicians.

And why is this so important to patients?
This piece of legislation addresses issues that lie at the very HEART of kidney patients and their families, as well as renal-care professionals.

We, as patients, will have the opportunity to look at what problems could be keeping us from choosing the treatment modality that works best for us, including dialysis at home. And education is essential for better healthcare. Don’t we all wish we had a little more knowledge to help us understand our disease? Awareness for those who are at risk for kidney disease is empowering.

The reimbursement component in this bill will improve upon and update the system we currently have. And the implementation of systematic training for patient-care technicians is something we’ve all talked about.

This is a dynamic opportunity for us as patients to get involved and lend our support to such an important piece of legislation. In doing so, we will help many people. With all of us working together hand-in-hand, we can make a difference!

How You Can Help
Contact your legislators. Call, visit, and write to them to share your personal experiences with CKD and your support for the bill. Help educate them about the challenges faced by you and other CKD patients, and help raise awareness of CKD and the ties between CKD, diabetes, and hypertension.

Please also visit the “Current Legislation” section of our website at RSNhope.org for additional information, tools, and resources.

April
National
DONATE
LIFE
Month
www.donatelife.net
Celebrate by educating your friends and family about the importance of organ donation!

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!
Riding in Tandem

Motivated by their success despite a disability, Bob and I finally purchased a tandem, thinking it just might be the solution to our dilemma. Well, we should have bought one sooner!

There are so many benefits to riding tandem. Before, I kept a death grip on the handlebars for fear of falling, and the arthritis in my hands would make them hurt terribly afterward. Now I can rest my hands and enjoy being pain-free.

I get to rest in other ways, too. The person in the back (that would be me!) just has to keep her feet on the pedals. I don’t have to worry about losing my balance—I had become rather famous for falling off my bike when I tried to slow down. It reminded me of that old show “Laugh-In.” The old guy is on his tricycle and just slowly falls over sideways…that’s me! I still get the benefits of exercise because my feet are going around. I’m just not applying pressure—until the hills. That’s when I kick in and start pedaling furiously!

In just a month, we worked up to doing a 16-mile ride without any problems. Previously—on my own—I became exhausted and out of breath after just two miles! The tandem bike has many physical benefits for me, but the biggest benefit? Doing something I love with the person I love!

A few years ago we moved from Ohio to Iowa, so now every year we send out a Christmas letter to our friends. Last year we included a picture of Bob and me in our Buckeye shirts just to reassure everyone that we will always be Buckeyes at heart. In our next letter, we thought a photo of the “Buckeyes” seated on the tandem would get some laughs.

After all, you do know what buckeyes are, don’t you? Just a couple of worthless nuts! But these two “nuts” are having the time of their lives!
I had never been a fan of bike riding until Bob, my husband, got me a really nice 24-speed several years ago and taught me how to use it. Wow! Was that ever an improvement over my old 3-speed! We began to ride several times a week. It was “our” time together—just us—and it was great! We dreamed, planned, laughed, and then celebrated our accomplishment when we completed a long ride. So exhilarating! The phrase “just a little farther... we’re almost there” became our inside joke. Bob used it more than once to keep me pedaling when we were still a very long way from our destination and I wanted to quit. Now, I’ve wised up and will counter, “Oh, really?”

However, as my creatinine has steadily climbed over the past year, I have had to either make compromises in what I do, or stop doing things completely. I try to make sure I have enough energy for the things that count most, like spending time with Bob and our family, and being active in our church where Bob is the senior pastor. But it seemed that our most enjoyable activity—riding our bikes together—would no longer be possible. My morale and self-esteem were taking a terrible beating since I knew that my health was depriving us of something we really enjoyed.

A friend of ours uses crutches and sometimes a wheelchair to get around, and she and her husband have a tandem bike. Once they hit the trail, they can ride 30 miles!