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-old.

Continued on page 8
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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 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. 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.
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.

**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-free at (866) 903.1728, ext. 101 or Jodie@RSNhope.org.

**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.**
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?”

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 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 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 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 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.

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

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Read the entire Thinking Beyond Traditional Advance Directives article on KidneyTimes.com Easylink Access No. 490.
“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 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.
I decided I would not let dialysis define me.

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 approxi-
mately three years, and uses the insight gained from
her medical and life experiences to encourage positive
outlooks in others despite their medical conditions.

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
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.
Finding the Funny

by Michael Elizondo

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 your 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 bachelor’s 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
Call for Submissions
Chronically Happy

YouTube 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

Available on ChronicallyHappy.com or call the number below.

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• CD Audio Book

• Audio Download

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“Her stories and words of wisdom have inspired others to embrace a joyful life in spite of their illness.”
Nephrology News & Issues

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“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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Programs & Services

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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

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I was thinking as I was watching the recent Meryl Streep film *It's 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...