Headline News

Patient Lifestyle Meetings in 2008

They’re back! The Renal Support Network (RSN) will host patient lifestyle meetings across the United States again this year for people with chronic kidney disease (CKD) and their guests.

Last year hundreds of people across the country gained knowledge and met new friends at these meetings. One attendee summed it up: “I was filled with hope for my future after seeing what other patients had overcome.”

Hope is the hallmark of RSN, and resonates in the theme of the patient lifestyle meetings: “Health, Happiness & Hope.” The meetings bring together caregivers, professionals, and those who live with kidney disease in a non-medical environment that fosters opportunities to ask questions and interact.

If you come to a meeting, you will hear presentations on life-enhancement and health-related issues relevant to living a fulfilling life with kidney disease, given by healthcare professionals and “kidney peers.” Topics vary at each meeting and can include:

Confessions of a Kidney Teen

Cinderella’s 3,000-Mile Journey to the Prom

by Michelle (“Mishy”) Kats

As a real David Bowie fan, I’ve watched the movie Labyrinth more times than I can count. My favorite part is the dream sequence in which the main characters are at a masquerade ball. I remember being a little girl and hoping that someday I would find myself going to a grown-up ball in a beautiful gown, with my hair and makeup perfect.

I knew that my prom would be just like that. But I’ve had medical problems all my life, and I realized as I got older and things got more serious that I might never be able to live that dream: to enjoy being young and being a princess for one night.

I knew about the Renal Support Network’s Renal Teen Prom for years, but I was always sick around the time it was held so I could never go. Then, this past August, I decided that this year was going to be different—I was going to do my best to go.

I started setting things up... dialysis, housing, travel. It took a lot of time and effort to get everything in place. I spent hours poring over prom magazines, feeling that I was finally doing something every girl my age...
Sometimes I think I hear the phone ringing, then I realize it’s only Johnny. He follows the ring with an impersonation of me answering (and it really sounds like me!). It goes something like this: “Ringgg. Hello, whatchadoin’? Uh huh… uh huh… yeah… uh huh… Could you hold on for a second? Beep.” (He does call waiting too.) Needless to say, having Johnny around is like tape-recording my entire life.

My dogs Max, a black poodle, and Chloe, a cockapoo, provide me with lots of unconditional love. They’re always happy and know how to use their charm to get what they want. Sitting up on their hind legs and looking at me with those big brown eyes is a favorite way to get my attention. They know that you get more bees with honey than with vinegar.

My cats Jack and Cali also have their unique lessons to teach. They’re very independent and don’t need much reassurance. They take time to look for and enjoy the little things in life: a small bug walking across the floor, a thread hanging from my jacket, or a spider spinning a web. They know the importance of taking a nap and basking in the sun.

All of my animals get along and have fun playing together. In the morning, while I’m sitting at my dining room table drinking coffee and reading the paper, I’m often treated to a game of “catch me if you can.” The cats run, the dogs chase them, and “safe” is in the bathtub. Johnny is the referee and often yells, “You are bad, get outside,” followed by “Go potty.” He’s definitely in charge of this menagerie, often reminding us of it by saying, “I’m the boss.”

My pets are an example to me of how to live. They teach me to listen and to be kind and loving no matter what. As I watch them play together and get along even though they’re different, I realize that it’s easier to accept one another if we have a common goal. They also remind me to pay attention to details, to take care of myself, and to live in the moment.

But the most important thing my pets have taught me is to just have fun!

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

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Pet Therapy: Wagging Tails Come to You

by Kathe LeBeau, weKAN Project Manager, PEPP Speaker

There’s no doubt that spending a lot of time in hospitals or treatment centers is not a lot of fun. One of the best ways to brighten those hours is with animals trained as therapy pets.

Not only is a warm fuzzy face or a wagging tail a friendly distraction, but spending time with therapy animals can actually have physical benefits as well. Studies have shown that interacting with animals can lower blood pressure, reduce anxiety and stress, and generally calm a person. As a dog, cat, or other animal offers loving and empathetic support, it also helps aid healing.

A person who may not interact with his caregivers and family members because of illness often comes to life when an animal enters the room. Even a child who has become sad or withdrawn will usually respond to puppy kisses with a smile or a laugh. A friendly animal brings a welcome distraction to the medical routine and can also provide a safe conduit for communication with healthcare staff. And what do the animals get? Their favorite thing: a lot of love and attention.

There are several organizations that support the use of therapy pets in medical facilities, including Therapy Dogs Inc., Delta Society, and Therapy Dogs International, Inc. (TDI). All are non-profit and voluntary organizations dedicated to providing pet visitation services in hospitals, chronic care homes, and other institutions.

As an example, TDI, founded in 1990, has grown into a network of more than 4,000 volunteers worldwide. These volunteers share their special canine friends with people—young and old alike—who sometimes suffer from isolation and a lack of rewarding experiences due to ongoing medical care and health issues.

At Albany Medical Center (AMC) in upstate New York, 15 regular therapy dogs visit each week, ranging in size from a small Boston Terrier to a 140-pound Newfoundland. The variety of sizes and dispositions works well, since each person is comfortable with and responds to different types of dogs. The program is approved by the New York State Department of Health, and all the dogs are certified through one of the above organizations. This shows that they have completed a training program and are healthy, up-to-date on all their shots, and “good canine citizens.”

Kelly Morrone, Manager of Volunteer Services at AMC, can’t say enough about the positive impact of pet therapy. “It’s such a wonderful program for everyone. You can just see the patients relax when the dogs come in.”

“Some folks really wait for and look forward to their visits,” Kelly reports. “People who miss their own dogs from home, and those who just love dogs—almost everyone enjoys it. Even the staff love the visits. It makes the patients happier and breaks up everyone’s day. The dogs visit the waiting rooms, offices, nursing units; they even lay on the floor in the clinics so the kids can pet them and play with them.”

Kelly also stressed that the program receives ongoing support from key people in administration. Many are dog lovers themselves, and that has helped make it a success for the last ten years.

On admission to the hospital, each person receives a form to request pet therapy visits. It’s even a regular part of the rehab process, and the animals often help out in group therapy sessions as well. A well-crafted hospital policy outlines such important items as sanitary considerations and areas where it is not appropriate for the animals to be, such as critical care and intensive care units.

Virtually everyone agrees that therapy pets can really make a difference in how people perceive any stay for medical treatment, and even how well they bounce back. Consider that if your dog or cat (or even ferret) is obedient and well-socialized, it could become a terrific therapy pet. Then together you can help turn frowns into smiles! ☺️
Sometimes I think I’d like a T-shirt or a bumper sticker that says: “I have kidney disease and I VOTE!” As I write this, I’m listening to President Bush’s final State of the Union address. He’s been focusing mainly on the economy and the war, but he’s also dropped several hints about what he plans to do—or not do—where health care and public and private insurance are concerned. A change that occurs only once every 30 years is coming, and I think we can take a cue from the president’s message as to what the thrust and focus of our advocacy work should be this year.

Specifically, one of the big issues on the 2008 federal agenda is Medicare reform, as these words by President Bush indicate: “Every member in this chamber knows that spending on entitlement programs like Social Security, Medicare, and Medicaid is growing faster than we can afford. We all know the painful choices ahead if America stays on this path: massive tax increases, sudden and drastic cuts in benefits, or crippling deficits.”

The end-stage renal disease (ESRD) program is an entitlement and is therefore potentially vulnerable to cuts. To safeguard the health of people with kidney disease and ensure their quality of care, we need to focus our efforts on the continuation of this program. While the bundling of dialysis services seems inevitable in the wave of planned cuts, we can seek to understand in this process how best to prevent cutbacks in services to maintain access to good care.

One issue critical to planned Medicare reform is the difference between states in the provision and availability of Medigap insurance policies (or Medicare supplements) for people under 65, such as those who benefit from the ESRD program. Currently, there are efforts in several states to gather support for legislation mandating the issuance of Medigap policies to all Medicare beneficiaries, regardless of age.

In addition to the District of Columbia, the following states do not offer Medigap policies for Medicare beneficiaries under 65: Alabama, Alaska, Arizona, Arkansas, Delaware, Florida, Georgia, Hawaii, Idaho, Indiana, Iowa, Kentucky, Montana, Nebraska, Nevada, New Mexico, North Dakota, Ohio, Rhode Island, South Carolina, Tennessee, Utah, Vermont, Virginia, West Virginia, and Wyoming.

Although challenges remain, there was some good news from Congress: The Charlie W. Norwood Living Organ Donation Act passed in December. This measure clarifies the legal basis for paired transplants of compatible living donors and recipients and could result in thousands more kidney transplants.

Other key bills on kidney disease were carried over to the second session of the 110th Congress:

- Kidney Care Quality and Education Act (KCQEA) (S. 691 and H.R. 1193)
- Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act (S. 2320 and H.R. 3282)
- Living Organ Donor Tax Credit Act (H.R. 1035)
- William H. Frist Gift of Life Congressional Medal Act (S. 1062 and H.R. 1764)

We will continue to work toward the passage of these beneficial bills. To check their current status, go to RSNhope.org and click on “Advocacy.” Urge your legislators to be aware of these bills, to support them, and to sign on as cosponsors if they have not done so already. In addition, encourage them to join the Congressional Kidney Caucus and the Tissue and Organ Donation Task Force to indicate their support for kidney and transplant issues.

Many weKAN members have been working on the presidential primaries and caucuses in their home states. Becoming involved has allowed them to meet many of the candidates and their staffs and to discuss ways to prevent kidney disease and the issues facing people who have it.

With party conventions and national elections still ahead, there are plenty of opportunities to inform, educate, and influence this year’s candidates for elected office at both the local and the national levels. You can help heighten awareness by being visible and involved.

In addition, keep up to date on our advocacy work at RSNhope.org. If you’d like to be a weKAN patient activist, please contact us. The renal community needs your voice!
should do. Secretly, I enjoyed having “PROM!” written in my weekly planner among my various medical appointments.

The most exciting part of the preparation was buying my dress. For months I looked at fancy dresses online, imagining how I would look in them. My aunt and my grandmother finally took me shopping, and as soon as I walked into the store, I saw my dream gown. It was so beautiful—very simple, but long and flowing.

I thought that shoes would be hard to find since I wear a cast on my right leg, but when I looked at the fancy heels, I found what I wanted right away—strappy black shoes with little crystals. I loved them! And they made me look… well… HOT!

I still felt nervous because I use a wheelchair and a walker and worried about going to a dance if I couldn’t dance! So I kicked up my physical therapy a notch, and at night when I couldn’t sleep I’d practice my dancing. I was so excited—and I was ready!

After months of anticipation and a 3,000-mile flight from Boston to Los Angeles, the big day finally arrived. My cousin did my hair, and I went to the MAC Cosmetics store to get my makeup done. At last I put on my gorgeous dress. I felt so pretty. Even in my excitement, I was still a bit afraid that maybe this would be just like every other dance I’ve ever been to and that people would look at me strangely, wondering why I had to use a walker. I was nervous when I first walked into the dance hall. At first I didn’t want my dad to leave my side, but I realized that I had to detach myself from him if I wanted to make friends. I told him that I needed to do this by myself.

Soon after, a couple of really nice girls walked up to me and asked me about my dress; then we started to talk. We all had so much in common, and it felt so good to fit in. I was relieved that I didn’t have to go into a long explanation about what I have, why I use a walker, and this and that.

Everything about prom night was perfect. I especially loved meeting Christy Carlson Romano; I think she’s a great actress and I found out that she knows Shia LeBeouf, my number one celebrity crush! I loved getting my picture taken—I’d even practiced my photo poses for weeks. I felt like I belonged, and I danced all night! I had so much fun that I even forgot how much my leg hurt.

At the end of the evening, I slipped out of my dress, put on my pj’s, and went straight to bed, knowing that I’d truly experienced a night to remember. I want to come back next year!

You’re invited to the RSN Renal Teen Prom to be held in the Washington, DC, area!

No cost to teens ages 14 - 24 who have kidney disease, and their guest.

Co-hosted by Children’s National Medical Center and DeMatha Catholic High School

To request an invitation, call RSN at 866-903-1728.

RSVP by APRIL 25!
“For the Love of Pets”
The friends that help us cope with kidney disease

“Cairny gets his name from Cairns, Australia. Cairny sounds like “canny,” meaning shrewd or smart—he’s both. He gets me walking every day, rain or shine. In the summer we swim together.” - Bill

“My cat Jeremiah provides such comfort to me—he lifts my spirits when I am down just by being there. He accepts me just as I am, and all he desires is for me to rub his tummy, stroke his head, and take a nap with him. I named him Jeremiah because my favorite verse in the Bible is from Jeremiah 29, verse 11. My cat is a constant reminder of the promise in this verse, that God has a plan for my life.” - Heather

“Snowcream is a great foot warmer when I am freezing. At night when I couldn’t leave my dialysis cycler machine, she would do tricks for me to keep me entertained. Of course she always listens to me talk, cry, or laugh, letting me hug her, pet her, and wet her with my tears. Snowcream never gets tired of being my friend. And I am never tired of being hers.” - Christine
“My dog and my cat are my best friends, a true part of my family. One time my dog Teddy saved my life when he noticed I wasn’t breathing well after I was given wrong medication. And I’m beginning to think my cat is some kind of dialysis nurse spy—he always stretches out right in front of the fridge when I want to get something to drink. I don’t know what I would do if I didn’t have them in my life.” - Mishy

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“Blu is my diligent friend and protector who doesn’t often take his eyes off me. Think how that makes a gal feel!” - Sharon

"Sophie teaches me daily that the moment we are in is the one to live now and that forgiveness is an essential part of love. She nudges me to stop work and play more, transporting me out of myself especially when I’m having a bad day. She makes me laugh often and spreads joy to everyone she meets with wiggly affection. Where else can you find that in life?” - Myra

“Ferrets never grow up, and the ‘weasel wardance’ and other antics always made me laugh while I was on dialysis. My cats always knew when I wasn’t feeling well and would curl up next to me and start purring. This would not only relax me, but put me right to sleep on nights I didn’t sleep well. Kona is still a puppy, but I’m already training her to be my running buddy. She’ll make sure I keep exercising!” - Mandy
RSN Salutes National Kidney Month with World Film Premiere: Seymour Jones and the Temple of Chronic Kidney Disease

Produced by the Renal Support Network, starring Dan Ponsky (pictured) and directed by Stephen Furst, the film short grabs attention with vivid demonstrations of the symptoms of kidney disease in a series of comic sketches. Share this important message with your friends, family, and colleagues!

View it at RSNhope.org or on YouTube.com (Search Word: Renal Support Network)
To order a DVD for the purpose of showing to groups, go to RSNhope.org for an order form.

weKAN: Wellness & Education Kidney Advocacy Network
A national group of people with kidney disease who advocate on behalf of fellow patients. Live & Give—weKAN’s quarterly newsletter for patients—informs, inspires, and educates patients, family members, and healthcare professionals.

PEPP: Patients Educating Patients & Professionals
PEPP patient-speakers are trained to give educational presentations about kidney-related issues to patients and professionals. To learn about the presentations offered or to schedule a PEPP speaker for a meeting of 20 or more patients or professionals, go to RSNhope.org and click on Programs, then PEPP.

KidneyTalk!
Online radio talk show hosted by Lori Hartwell & Stephen Furst, covering a wide variety of kidney-related topics. Listen at RSNhope.org or download podcasts from iTunes.

RSN Renal Teen Prom
Annual prom held both in Southern California and the Washington, DC, area for young kidney patients. Open to teens ages 14 to 24 from throughout the United States.

HOPEline
A toll-free call-in line offering patient-to-patient encouragement and support from operators who have lived successfully with chronic kidney disease. Call 800-579-1970 Monday - Friday, 10:00 a.m. - 8:00 p.m. (Pacific Time).

Regional Patient Lifestyle Meetings
Based on the theme of “Health, Happiness & Hope,” meetings offer a setting where people with kidney disease and their families can learn about issues related to their illness in a relaxed, friendly atmosphere.

National Meeting Highlights
Watch highlights from RSN’s National Patient Leadership Meeting, Health, Happiness & Hope, at RSNhope.org or YouTube.com (YouTube Search Word: Renal Support Network)

KidneyTimes
An online resource with articles written by kidney patients and professionals on medical, social, nutritional, and lifestyle issues. Home of the annual “KidneyTimes Essay Contest.”

KidneySpace
An online discussion forum to air your questions, thoughts and opinions on lifestyle issues related to diabetes and kidney disease. Go to KidneySpace.com to join the conversation!

For more information about RSN and RSN’s programs, visit our website:

RSNhope.org
Have you ever tried to talk to someone about dialysis? People have asked me questions like, “What exactly do they do to you? Don’t they drain your blood and give you a new supply? Don’t they stick you with huge needles? Isn’t it painful?” People make remarks like these because they don’t have the facts about dialysis or think a person on dialysis is someone to be pitied. What they don’t know (and what I’m quick to tell them) is that dialysis is not something to be approached with dread, but rather with a focus on the facts. Dialysis can transform a sick body into one that enjoys a better quality of life. This metamorphosis takes place as we work within the parameters set for us by our physician and the dialysis staff.

As I approached retirement in 2001, I often shared my plans with others. “When I retire,” I said, “I want to work part-time on Tuesdays, Thursdays, and Saturdays. I don’t want to drive in the morning or evening rush hour traffic. I want to work from 10 a.m. to 2 p.m.” Well, when I was being dialyzed in the hospital, the social worker handed me a letter informing me that I would be coming to dialysis beginning December 2, 2004, on Tuesdays, Thursdays, and Saturdays from (yes, you guessed it) 10 a.m. to 2 p.m! I couldn’t believe my eyes! People at our dialysis facilities are working for us. They are concerned about our welfare and our quality of life. Go to dialysis as if you’re going to work. As you monitor your fluid intake and learn what your lab results mean, think of dialysis as a job that only you can do. Although this job requires perfect attendance and there’s no vacation, it offers a great salary—feeling better. We just have to do our part. That’s our job. We are works in progress, and we need to continually try to improve. We’re fighting the good fight for health, and our mantra should be “compliance, compliance, compliance!”

I so much look forward to dialysis because I love this job. Where would we be without it? We all know where! Bloated, short of breath, and knowing that we need the lifesaving treatment that dialysis can provide—treatment that we owe ourselves. Never say “die,” say “dialysis.” There’s a lot of living to do! Don’t miss out on yours.

I won’t say that it’s always easy. But it’s worth it. It’s absolutely worth it.

Celeste Compton, now 68, retired from her position as Office Manager at Mount Sinai Hospital Medical Center of Chicago in 2000 after a diagnosis of kidney failure and subsequent kidney transplant. Since the rejection of her kidney she has been on dialysis for three years, enjoying an excellent quality of life. She is married with five children, seven grandchildren, and one great-grandchild.

The meetings are held at no cost for people at any stage of CKD, and each can bring a guest, also at no cost. Two-week advance registration is required. Come on out to a meeting near you and learn how to add “life” to your years!

See the sidebar for upcoming meeting locations. For more information and to register online, go to RSNhope.org or call 866-903-1728 (toll free). We hope to see you there!
Despite popular opinion and misguided stereotypes, depression is not a personal weakness or the sign of a flawed personality, nor is it just an ailment that can be “willed” away.

Depression is a complex medical condition made up of specific physical, cognitive, and emotional symptoms. Left untreated, these symptoms cause significant distress and disruption to a person’s life, as well as problems for family, friends, and co-workers.

Untreated depression is the number one cause of suicide in this country. The tragedy is that many of these instances of depression might have been successfully treated if they had been recognized or reported.

Depression and Kidney Disease

Living with a chronic disease increases the likelihood that a person will develop depression. Diseases such as diabetes, multiple sclerosis, Parkinson’s, and rheumatoid arthritis have been shown to be associated with significantly higher rates of depression.

The same is true of living with kidney disease. In general, estimates are that in the United States, about ten percent of the population will experience a bout of major depression in any given year. In people with chronic kidney disease, some studies have shown the rate to be as high as 25 to 40 percent a year.

Signs of Depression

Depression is very different from the normal periods of sadness or “blues” that we all experience from time to time. For example, if someone you love dies or if you don’t receive the promotion that you were anticipating, it’s expected that you will have a reaction that could be described as being sad, disappointed, or “depressed.”

However, major depression (or clinical depression as it’s often called) is very different from this. People who are clinically depressed tend to get worse over time rather than improve, as most people do after the death of a loved one or a personal setback.

Classic signs of depression include the following:

- Losing interest in or finding no pleasure in activities that you once enjoyed
- Feeling sad or down for most of the day nearly every day
- Having difficulties sleeping (sleeping too much or too little or waking at night)
- Finding it difficult to concentrate or make decisions
- Experiencing changes in appetite (weight gain or loss)
- Having unexplained feelings of guilt or worthlessness
- Thinking often of death or suicide
- Experiencing fatigue or loss of energy nearly every day
- Feeling like you’re moving in slow motion or noting other observable issues of psychomotor retardation or agitation

Professional Points

No winter lasts forever; no spring skips its turn.

– Hal Borland, journalist

Addressing Depression

If you think that any of these symptoms sound like something you’ve been dealing with, it’s important that you voice your concerns to a physician, a social worker, or another medical professional. Remember, being depressed is not a sign of being weak, and talking to someone will help you not feel so alone.

Millions of Americans are struggling to deal with depression, and in many cases, it’s a needless struggle. Advances have been made in antidepressants (the medications used to treat depression) and they have fewer and less disruptive side effects than in the past, once the right dose and type of medication have been found.

In many instances of mild or moderate depression, an antidepressant might not even be the best answer. Instead, engaging in an effective form of counseling known as Cognitive-Behavioral Therapy can often help relieve depressive symptoms and help you cope with the day-to-day challenges of living with kidney disease.

Whatever form of treatment you choose, remember that depression can be treated. You can find relief from the devastating symptoms of this disease.
Dean Kujubu, MD, is a staff nephrologist at Kaiser Permanente Los Angeles Medical Center as well as Program Director of the Nephrology Fellowship Program.

A Friend Named ‘Maggie’
excerpted from an essay by Jim Dineen

There she was again—just like every morning after my treatment. Each time I went through this, her eyes told me that she understood what I was feeling, and I could tell that she was sad.

...I was diagnosed with kidney disease in June 1998 and met Maggie in October of that year. I believe that God brings relationships into our lives when we need them the most.

...She’d soothe my pain when I got home from each surgery and talk to me, in her own way, about my healing.

...We’ll always be special to each other. After all, we’ve been through a lot together. Friends—and dogs—are like that.

To read the rest of the story, go to KidneyTimes.com and type #208 in the EasyLink Access search bar.
Tips to Remember

Being Safe with Pets
by Dean Kujubu, MD

Pets provide unconditional love and companionship and have been part of households for thousands of years. Americans in particular love their pets, and many people consider them part of the family.

Recent studies suggest that pets lower stress and blood pressure, improve well-being, and reduce depression. In some cases, they even give people a reason to live. As a result of these studies, pets have been introduced into hospitals and nursing homes with beneficial effects on patients. Blood pressure or antidepressant medications have even been reduced in some patients as a result of pet therapy.

However, in addition to these definite health benefits, pets also pose some health risks, particularly for those with compromised immune function. Hugging pets, petting and stroking them, feeding them, and cleaning litter boxes and cages are all part for the course for people with healthy immune systems. Dialysis and transplant patients, however, must take special precautions to avoid serious, or sometimes fatal, infections.

Some general precautions include the following:

✓ Make sure your pet has current vaccinations. Take your pet to a veterinarian to be examined if it has diarrhea, is coughing or sneezing, or is not eating well.

✓ If you’ve had a kidney transplant, have someone else...