Winning in the Game of Life
6th Annual Renal Teen Prom

The teenage years are tough. Not too many people will say they felt comfortable in their own skin during this period of their lives. Throw in being a teen with kidney disease and the equation gets even more complicated. But the Renal Teen Prom, held in California each year, provides an opportunity for these teens to have a great time with others their age who understand the struggle of living with kidney disease.

On Sunday, January 16, Notre Dame High School in Sherman Oaks, California, again hosted the Renal Support Network’s 6th Annual Renal Teen Prom. This year’s theme was “Viva Las Vegas!” and more than 100 young people with kidney disease (ages 14 to 21) and their guests attended the festivities, boosting the total count to over 250.

“It’s real fun to get to meet all sorts of people going through the same thing as me,” said Latrina Spruille, a patient on hemodialysis who traveled from San Diego to attend the prom.

Although the majority of those in attendance came from Southern California, this year’s prom attracted teens from outside the Golden State. Some traveled from Arizona and Texas, a testament to the reputation the prom is garnering and the lengths young patients will go to meet others in their peer group.

A proposed revision to this policy has recently been released by CMS. This policy change is part of CMS’s attempt to make sure that the amount of money that the government spends to provide care to patients with chronic kidney disease does not increase.

Under this proposed policy, the government will ask dialysis centers to provide documentation that defends the use of EPO whenever CMS believes that your hematocrit and hemoglobin levels, or the dose of EPO you are receiving, is too high.

Why do we need erythropoietin (EPO)?
Patients with chronic kidney disease, especially dialysis patients, are unable to make enough red blood cells, so we commonly receive EPO to help increase hemoglobin and hematocrit levels. Each person needs a different prescribed dosage to keep their blood count within a normal range. Clinical studies have shown that dialysis patients with higher hemoglobin levels have better outcomes and more energy compared with individuals who have lower levels.

Blood Count Levels At Risk

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Renal Community’s Concern

Many people are concerned that if this draft policy goes into effect, it may mean that dialysis centers will start changing the way they give EPO to make sure that they
Dear Friend,

I am excited to introduce the first issue of the weKAN Live & Give newsletter. The title of this newsletter represents the core belief system of the Renal Support Network (RSN) and the weKAN Patient Activists—we can live, and give!

As weKAN Patient Activists, we believe that it is important to provide hope, encouragement and support to our peers. We need to help one another get through the trials and tribulations kidney disease can often present as well as advocate for the best possible care.

Stories of hope, ways to better your life, and ideas on how to help fellow patients will be the main thrust of our newsletter. Our newsletter—because “you” becomes “we”—unites fellow patients in our desire to improve the lives of chronic kidney disease survivors.

In my 35 years of living with kidney disease, I know that experience is the best teacher. As I have visited over 500 dialysis facilities and given presentations in over 40 states, it is evident to me that there is a plethora of talent within the renal patient community. We need you! It is weKAN’s goal to help patients help patients.

weKAN Patient Activists work to empower fellow patients to make informed decisions about their care, to become actively involved in decisions affecting their lives, weKAN promotes self-advocacy and self-determination.

weKAN Patient Activists are already making a difference. We are getting to know our elected officials and educating them about kidney disease and what patients need to ensure quality care. We are planning patient education meetings around the country as well as being invited to participate as speakers. In addition, there are many “behind the scenes” committees that make decisions about our care. Several weKAN Patient Activists are participating on some of these committees and providing the patient’s perspective.

weKAN is a small group of Patient Activists with big ideas! Our wish is to inspire you and give you the tools that will help you make a difference in your community. “An illness is too demanding when you don’t have hope.”

It has been a privilege to work with so many dedicated Patient Activists who are truly making a difference! A special thanks to Shari Gilford for all her hard work in creating the layout of this newsletter.

Chronically Yours,

Lori Hartwell
President and Founder of Renal Support Network

Pushing Your Comfort Zone
by Sharon Pahlka

It is easy to get stuck in our comfort zones and limit the amazing possibilities we have in our lives.

Recently, I had a major life transition that pushed me to try new things.

I have been a member of Toastmasters for quite some time. I have learned that it is one of the best ways to improve your ability to communicate well, lose your fears of public speaking, and learn skills that will help you be more successful in whatever path you’ve chosen in life. (Visit www.toastmasters.org for more information about this helpful organization.)

I never thought I would have the courage to put my new skills to work. After some encouragement from fellow Toastmasters, I decided to enter a speech contest—which scared me to death! But, in the end, it was a great learning experience and I learned a lot about myself and how much my speaking has improved.

The audience responded well to my presentation and the experience opened “doors” that I never expected. This made me realize I have a powerful message to share with others.

Purposely stepping out of my comfort zone taught me (and is still teaching me) to carry that fearlessness and to speak in policies that impact their life, and to speak up. By educating patients on how to become actively involved in decisions affecting their lives, weKAN promotes self-advocacy and self-determination.

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TELL US WHAT YOU THINK

write to RSN
e-mail info@renalnetwork.org
go to www.renalnetwork.org

(Click on Your Thoughts in the Patient Action Center)
We’ve all heard the saying “knowledge is power”. It was coined by Sir Francis Bacon in the 1500’s and yet still has great meaning today.

As someone with chronic kidney disease, I have found that knowledge has aided my ability to cope with my illness. If you saw me leaving the local public library, you might see just a pair of legs sticking out beneath a pile of books! I love to read, and that’s how I learn more about many different topics, including ways to live a more active life with kidney disease.

Learning Style
What is your style of learning? What activities help you learn? What are the ways that you learn best, and under what type of circumstances? Do you like to learn with one-on-one training, by reading, or by listening to someone teach either in a classroom or on a tape? Do you like to be able to discuss what you’re learning with others? I like to read, but I also learn best when doing a hands-on activity.

There is a Chinese proverb that says: “Tell me, I’ll forget. Show me, I may remember. But involve me and I’ll understand.”

Take a moment to think about something you want to learn in the next month. Now, think about how you can facilitate a learning environment for yourself. What steps do you need to take? The Internet, books, videos, television, cassette tapes, classes, and other people can all be resources for knowledge.

Suggestions
Let’s say for example that you want to learn how to make healthy foods that fit your renal diet. You could learn this skill many ways, depending on your learning style. Below are some options. Remember, these can apply to anything you want to learn:

✓ Have someone show you. Find someone who eats healthy and set up a time when they can show you how to cook specific dishes.

✓ Listen to an expert. Ask your dietitian for suggestions to add flavor to your diet, and which foods you can include.

✓ Read. Go to the library and check out some cookbooks. Or visit www.iKidney.com for a large selection of renal-friendly recipes. Pick a few new recipes to make and invite others to share your creations.

✓ Explore creative options. Visit your local health food store and browse to find new foods to try or ask employees for their expertise.

✓ Attend a class and learn with others. Find an adult education class focusing on eating nutritiously. These are usually offered at a community college, health food store, library, cooperative extension, hospital, or recreation center.

As you can see, there are many styles of gaining more knowledge. Learning helps us to keep active, focused, and involved in life.

Knowledge does give us power to feel better about ourselves and to pursue our interests. It also can give us the ability to affect someone else’s life in a positive way.

The Challenge
Here is the challenge. Share your new knowledge with at least one other person. Ask them how they learn best, and find a way to communicate your new knowledge with them using that medium.

As each of us continues to take opportunities to learn, we can help one another to achieve a greater quality of life. Go, learn, and share!
Lori Hartwell also was a kidney patient during her adolescent years. After 12 years on dialysis and a successful kidney transplant in 1990, Lori knew that having one friend who could relate to what you are going through could make all the difference, especially in the life of a teenager. With the goal of getting teens with kidney disease to meet one another in a fun, non-medical environment, Lori dreamed up the Renal Teen Prom. What better way for kids to socialize than to get dressed-up, be treated like princes and princesses, and dance the night away? Teens who might not go to their own high school’s prom could have a prom all their own.

Unlike most high school proms, the Renal Teen Prom is one that a teen or young adult can experience year after year. To many of the returning guests, the prom has become a sort of reunion of friends. These connections are exactly what Lori Hartwell hopes to instill in the younger generation of patients when she spreads the philosophy of “One Friend Can Make a Difference.”

“Each year, I am inspired by the teens I get to spend the evening with and am continually reminded how much we have in common simply because we are kidney patients. Remembering that we have such a powerful support system in our fellow patients is a lesson that all of us who live with kidney disease can take away from the prom experience.”

-- Malia Langen
Winning in the Game of Life

Continued from page 1

Notre Dame High School’s gymnasium was transformed into a Vegas nightspot complete with trees and a real fountain. Table games lined the perimeter with dealers enticing the teens to try their luck. An Elvis impersonator got the crowd “all shook up,” and the dance troupe Groovaloos got everyone dancing.

And what is Vegas without a buffet? A renal-friendly dinner and dessert buffet was served and appetizers were hand-passed by Notre Dame alumni dressed as Vegas showgirls.

Actors Gary Sinise (Detective Mac Taylor in CSI: NY; Lt. Dan Taylor in Forest Gump) and Michael Welch (Luke Girardi in JOAN OF ARCADIA) dropped by to meet the teens, sign autographs, and have pictures taken with guests. A teen himself, Michael Welch fit right in at the prom, dancing with the girls and having fun. He promised to see everyone again next year.

Renal teens got to feel like stars in their own right with rides in a Hummer limousine. They also had glamour shot pictures taken in a studio setting so they can remember this special night.

An Enrique Iglesias impersonator, who made a return appearance at the prom, shared some words of wisdom with the teens. When referring to the fact that he pretends to be someone else for a living, he offered, “It is nice to be a pop star, but it is better to be yourself.”

This year’s prom succeeded once again by giving teenagers with kidney disease a chance to do just that—be themselves—in a fun, welcoming environment surrounded by friends who really understand them.

Marissa’s Story

Fourteen-year-old Marissa traveled from the White Mountain Apache Indian Reservation in Arizona to attend the prom. Upon returning home, she told her social worker that she was amazed to see so many teens with kidney disease. It was Marissa’s first trip to California (and her first time on an airplane).

Many people helped Marissa come to the prom. Her school raised money. The Apache Diabetes Wellness Center purchased airline tickets for both Marissa and her mother. Someone donated hotel points for their California stay. And another donated a beautiful dress and accessories.

She was excited to meet Hollywood celebrities and had fun playing Casino games. More than anything, she enjoyed making new friends. She commented, “I was surprised to see so many teens with kidney disease. I thought I was the only teenager who had kidney disease.”

She cried when the night was over and had to say good-bye. However, she reports that she has been receiving phone calls and letters from people she met on that special night. “They are becoming my best friends.”

Since then, she has been talking more positively about her future. When her social worker asked her if she would like to go back again, she enthusiastically replied, “Sure, of course! I can’t wait!”

Marissa got to choose a prom gown to wear from over 300 dresses donated by many people over the past few years.

Marissa traveled all the way from Texas to attend the prom.

Johnny and Norma are engaged! They are both kidney transplant recipients who met while volunteering at a hospital.

Lauren traveled all the way from Texas to attend the prom.

Malia Langen was diagnosed with kidney failure at age 13 and spent her teen years on dialysis. She then received a kidney from her mother which has kept her healthy for the past nine years. Since she can relate to younger patients, she enjoys helping them learn how to maintain life outside of the medical realm. For the past few years she has volunteered as a driver for the Renal Teen Prom.

NEXT YEAR’S PROM

Sunday
January 15, 2006
SAVE THE DATE!
Confused About the $600 Credit?

by Pearl Lewis

Medicare-approved Discount Drug Card

All those on Medicare are eligible for a Medicare-approved discount card (MDDC) offered by various companies. Each company gives different discounts for different medications, so you need to find out which company offers the best prices for the specific drugs you take and then apply for that MDDC. Usually the discounts are significant, so it’s worthwhile to apply.

A MDDC is not dependent upon your income. The only eligibility requirement is that you are a Medicare recipient.

Even if you have another prescription drug plan, you might benefit from a MDDC. Some insurers have an annual cap on drugs as well as a formulary specific to that plan. A MDDC provides flexibility by allowing you coverage for non-formulary drugs and access if you have met your plan’s annual cap.

$600 Credit

Once you receive your MDDC, you then also may be eligible for a Medicare credit. This is separate from the discount card, but you can only receive it if you already have a discount card. If you qualify, the credit will automatically be applied to your card. The $600 credit is based on your income. You can only receive a credit if your income is below $12,919 per year for a single person or below $17,320 per year for a married couple. (If your income is more than these amounts, you can still apply, but you may have to pay a small copayment for each prescription when you apply the credit toward your prescription charges.)

If you are not sure if you qualify, call Medicare and speak to a representative.

Apply Now!

To receive a full $600 credit, you need to apply for the credit before March 31, 2005. After that, the amount decreases $150 every three months. If you qualify, be sure to apply soon! This is “free” money!

If You Already Applied in 2004

If you received a $600 credit in 2004 and didn’t use it all, the amount remaining will automatically roll over to 2005. You will not lose that amount. If you applied for a credit in 2004, you don’t have to reapply for 2005. The full $600 credit for 2005 will automatically be added to your card, even if your income changes.

Get the Best Deal for Your Prescriptions

✓ Make a list of all your medications.
✓ Identify the Medicare-approved discount drug cards available in your area by calling your state Department on Aging, Medicare (1-800-633-4227), or by going to www.medicare.gov (select “Prescription Drug and Other Assistance Programs”).
✓ Once you have found the company that gives the best discounts on your specific medications, and that contracts with a pharmacy in your area, then apply for the card they offer.

The Empath

by Pearl Lewis

Touching, gathering strength one from the other
We travel through time, one for another
If, for but a moment
we could merge and once again separate
J, having taken upon myself
all the pain you endure.
Two men were talking about their problems while waiting to see the nephrologist. One said to the other, "Just when we learn to take things with a grain of salt, the doctor puts us on a salt-free diet!"

Ten Transplant Tips  
Continued from page 6

Be aware of medication side effects. Inform your doctor if you have any of the symptoms. Know if your medicine interacts with any foods or other medications. Do not take any other medication (including over-the-counter and herbal remedies), or get any vaccination without talking to your doctor first.

Keep your appointments. Clinic and lab appointments are very important. They will be frequent at first to catch problems quickly, but will decrease once your transplant is stable.

Check your vital signs regularly. Any slight fever, change in weight (3 to 5 lbs), or elevated blood pressure should be reported.

Avoid infections. Wash your hands often. Keep liquid hand sanitizer or antibacterial hand lotion in your purse or car. Avoid people with colds, coughs and other infections. Let someone else clean up after pets. Avoid sun exposure and wear sunscreen. Keep any skin lacerations clean and covered until they heal. Ask your doctor about gardening and any dietary restrictions (such as not eating sushi).

Follow advice for dental visits. Consult your transplant team before going to the dentist (this includes routine cleaning). You will need to take an antibiotic beforehand.

Join a support group - share your experience. It is always good to hear from those who have "been there and done that." You will find out that you are not alone, and you’ll have opportunities to encourage others.

Resume normal activity and enjoy your life! Eat healthy and enjoy the variety of foods you can have now! Drink lots of water! Include a daily exercise routine! Count your blessings! (continued on page 8)

If your doctor ever tells you to lighten up, do not be offended. Such a prescription may sound ridiculous, but research shows that laughter and a positive attitude can be healing. There’s nothing funny about kidney disease, but people are living happy, productive lives today because they learned to lighten up when things were not going as planned.

Illness can be a stressful event. Hospitalization, separation from family, invasive procedures, complex technology, or unfamiliar caregivers can all create feelings of anxiety, loneliness, discomfort, anger, panic, and depression. These emotions are known to produce physiological changes that are harmful to the body, which the use of humor and laughter can ease.

Laughter is a pleasurable experience. It momentarily banishes feelings of anger and fear. It gives us a feeling of power and control. We feel carefree, lighthearted, and hopeful during moments of laughter.

The Cheapest Medicine  
Most people agree that humor is a stress reliever, similar to other positive emotions. Laugh and you feel better. Laughter helps the body to provide its own type of medication. Laughter stimulates the immune system, offsetting the unwanted effects of stress.

Many believe that humor leads to health and longevity, and is necessary for human survival. Yet, scientific research in the area of health-related humor has been sparse. One reason is that until the last two decades, we did not have the scientific technology to study the biochemical and physiological effects of humor has been one factor.

But the major obstacle to researching the effects of humor is that the main focus within the healthcare system is on disease, illness, and the serious nature of health care.

In reality, humor has always been a form of communication between patients and healthcare professionals. I can say without hesitation that I always liked being taken care of by someone who had a sense of humor.

In this age of high technology, scientific miracles, and medical breakthroughs, it just might be something as simple as laughter that turns out to be the best medicine. We must think of laughter as an exercise and make sure we get in a good laugh every day.

Deep in the human psyche, people know that if they don’t lighten up when things get tough, they’re going to tighten up and snap. Next time you have on a hospital gown, why not parade around and tell everyone it’s a new design created by "Seymour Butts." (continued on page 8)

Learn to Play  
Join some children and help them do a puzzle, color, or play hide-and-seek.

Have a Party  
Invite a few friends over for an evening of laughing and fun.

Take a Mini-Vacation  
Sometimes getting away can help to lighten our attitude.

Photo Fun  
Find a photo booth, sit down, pull the curtain, and take four funny-face pictures. Carry them in your wallet to look at when you need to laugh at yourself.

Learn a Joke  
Get a joke book or go to www.jokes.com and learn a new one each week. Share it with the dialysis staff and fellow patients.

Laugh with others. You will be surprised by the response you receive.

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Spring 2005  
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The Inaugural RSN National Patient Meeting – “Health, Happiness & Hope” – held in Denver, Colorado, last October brought together close to 100 patients and family members in order to learn and connect. Held in conjunction with the annual National Renal Administrators Association (NRAA) conference, it also provided opportunities for professionals and patients to interact.

During the three-day event, patients enjoyed many informative workshops on topics such as understanding the dialysis machine, preparing for a kidney transplant, ways to help other patients, and the ins and outs of patient advocacy. Between workshop sessions, patients and NRAA attendees mingled around the food and exhibits.

At the “Be Your Own Expert” luncheons, a spokesperson at each table hosted a discussion in which patients could interact around a specific topic.

Patients and professionals both tried their luck at Casino Night, and patients enjoyed dinner and dancing to a popular Denver band the following evening. It turned out that the drummer had just begun peritoneal dialysis, and he shared his joy at still being able to play drums and lead a normal life while on dialysis. New friendships were formed as many patients realized that they are not alone in living with the ups and downs of chronic kidney disease.

Due to its success, the RSN National Patient Meeting will again be held jointly with the NRAA conference this fall. Make plans to come to Chicago, Illinois, from September 29th to October 1st, 2005, for the Second Annual RSN National Patient Meeting!