

A PROGRAM OF
RSN
Renal Support Network

Live & Give

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The bi-annual update helping educate and motivate people living with chronic kidney disease.



Jack Black poses with Bianca Renteria while signing autographs at RSN's 2010 Renal Teen Prom. Photo: Jodie Younse

RSN Report



Jack Black Surprises Young Patients at RSN's 11th Annual Prom

For one precious night, movie star Jack Black helped more than 300 teens forget about dialysis and renal disease and enjoy a rite of passage most kids take for granted—the prom.

Maria Curiel, 19, was part of the crowd that erupted into cheers and fist pumps on January 17th when Black arrived in a mask and surprised them with photos, personal autographs, and an acappella concert at the 11th annual Renal Teen Prom.

Curiel, of Los Angeles, says the prom is a chance to experience normal teen life. “It’s fun to go to a real prom with other people who understand what I’m going through,” she said. “I missed a lot of high school because of dialysis.” Curiel—attending her 4th renal prom—was eager to share news of her recent kidney transplant.

Lori Hartwell, founder and president of Renal Support Network, created the Renal Teen Prom in 1999 because she missed her own prom due to chronic kidney disease. “I spent all my teenage years on dialysis. It’s so important for these kids to get together because they can feel so isolated,” she said. “Being with hundreds of kids who have gone through something similar makes them happy and creates friendships that last a lifetime.”

KidneyTimes Essay Winner



Finding the Strawberry

First Place (Theme-What Brings You Joy?)

by Ronda Matthews Cluff

Pema Chodron, an American Buddhist nun, tells the story of a woman being chased through the jungle by tigers. She comes to the edge of a cliff and, with the tigers behind her, has no choice but to climb down a vine. Once she does, she sees tigers below her, too. What’s more, a mouse is now gnawing at the vine to which she clings. What to do? She sees a ripe strawberry growing within reach, tosses it into her mouth, and thoroughly enjoys the treat.

When I read this story for the first time a couple of years ago, I was

stunned. Yes, life is often a case of “tigers above, tigers below,” as Chodron phrases it, but I couldn’t wrap my mind around the idea of whole-heartedly, without a single reservation or concern, immersing myself in the joy of a small moment in the midst of a life-threatening challenge.

Over the days that followed, I began to own “the strawberry story,” because I have a potentially life-threatening challenge: polycystic kidney disease. I also have a “strawberry:” my 7-year-

Continued on page 8

Look Inside!

- 3 **LORI'S LINES**
One Teacher Made a Difference
- 5 **IT'S YOUR TURN**
Thinking Beyond Traditional Advance Directives
- 6 **KIDNEYTIMES ESSAY WINNER**
It's All About the Game
- 7 **KIDNEYTIMES ESSAY WINNER**
The Little Things
- 9 **PERSPECTIVES**
Finding the Funny
- 12 **LEGISLATIVE UPDATE**
It Sure is Complicated

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One Teacher Made a Difference

by Lori Hartwell



We have all had an experience with a person that has significantly influenced our life. Our interpersonal relationship with this

individual, whether permanent or fleeting, caused a significant change in the way we perceive or lived our lives. They are individuals whom we admire and revere, whose noble qualities make them our own personal heroes.

If we take a moment and reflect, we can often see a clear picture of our personal heroes. For me, there is one woman who comes immediately to mind. When I was ten years old, my Mom and I moved from California to Florida. While moving initially seemed exciting, my health deteriorated rapidly. My sixth grade teacher, Mrs. Rincones, was also new to the area and became concerned because of my continued absences. During the inevitable parent-teacher conference that resulted, my mom confided in my teacher that I was getting sicker by the minute. The problem was compounded by the fact that there was not a pediatric kidney specialist in the area, and the best solution was to move back to California where doctors who were familiar with my case could care for me. Unfortunately, we did not have the financial resources to make the move possible, and my mom was fearful that I would not survive.

Mrs. Rincones immediately said, "Well, we just need to raise the money to get your little girl back to the doctors who can care for her," and she went to work trying to figure out how to accomplish this goal.

I often think it would have been easy for her to say, "I am too



We did not have the financial resources to make the move possible, and my mom was fearful that I would not survive.

busy," "I have kids of my own," or "I have my own problems." But no! Mrs. Rincones wanted to help a child in need, and I just happened to be that lucky child. With the help of her friends, Mrs. Rincones raised the money for me to receive my lifesaving care.

My mom packed our gold Oldsmobile and my cherished black poodle and we made a five-day trek back to the care I desperately needed. And just in time! By the time we arrived to Los Angeles I was in congestive heart failure and needed emergency dialysis.

Over the years I often thought about Mrs. Rincones and her generosity of spirit. I lost contact with her after the move back to California, and I wondered if she was happy, healthy, and enjoying life. She deserved the best that life had to offer.

When I was sitting at my computer one day I decided to see if I could find her on the Internet. Through the wonders of Google, it took me less than ten minutes to

find her phone number. I nervously dialed the phone, wondering if she would remember me. She immediately picked up and I asked, "Is this Mrs. Rincones who taught sixth grade in Ft. Pierce, Florida?" When she replied yes, I asked if she remembered a little girl named Lori James whom she had helped get the medical care she needed in 1978.

I could feel her tears well up over the phone. "Oh my! Is it really you, Lori? I often wondered what happened to you, if you lived."

Time stood still for a second as I became a little girl again and I thanked her for helping save my life.

She then responded, "That event changed the course of my life." The sequence of events she then described provided background information that I had never known on how she had raised the money to fund my lifesaving return to California. As she stated: "When I learned a young girl was sick and needed help, I immediately went to the church to ask for their assistance. Their response was shocking. The church said they would help only if I could answer one question affirmatively: 'Is the little girl white?'"

Living in a predominantly black demographic of Florida, being white was not a very high probability. But Mrs. Rincones refused to dignify the church's question with an answer. She found another way to raise money by putting jars in bars and diners alongside the cash register, asking people to donate their extra change. By pounding the pavement and asking hundreds of people to help out, she was able to raise enough money for me to return to California for the care I desperately needed.

"Lori, that event changed my life and I never was the same

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Continued on page 4

KidneyTimes.com

Gout and CKD - A New Era of Hope

By Peter Laird, MD

EasyLink Access #: 486

How to Multi-List for a New Kidney

By Ronald (Ron) Taubman

EasyLink Access #: 481

The National Kidney Registry

By Garet Hil, Founder

EasyLink Access #: 485



KidneyTalk Podcasts (Available on iTunes and KidneyTimes.com)

Eyewitness Account of Living Donation

Guests: Phillip Palmer, ABC News Anchor, kidney donor & Dale Davis, kidney transplant recipient.

EasyLink Access #: 492

The RightStart Program

Guest: Rebecca Wingard, RN, CNN, VP Quality Initiatives at FMC

EasyLink Access #: 489

Transitioning out of Childhood for Young People with CKD

Guest: Dr. Maria Ferris, Pediatric Nephrologist, University of North Carolina at Chapel Hill

EasyLink Access #: 491



One Teacher Made a Difference

Continued from page 3

afterwards," she told me. "My goal in life became to share the fact that all children are important, no matter what color they are."

In the south in the late 1970s, prejudice was rampant and to think that the color of my skin could have been the deciding factor of whether I lived or died is shocking. Luckily, I had such an extraordinary teacher who cared deeply about all of the people in her community.

I subsequently visited Mrs. Rincones when I was in Florida, and we had a wonderful lunch. She still teaches—both in the classroom setting and helping people in her community. I am sure that hundreds of children and adults still are inspired to live up to her standards and model their lives by her example. She is a hero and a great role model for all.

It is always helpful to think about our personal heroes. Ask yourself: Who has made a difference in my life? Have I thanked them? [It is likely that they did not expect your thanks (although it is always appreciated).] More importantly, have you reciprocated the favor by trying to help others like someone once helped you?

At different points in our lives we are all students or teachers. I encourage you to embrace both roles, and strive to positively influence the lives of others. ✎



Have an article, topic or story you would like to share? Write for *Live & Give* or *KidneyTimes.com*.

For writing guidelines see *KidneyTimes.com* EasyLink # 494 or call Renal Support Network at 866-903-1728.

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Why Does *Live & Give* Now Have Advertisements?

Renal Support Network (RSN) is excited to announce that this is the first issue of *Live & Give* that features advertisements. In the past we have run ads for our own programs and included our sponsors on the back page. As it is throughout the country, we at RSN have felt financial strain as a result of the unstable economy. In order to continue providing you with our unique programs and services at no charge we have had to become more creative with alternative funding sources. As a result we have opened up our online and print publications to ads. We encourage you to embrace our funders and review their messages to see if something can help enrich your life. We guarantee that our articles have the same message and our quality has not changed. Thank you for your continued support and readership.

If you or your company would like to advertise with RSN, please contact JodieYounsetoll-freeat(866)903.1728,ext.101orJodie@RSNhope.org.



Thinking Beyond Traditional Advance Directives

by Denise Eilers

Advance Directives and end of life care are not easy subjects to think about let alone discuss. Those topics aren't exactly the stuff of idle party chatter: "Hi there; it's nice you could come. Great outfit! How are things with your family? Oh, and by the way, how do you envision the last years of your life and your death?"

A living will spells out what types of treatment we want if we are unable to make those choices ourselves.

decisions for us if we can no longer do so. Since there are so many complexities inherent in today's medical care and not every scenario can be anticipated, it is vital to complete both documents. Although there are numerous variations of advance directive forms, "Five Wishes" is one commonly used

care plans and file the papers away to gather dust. Give copies to both your health surrogate and your physician. Tuck a copy into your luggage when traveling. Since individuals change and family circumstances fluctuate, it is also important to revisit and reevaluate your wishes on a regular basis.




Despite our technology, or maybe because of it, the end of life still remains a somewhat taboo subject. For today's no-holds-barred generation, all aspects of birth seem to be fair game for social interaction—but not illness and death? We plan ahead for every one of life's other milestones, but nervously skirt conversations about dying. Yet what could be more important than completing life on our own terms? In his book *What Dying People Want*, Dr. David Kuhl sums up one reason for our aversion: "Talking about death is very difficult. We are afraid that talking about death beckons it."

Advance Directives

The foundations of advance care planning are the legally recognized documents which allow a person to retain control of their health care. A living will spells out what types of treatment we want if we are unable to make those choices ourselves. Durable power of attorney designates a surrogate to make

format that is legally recognized in an increasing number of states. For more information and help in completing directives, check with the social worker in your unit or at your local hospital. These directives go into effect only when a situation renders a person incapable of making decisions for themselves and can be revoked at any time by destroying the copies, by notifying your physician and your designated surrogate, or by executing a new document. Any competent person of legal age can, and should, execute advance directives. Unfortunately, even young people can be involved in accidents or suffer from sudden, life-threatening illnesses. After all, no one can predict the future.

The bottom line, though, is that all the end-of-life planning is useless if you fail to communicate your wishes to your loved ones. Talk with your family, friends, and health care professionals even though the conversation may be uncomfortable. Don't just complete your advance

Despite all our protests and denials, death is not an optional event. In his book *Medical Care of the Soul*, Dr. Bruce Bartlow begins by observing that "all of us will come to the end of our lives, but so few of us will die well." Planning the proverbial good death takes time and soul searching. By refusing to acknowledge the end of our life, by shying away from these discussions and by neglecting to prepare advance directives, we may ultimately leave our loved ones an unintended legacy of frustration, guilt, and a huge mountain of "if onlys." In the end, advance care planning is as much about living the rest of our lives with purpose and joy as it is about dying. 



Denise Eilers is both a Registered Nurse and a family member. Her husband Jerry was on home hemodialysis from 1980 until his death in 2004. Denise, who lives in Davenport, Iowa, teaches nursing at United Township Area Career Center in East Moline, IL. She is also a member of the Network 5 Kidney End of Life Coalition and volunteers for Genesis Hospice.

Read the entire *Thinking Beyond Traditional Advance Directives* article on KidneyTimes.com Easylink Access No. 490.



It's All About the Game

Second Place (Theme-What Brings You Joy?)

"Hey, batter, batter, SWING!" These are some beautiful words to my ears. I've been a hemodialysis patient for 14 years, but, more importantly, I've also been a volunteer coach in a youth baseball program for the past 25 years. My kidney failure and my years and years of dialysis have robbed me of some of the things that many 53-year-old men take for granted – like being able to work or being able to play 18 holes of golf on a hot summer day. But ESRD and dialysis have not taken away my desire to be a volunteer in my community. Helping little kids learn to love the game of baseball is one of the greatest joys of my life.

At the youth baseball complex where I volunteer, I'm not a dialysis patient, I'm not a sick man, and I'm not disabled. There, I'm simply "Coach" to 15 precious nine and ten-year-old kids. Yes, the players on my team know that I can't do everything else that other coaches do. They see the scars on my arms from failed dialysis accesses, but it doesn't bother them. They touch the working fistula on my forearm and call it a "magic bumblebee" because it buzzes. They understand that I'm different, but it doesn't matter to them. In spite of everything else about me, my players know that I love the game of baseball and that I care about each and every one of them.

When I'm on the field with the kids, I don't have time to think about

my health, my dialysis treatments, my doctors' appointments, my phosphorus level, or my physical limitations because there are more important things. Who's going to start on the mound today? Who's batting clean-up? Does every kid remember the signs for "bunt" and "steal"? Have we prepared our minds to be on top of our game? Did we give it our all? When the game's over, are there enough hot dogs for every child to have one (even

if I can't eat one myself because they're so high in phosphorus)? Does every kid have a ride home? Did everyone have a good time and learn something? These are the important questions on a youth baseball field.

Being a youth baseball coach in my little town, I have a clear purpose and I am needed. I live in a rural, socioeconomically disadvantaged area of the country. Most of the kids on my team have been labeled "underprivileged," and many of them are being raised by single moms or, for some, grandmothers. Some of them come from families that are struggling just to keep food on the table, and a couple of them live in the government-subsidized housing



Burney poses with a couple of youth baseball participants.

project in town. Few of them have contact with a positive, adult male role model in their homes.

The kids on my team need me to teach them about sportsmanship, how to practice hard and then play hard, how to win with grace and, sometimes, even lose with dignity. They need me to show them what it means to be part of a team; they need to see that raw talent and brute strength alone are not enough

and that, instead, determination and perseverance will carry them a lot farther. They need me to pat them on the back when they've done something good and to bench them when they get out of line. More than anything else they need me to be there at that field; they need to hear my laughter and see my smile. They need me to teach them "life's lessons," and if they learn something about the game of baseball too, that's just icing on the cake. ☞



Marvin Burney lives in southeastern North Carolina with his wife, Marsha. Even though they have no children, the Burneys have volunteered in the youth baseball organization in their small town for 25 years. Marvin started dialysis in 1995 but got a three-year break in 2000 when his wife gave him one of her kidneys. He has been back on dialysis since 2003.

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8th Annual RSN KidneyTimes.com Essay Contest

Theme: *Lessons Learned From a Book, Movie, or Song that Help Me Deal with CKD*

Compose an essay of no more than 750 words that best expresses the theme. Be sure to include your complete name, address, and phone number, as well as e-mail address if applicable. You must be diagnosed with chronic kidney disease in order to participate in the essay contest. Submissions must be received no later than 8/15/2010. Essays may be submitted in one of the following ways:

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For more details go to KidneyTimes.com and look up Easy Link Access number 204.

KidneyTimes Essay Winner



The Little Things Third Place

(Theme-What Brings You Joy?)

I was born in 1934 in the middle of the first big Depression. We had very little in the way of toys or things to play with. But we always had enough to eat, clothes to wear, and love in our house. I was the only child in the neighborhood in my age bracket, so I mostly entertained myself. I learned to watch the birds build their nests, delighted in a rainbow after I had played in the rain, watched the sunsets, and only went inside when I was called by my full name. I found joy in the smallest things like climbing a big tree and crawling under the house to hide and drink an Orange Crush that I had charged to my Dad at the grocery store. I was also the neighborhood gossip. I went door to door and repeated everything I heard the grownups say at my house and was rewarded with cookies and milk. So I can honestly say that I have been living a joyful life as far back as I can remember!

No one lives to be 75 without having many tragedies in their life. I have had more than my share but I refuse to let them get me down. I always have hope that tomorrow

will be better and it always is. When I start feeling depressed, I do something for somebody else. I call a friend, write a letter, say something kind to those around me. I revert to my childhood and start finding joy in all the little things around me. I also call upon my sense of humor to brighten my perspective.

When I learned that I would have to go on dialysis, I was afraid. I could not imagine what my life would be like. My kidneys had been failing for nine years, but I thought at my age I would probably not live long enough for them to completely fail, but I was wrong. I was very ill and

in and out of the hospital several times in the four months before I was placed on dialysis. My primary physician was totally misinformed and told me it would be terrible for me. But I didn't take his word for it; I got on my computer and started reading everything I could find about the machines. I also called a clinic and asked for permission to go and take a look at the facility and talk to the staff. They were extremely helpful and explained everything

to me. One by one by fears were alleviated. The patients were sleeping peacefully or watching television.

I decided I would not let dialysis define me. I was the same person with the same capacity to find joy in my life. Dialysis was only a small part of my life and so what if I had to be on that machine for the rest of my life. Surely giving up a few hours a week to save my life and to feel better than I have felt in years was not too much to ask.

It has been almost two years since I started on dialysis. My health has greatly improved. I can drive my car now, travel-which is one of my great joys in life-and I live a rich and joyful life. I have a wonderful family who are very supportive and I have made so many new friends. I am now a patient advocate for my clinic and hope to start a support group in the near future.

I have a little plaque in my office that pretty well sums up the way I prefer to live my life. It says

"Life isn't about waiting for the storm to pass. It's about learning to dance in the rain!" ☺



Jorita Lehman, a diabetes patient with a history of heart problems, parks her boots in Weslaco, Texas, with her daughter Charlena's family when she isn't traveling. She has been receiving dialysis for approximately three years, and uses the insight gained from her medical and life experiences to encourage positive outlooks in others despite their medical conditions.

Finding the Strawberry

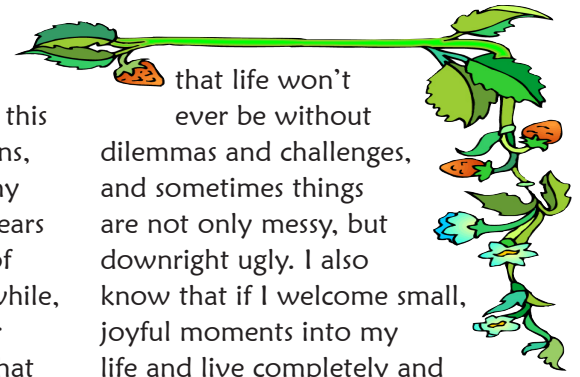
Continued from page 1

old daughter. She's a live wire and she has brought me into the world in a way that my introverted temperament never allowed. But because it's in my nature to dwell on my fear of the unknown and the things I can't control, I sometimes need to stop and ask myself out loud, "Where is the strawberry?" Most of the time, the answer is this 4-foot-tall creature who doesn't take no for an answer and lives for small moments of joy. It is amazing how many joyful moments there are and how powerful they can be when you're really paying attention.

I'm 42 years old and while my kidney function is pretty close to normal right now, I know it won't be that way forever. The impact of PKD

on generations of my family has been enormous, and I've watched this disease take its toll on aunts, cousins, and my own mother. As I write, my mom has been on dialysis for 18 years and a cousin is nearing the point of getting on a transplant list. Meanwhile, my own blood work and need for blood pressure medication show that PKD is staring me down, too. "Tigers above, tigers below."

But in every day there is at least one strawberry: an unexpected hug given so enthusiastically that I nearly lose my balance, sitting down as a family to watch *The Wizard of Oz* (for the 100th time), or going for a walk hand-in-hand on a late spring day (despite the salt-marsh mosquitoes). I accept



that life won't ever be without dilemmas and challenges, and sometimes things are not only messy, but downright ugly. I also know that if I welcome small, joyful moments into my life and live completely and without reservation while in them, I will continue to be able to lead a joyful life. ✨



Ronda Matthews Cluff lives in southern New Jersey with her husband, daughter, and three cats. She was diagnosed with polycystic kidney disease at age 13 and recently lost her mother to complications of end-stage renal failure. She is a freelance public relations specialist for nonprofits and in her spare time enjoys reading, writing, and backyard birding.



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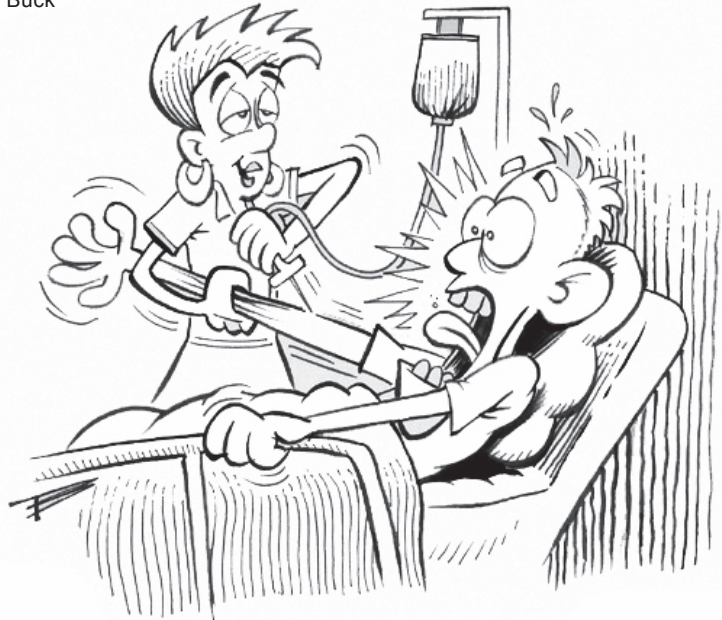
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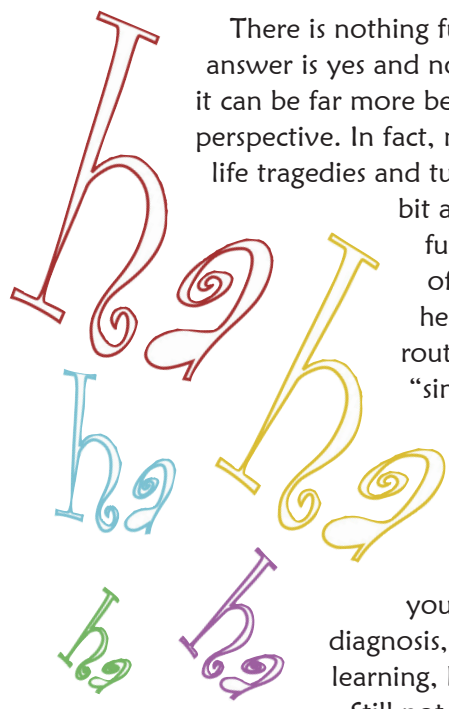


There's nothing to fear but fear itself and an unskilled IV nurse.

See more cartoons on our website
RSNhope.org

left column, Video/Cartoon Gallery.

There is nothing funny about being sick, or is there? The answer is yes and no. Surely, it's no fun having an illness, but it can be far more bearable when viewed from a humorous perspective. In fact, many professional comedians have taken real life tragedies and turned them into comedy gold. Richard Prior's bit about experiencing a heart attack is one of the funniest I've ever heard. Louie Anderson tells of growing up with an alcoholic father and he brings down the house. Robert Schimmel's routine on surviving cancer has been called "simply hilarious."



Clearly, there is something about surviving adversity and illness that tickles our funny bone. I believe it was Woody Allen who said "tragedy plus time equals comedy." The key word here is time. Once you've put some distance between you and your diagnosis, you can view it not as a tragedy, but as a learning, humbling, and yes, humorous experience.

Still not convinced? I felt the same way when I was first diagnosed with Nephrotic Syndrome back in June of 1989. Nephrotic Syndrome is a type of kidney ailment, categorized as an autoimmune disease, in which damage to the capillaries of the glomeruli (microscopic blood vessels in the kidneys) cause the protein albumin to leak into the urine. If the leakage of fluid from blood vessels into tissues depletes the liquid component of blood and the blood supply to the kidney is diminished, there is a considerable risk of kidney failure. This proposition made me cry, not because of the fear of possible kidney failure, or the uncertainty of living with kidney disease, but because the biopsy hurt like a SOB. The fact that my procedure was done at County USC Medical Center in Los Angeles made it all the more terrifying. The place was scary. I walked in and saw a guy on a ventilator hand cuffed to his own gurney—obviously a flight risk. I don't want to say the hospital was a dangerous place, but when I was admitted, they didn't give me a gown; they gave me a bullet-proof vest—that opened in the back—for easy access.

These are just a couple of real life examples of how humor can be found in even the most challenging of circumstances. The point is: the sooner you can find the funny in your own crisis, the sooner you can experience the medicinal value and healing power of humor.

It's been said that laughter is the best medicine. For me, it's been an integral part of the healing process. Sharing this insight and making people laugh is the reason I give humorous presentations. The key is not to take life so seriously. Give yourself permission to laugh and it will pay off in droves. Remember, there is something funny that can be found in illness; all you have to do is allow yourself some time, and be willing to laugh.



After receiving a bachelors degree from San Diego State University, Michael got involved in stand-up comedy. He began at the Comedy Store in La Jolla California and moved up to performing at comedy clubs across the country. Due to ongoing health issues, including Ulcerative Colitis and Nephritic Syndrome, Michael has curtailed his travel and now focuses on humorous speaking for the health care industry. Michael is available for health-related humorous presentations and can be reached via his website www.Dochumor.com

It Sure is Complicated

Continued from page 12

may—after a year of negotiation—be back to square one. CMS may have issued its Final Rule regarding a Prospective Payment System for dialysis reimbursement and the Quality Measures proposal may be in the works for comment. The conversations about lifetime immunosuppressant coverage, Medigap access, and more frequent dialysis will continue, and each will have voices within the industry for and against them. It's so important that the patient voice is heard loudest of all on these issues, as we are the ones that will be most directly impacted by future decisions and policy. RSN has recently opened membership to our advocacy arm, the Wellness and Education Kidney Advocacy Network (weKAN) to accommodate people with chronic kidney disease who have an interest in being informed and proactive on any of these issues. So check into the KPP101 board and drop us a line at info@RSNHope.org if you are interested. There is so much work ahead; but with the sharing of resources and connections among all of us, it doesn't have to seem quite so complicated.



Diagnosed with kidney disease in 2004, Kathe LeBeau began home hemodialysis in April of 2007, and is presently on the kidney transplant waiting list. She is the Project Manager for RSN's weKAN group, and is also a PEPP speaker and HOPEline operator. Kathe lives in the Capital Region of New York State with her husband of 14 years, Loren Fadding.

If you're a patient and are interested in joining the Wellness & Education Kidney Advocacy Network (weKAN) contact Kathe LeBeau at info@RSNhope.org.

Call for Submissions Chronically Happy



Video Contest

Share your tips for chronically happy living through video.

Grab your new flip camera you got for Christmas—or any other digital video camera—and capture some tips on how you live a joyful life in spite of kidney disease. If you or someone you know has chronic kidney disease, we want to hear from you! Tell us your tips and strategies on how you manage your disease; share words of wisdom and guidance on how you keep a positive outlook on a daily basis.

Videos can *only* be submitted by uploading your file to YouTube and emailing RSN the link to the video. Projects should be between 30 seconds and 4 minutes. No inappropriate material will be considered. Cash prizes available for first, second, and third place winners. Deadline for links to be emailed to us is July 18, 2010. Send the link to your video, your name, address, and phone number to video@RSNhope.org with the subject “RSN Video Contest.” Be as creative as you want!

For more details go to KidneyTimes.com Easy Link Access number 493.

Chronically Happy

by Lori Hartwell

Joyful Living in Spite of Chronic Illness



Lori Hartwell, President and Founder of Renal Support Network has lived with a chronic illness (kidney disease) since age two.

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Nephrology News & Issues

Contact us toll-free at **866-903-1728**

“To know the road ahead, ask those coming back.”

-Chinese Proverb

weKAN Live & Give is a publication of the Renal Support Network, a patient-run nonprofit organization whose mission is to identify and meet the non-medical needs of those affected by chronic kidney disease.

weKAN Patient Activists serve to mobilize, educate, motivate, and empower fellow chronic kidney disease survivors to advocate for themselves and for one another. Together we can make a difference.

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www.RSNhope.org

Give the gift of health, happiness & hope!

- Yes!** I would like to receive a free subscription to the *weKAN Live & Give* newsletter.
- Yes!** E-mail me *renALERT*, RSN's electronic update! (Please provide your e-mail address.)
- Yes!** Please send me _____ additional copies of *weKAN Live & Give* to distribute.

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- YES!** I would like to help RSN continue the programs that help educate and motivate those affected by chronic kidney disease.

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 - transplant PD hemo
- Family Member Administrator
- Physician Nurse
- Dietitian Social Worker
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Cut form on dotted line and mail or fax to the Renal Support Network. Thank you!

Renal Support Network

1311 N. Maryland Ave.
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Programs & Services

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).

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 in the Southern California area each January for teenage kidney patients. Young people with CKD ages 14 to 24 come from across the United States to enjoy a night of glamour.

Regional Patient Lifestyle Meetings

Based on the theme of "Health, Happiness, & Hope," meetings held nationwide offer a setting where people with kidney disease and their families can learn about issues related to their illness in a relaxed, friendly atmosphere.

KidneySpace

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

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 patients or professionals, go to **RSNhope.org** and click on Programs, then PEPP.

Chronically Happy: Joyful Living in Spite of Chronic Illness

Written by Lori Hartwell, *Chronically Happy: Joyful Living in Spite of Chronic Illness* is an upbeat, motivational book that helps people living with chronic illness create joyful, fulfilling lives. **Available on Amazon.com for Kindle or in paper back. Also available from RSN in audio.**

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 biannual newsletter for patients—informs, inspires, and educates patients, family members, and healthcare professionals.

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."

KidneyTimes.com

*In this issue of Live & Give...
A dose of hope!*

Legislative Update



It Sure is Complicated

by Kathe LeBeau

I was thinking as I was watching the recent Meryl Streep film *Its Complicated* that the title perfectly sums up where we are and where we are going with legislative and regulatory advocacy in renal care and the larger health care debate. Boy, is it complicated! There is so much to know, and several differing opinions for every conceivable facet of the discussion, and just when you think you understand and have it clearly fixed in your mind, another shoe drops to change the landscape.

At RSN we are trying to help wade through the morass of information and public comments on and the pros and cons of the major issues at both the federal and state levels. To that end, we have modified our Kidney Public Policy 101 (KPP101) discussion board

(www.KidneyPublicPolicy101.com) created in 2009 to sort through and facilitate dialogue on the CMS' PPS bundling proposal. KPP101 is now a broader venue where anyone interested in advocacy issues can come to learn about and contribute to information on all facets of renal care as policies are created through legislation and modified and implemented through regulation. You can find everything from the bills before Congress to the status on state issues to comment period deadlines to contact information for every official agency and governing body that has a hand in deciding how renal care will be delivered to patients in the United States.

By the time you are reading this, the health care reform debate

Continued on page 9

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