

## The Patient Self-Advocacy Issue



### The Desperate Truth-Seeker: *How a Patient With Chronic Kidney Disease Became Her Own Best Advocate*

*1st Place Essay Contest Winner: Risa Simon*

My greatest fear had suddenly become a chilling reality when tests confirmed that I'd inherited the same kidney disease that took my father's life in his early forties and my grandmother's life before I was born. I felt kidnapped by my own genetic inheritance and doomed by its legacy.

I'd prayed that my life would be different. The reality of someday having countless cysts overtake my kidney function rattled me to the core. Oddly enough, I was told, "Relax. You have lots of time. You're not sick enough yet." The notion of becoming sick enough continued to haunt me.



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# EMBRACEHOPE

by lori hartwell

# JEWELRY



*EmbraceHOPE Jewelry is assembled by people who have been affected by chronic kidney disease, providing them with the opportunity to help Renal Support Network and to share their experiences, strength, and hope with one another at the same time.*



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# Avoiding the Holiday Blues

by Lori Hartwell

You walk into your local grocery store and you're bombarded with holiday cheer: "Winter Wonderland" gives way to "Frosty the Snowman" over the loudspeaker, even though you're in sunny Southern California and it's warm enough to wear flip flops. Every aisle is littered with holiday snacks that companies have spent millions of dollars advertising in order to get you to buy them. Unfortunately, the fact that none of the choices are renal friendly doesn't stop your taste buds from salivating in anticipation. For a moment, you think that maybe you should get a few bags to take to that holiday party you were invited to, but you already know that tons of goodies on the forbidden list will be provided and that adding more temptation to the buffet table isn't going to help you get a good lab report. The next stop is the checkout stand. You leaf through the magazines as you wait for the line to inch forward. No matter which magazine you pick up, alcohol promotion is everywhere. Having to abide by a fluid limit and knowing that alcohol doesn't mix with the 15+ meds you take makes the bah-humbug effect start to set in. Depression is the often unwelcome guest that invites itself into your life at this time of year and wreaks havoc. Holiday stress, anxiety, family-related issues, loneliness, and unrealistic expectations can make you feel like Ebenezer Scrooge himself.

Here are a few tips I've picked up along the way to help overcome the blues that sometimes accompany the holidays:

## Food

A restricted diet can put a damper on any holiday party, and I've learned that if I don't know which types of food could be there to tempt me, I'd better eat before I go. I've also found it helpful to bring a dish or appetizer that I can eat. If a family member or friend is hosting the party, it's a great opportunity to educate him or her about the renal diet I've often asked the person hosting an event what I could bring because I was on a special diet. This usually prompts a question about the types of food I can eat and the offer to make something yummy that all the guests can enjoy without making my dietitian go into hysterics.

## Alcohol

My nephrologist has never told me that I couldn't have a drink. The advice I was given is that if I do drink, to do so in moderation and to avoid mixing alcohol with my medications. I was further told to learn what the potassium and phosphorus levels in particular beverages are and to count alcohol in my daily fluid allotment. For example, I like a glass of red wine. A typical 3.5-oz glass has 5 mg of sodium, 82 mg of potassium, and 14 mg of phosphorus. Make it a point to discuss the whole question of drinking alcohol with your doctor.

## Holiday Blues

People are under a lot of pressure to be joyful during the holidays, and sometimes I feel bad because I'm not Ho, Ho, Ho-ing along with everyone else. I know that I'm going to be much more emotional during the holidays and I have to be prepared so I don't go into a funk. The key for me is engaging in a creative activity, such as making cards, holiday ornaments, or presents for my friends. When I visit family, I always have a game or activity in mind to help connect on a positive level. This helps prevent family members from gossiping, which can be stressful too. It's also important to plan events that you look forward to. I can't think of anything more fun than planning to see a movie with my husband and inviting our friends to join us. And one quick way to feel joy is to smile and make eye contact with people and wish them a Happy Holiday. Open the door at the mall for a stranger, let another driver have a parking spot, and spread holiday cheer by your actions. You'll feel better for it.

Lori Hartwell, founder & President of the Renal Support Network (RSN), was diagnosed with kidney disease at the age of two. In 1993 she founded RSN to instill "health, happiness and hope" into the lives of those affected by chronic kidney disease. Lori is also the author of the book "Chronically Happy: Joyful Living in Spite of Chronic Illness" and is a four-time kidney transplant recipient.

## The Desperate Truth-Seeker

Continued from page 1

While it didn't happen all at once, my numbers started declining as the years went by. Desperate for guidance, I jumped on a plane to attend a premier kidney conference. The timing couldn't have been better. All of my uncertainties were addressed. The truth was out. Patient advocacy was in.

My mind was reeling the entire flight home. At 35,000 feet, I reset my internal compass to debunk all of that "get sicker first" gibberish. I was on a mission to become my own best advocate with a new mantra, *Vincit Omnia Veritas—Truth Conquers All*. By the time the cabin door was aligned with the gate, I felt an incredible sense of renewal. I knew I was onto something big. I snatched my bags and hit the ground running in search of the best life possible.

I became an inquiring mind on a laser-focused expedition. I researched, interviewed, and polled those who had walked this path before me. The more I learned, the more I realized how much I didn't know. I discovered staggering differences between dialysis and transplantation. I also discovered that dialysis before transplantation posed significant disadvantages. For the life of me, I couldn't understand why I'd been duped into believing that both dialysis and transplantation held similar value. Short of being educated on their respective procedures, I was in the dark about their comparative outcomes and quality-of-life differences. While I didn't need renal replacement at the time, I knew that the day was approaching.

I burrowed my way through a maze of choices and found the magic kingdom of preemptive

transplantation—the golden ticket to bypassing dialysis through living-kidney donation. Astonishingly, that was an optimal choice that was never discussed with me.

I then studied our nation's shortage of organs from deceased donors, the dreadful waiting list and inconceivable timeline. I felt strongly that something had to be done, so I started sharing these facts with anyone willing to listen.



Eventually, I built up enough courage to weave my own story into the conversation. The response was deeply inspiring. Most listeners wanted to learn more, and nearly two dozen offered to help in some way. Over the course of a year, a handful of these precious souls stepped forward to be tested on my behalf.

Sadly, all of them were disqualified. Daunted by disappointment, I refused to let unfavorable circumstances make me abandon my mission. I knew in my heart that my ideal donor was out there. I reflected on my journey and realized that my need had become stronger than the promise of its subsequent blessing. I said goodbye to the person in need of what she didn't have and became a person who already had everything she

needed. Within 10 days of owning this newly liberated point of view, my ideal donor appeared.

She wasn't the typical volunteer for this type of engagement—not a family member, distant relative, or lifelong friend. She was a transplant nurse who'd witnessed too many unnecessary deaths from organ donation reluctance.

We were newbie acquaintances. Kindred-spirits is how she described it. According to the lab, our kinship went beyond all the visceral intangibles. Melissa and I had a 5 out of 6 "sister-like" match. I felt immensely blessed.

After our surgeries, I affectionately nicknamed my new kidney MAK—a fitting acronym for Melissa's Amazing Kidney. Melissa insists that the gift she gave was just as much a gift to her as it was to me. Never claiming to be a hero, she says that she simply did what she felt was right.

As for me, I describe it all in one word: grateful.

I'm grateful Melissa chose me. I'm grateful for the gift of MAK. I'm grateful for this extraordinary life-changing experience. I'm also grateful that I found the courage to proactively advocate for the best possible life—the life I now live.

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*Risa Simon's determination to avoid dialysis—and thrive, not just survive, is what compelled her to become her own best advocate. The compelling ideologies and trailblazing systems she reveals in her new book *Shift Your Fate: Life-Changing Wisdom for Proactive Kidney Patients*, guide transplant-eligible CKD patients to reclaim the quality of life they deserve.*



# Before and After Obamacare



## *Lifetime Caps & Pre-Existing Conditions*

By Priscilla  
Ring VanderVeer

I was 20 years old when my transplanted kidney failed and I went back on dialysis. Although I was able to stay on my parents' insurance for several years, once we moved to a new state I was on my own.

Medicare did pay for 80 percent of my hospital costs, but it was all I had. I couldn't purchase private insurance to help with the remaining costs because I clearly had a pre-existing condition. Also, this was before Medicare Part D, so I had to pay for all of my medication myself.

I had a part-time job, went to school full-time, and spent the rest of my time on dialysis. Little did I know that having a part-time job would make my situation

worse; it put me about \$20 above the state's Medicaid threshold.

But I was lucky, my dialysis center looked at my income and my expenses and decided that it would pay for the 20 percent of the treatment costs not covered by Medicare. The hospital and doctors' offices I frequented agreed to do the same, even making sure that when I got my transplant—which was not without complications—the cost to me was less than \$1,000. When there were emergencies and I ended up at another local hospital, I received bills in excess of \$10,000, which I never would have been able to pay without help from my family.

After I graduated from college in 2001

and started my career, it became immediately clear to me that I had to have a job with comprehensive benefits. Otherwise, I would quickly become one of the many people in this country who face a future of escalating medical bills and, ultimately, bankruptcy.

My response was to get a full-time job with benefits as quickly as I could. Although my jobs provided me with health insurance despite my pre-existing conditions, I still lived in fear because it wouldn't be very hard for me to reach the lifetime cap of \$1 to \$5 million. That might sound like a lot of money, but for people with kidney disease, hitting that cap is all too possible.

The Affordable Care Act (often called Obamacare) lifted some of this weight from my shoulders. If I were to lose my job or decide to become a freelancer, Obamacare gives me options. It allows me to purchase insurance in the private market, and I no longer have to live in fear of reaching a lifetime cap on my health care costs.

The restrictions I've described might not sound like much, but they were a part my life for a very long time, and I stayed in dysfunctional and unhealthy job situations far longer than I should have for fear of losing my insurance.

Obamacare is far from perfect, and much work remains to be done to give all of us across the country access to the health care we need. What the law did do, however, is to give many of us the freedom to live the lives for which we have fought so long.

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*Priscilla Ring VanderVeer was diagnosed with CKD in 1982. A former peritoneal and hemodialysis patient, she's also a two-time transplant recipient. She's had her current transplant since 2000. In her day job, Priscilla is a health care practice director at the Washington, DC office of APCO Worldwide, where she manages broad communication, stakeholder engagement, issue and earned*



*media campaigns. She lives in Silver Spring, Maryland with her husband, Ken and their two dogs, Bea Arthur, a tiny 5 lb. Maltese and Henry, a slightly larger-than-average Yorkshire Terrier.*

# The Black Binder

*Dividers with tabs. Check.  
Black Sharpie marker. Got it.  
Hole punch and reinforcements.  
Ready to be used.  
Big black binder. Perfect.*

2nd Place Essay Contest Winner: Mary H. Wu

Crisp and wrinkled medical documents encircled me in the neat and meticulous piles that I'd made. I was a human "spin-the-bottle" in the middle of massive amounts of paperwork, wondering which pile I should tackle first. I was 22 years old. Ten years after receiving my second kidney transplant from my precious deceased 4-year-old donor, I was about to embark on my new health care journey: I was about to see my nephrologist all on my own, with no parent there to hold my hand and ask all the questions. Only my nephrologist and me. It was time for me to take full responsibility for my own health, body, kidneys, and life. When I was 7 months old, the health care professionals who had become my second family diagnosed renal agenesis, which means that my kidneys had never fully developed (one was shrinking and the other was deformed). All of the papers that surrounded me summed up my life with chronic kidney disease: reconstructive bladder surgery in an attempt to "fix the plumbing," peritoneal dialysis for 2 years starting when I was 3 years old, my first kidney transplant when I was 5, years

of bed-wetting and an arthritis diagnosis after that first transplant, a second transplant when I was 12, worsening joints, and more. When I was growing up, health care professionals always spoke

smiled, and swooned over how cute I was with my moon-pie face from prednisone; they pinched my chipmunk cheeks and placated me. Little did they know that I was listening to every conversation and



to my Dad about my body and the condition of my defunct kidneys. Those professionals didn't know that an active participatory patient was waiting to be released when I finally became a legal adult. White-coated people looked at me,

every word they and my father uttered about me. Truly listening to my body, as well as playing the quiet, intuitive observer and listening to the discussions about my body, was the first step in becoming a proactive patient

Proactive patients quickly learn that from listening and observing comes careful thinking, along with decision making and then, finally, corrective and maintenance actions aimed at managing one's own health. I knew my body better than anyone. I was a pint-sized, unique person who packed a punch with the volume of my voice and the articulation of my words. Yes, I was short at only 4'11", but loud in life and living, and especially in taking care of myself. Now that I was going to see my nephrologist all by myself, I was going to prove that I packed a punch in the active participation of my health, body, and precious, pre-owned kidney. Sprawled on the floor, I leafed through the piles of paper with slight trepidation. How was I ever going to organize all these papers? How was I to make the transition from child to adult and prove to my health care professionals and myself that I could handle everything involved with my health, from dealing with the paperwork to being a proactive patient? How was I ever going to solidify the position that I was indeed a patient who asked to be taken seriously and wanted to work alongside my health care team rather than beneath or even above them?

I began to carefully punch holes in as many sheets as I could. Then I labeled each divider and filed every single piece of paper correctly in the sections I had created: Lab Results, Insurance, Doctor's Notes, Correspondence, Prescriptions, etc., etc.. My hands were getting numb from all the filing. My eyes were weary and watery from looking at all the small print, but this torture left

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me strangely satisfied. Small steps led to achieving the greatest goals imaginable. I was prepared and ready. I was independent. My meticulously organized black binder was done. I would obtain copies of any medical documentation at my first independent appointment with my nephrologist—and the many after. I had taken the first steps to

managing my own health and body. I was a proactive patient who could take on anything to keep my kidneys functioning at top speed!



Mary Wu was diagnosed with kidney disease as a child. She is the author of "Confessions of a Kidney Transplant Recipient" and is passionate about educating the community about the importance of organ donation.

# TAKING THE BITE

*Most people understand the relationship between sugar and dental cavities. But in general, people don't know what gum disease is or how it affects those with chronic kidney disease (CKD).*

Cher Thomas, RDH

*When I first started working in the early 1980s, bonded fillings and preventive dental sealants for children were pretty new. Thanks to dental research, most patients who have cavities get bonded fillings instead of the old silver ones. Children have fewer cavities because of those sealants. And we now know that soft drinks (even if they're sugar free) often lead to cavities and sensitive teeth because of the phosphoric acid they contain. That's another reason for patients with CKD to avoid them! Dental research has shown how gum disease affects overall health. Let's start with a few basics:*

## *What is gingivitis?*

Gingivitis is a reversible, low-grade bacterial infection of the gums. It's diagnosed when gums bleed easily and look red or swollen, but all of the bone holding the teeth in position is still present. Gingivitis goes away quickly with regular brushing and professional dental cleaning.

## *What is periodontal disease (gum disease)?*

When gingivitis is left untreated, infection makes the gums and the bone structure around the teeth recede. Unlike gingivitis, periodontal disease is not reversible. Patients rarely feel any discomfort until a lot of damage has been done.

## *What are the risk factors for gum disease?*

- Smoking. Not only is it easier for smokers to get gum disease, it's more difficult to treat in this population.
- Hormonal changes in girls or women. These changes can make gums more sensitive and make it easier for gingivitis to develop.
- Diabetes. It raises the risk for developing infections, including gum disease.
- Other illnesses. Cancer or AIDS and their treatments can negatively affect the gums. Patients with CKD have a higher incidence of gum disease as well.
- Medications. Hundreds of prescription and over-the-counter medications can reduce the flow of saliva, which has a protective effect on the mouth. Without enough saliva, the mouth is vulnerable to gum disease. Many dialysis patients experience chronic dry mouth. And some kinds of blood pressure medication and immunosuppressants can cause abnormal overgrowth of the gum tissue, making it hard to keep the teeth and gums clean.



*Cher Thomas, RDH is a registered dental hygienist. She received a kidney transplant in 1999 from her brother and was the 2005 recipient of the RDH-Sunstar/RDH Award of Distinction. She lives in Galveston, Texas.*

*Tune in for free to RSN's KidneyTalk conversation with Cher Thomas.*

*Gaining that Winning Smile: Healthy Gums for a Healthy Life  
Web ID 613 See back page for how to access the podcast via iTunes or RSNhope.org.*

# OUT OF GUM DISEASE

## *How is gum disease treated?*

In the 1980s, gum disease was usually treated with hydrogen peroxide and baking soda. Today, dental professionals know that brushing with 100% hydrogen peroxide is too acidic and can cause teeth to become hypersensitive to heat and cold. And although baking soda is a good cleaner, it's too abrasive to use every day and can cause tooth enamel to wear away prematurely, also making teeth hypersensitive to heat and cold. Today, most patients with gum disease receive a deep cleaning by their dentist or are referred to a gum specialist, known as a periodontist, who performs minor gum surgery as well as deep cleanings. Since gum disease can't be cured, patients often see their dentist more frequently to keep bacteria from building up.

## *How does gum disease affect CKD?*

In patients with CKD, the bacteria from gum disease can cause inflammation or infection and wreak havoc in the immune system. In patients who also have diabetes, infection can affect insulin levels, but gum disease is often overlooked as a potential source of infection. Patients who have trouble controlling their blood sugar should ask their doctor whether gum disease could be a contributing factor.

Dialysis patients, who are on fluid restrictions and prescription medications, produce less saliva and can't eliminate mouth bacteria efficiently. Good brushing and regular dental visits, as well as one of the many over-the-counter saliva products, can help keep bacteria to a minimum. Kidney transplant recipients are at higher risk for infection because they take immunosuppressive medications, which also make the gums swell. Frequent trips to the dentist are in order.

## *What can be done to prevent gum disease?*

Clearly, if we're not careful, gum disease can sneak up on us and cause problems elsewhere in the body. People with CKD should ask their doctors and dentists if their gums are healthy. Brushing and visits to the dentist aren't just about preventing cavities; they also help prevent or control gum disease.

### *The stages of periodontal disease*



1. Healthy



2. Gingivitis



3. Periodontal Pockets



4. Periodontitis

# HEALTH INSURANCE MARKETPLACES

***On October 1, each state will begin enrollment for insurance coverage through state Health Insurance Marketplaces. These state marketplaces include individual health insurance plans and a Small Business Health Options Program (SHOP), where employers with less than 50 employees can direct workers to purchase a policy. People who already have health insurance can keep their current plan and are not required to make any changes to their coverage or enroll in a marketplace plan.***

## ***What are the requirements for health insurance starting in 2014?***

- Starting in 2014, most people will be required to have health insurance or pay a penalty of either 1% of their income or \$95. The penalty will increase in future years. Those who already have Medicare, Medicaid, employer-provided insurance, or individual coverage through the private commercial market don't need to do anything because their current insurance fulfills the requirement
- For people who don't have health insurance, enrollment through a state health insurance marketplace starts October 1. Enrollment continues through March 31, with insurance coverage beginning January 1, 2014.
- The following groups are exempt from the requirement to have health insurance :
  - People who would have to pay more than 8% of their income for health insurance
  - People with incomes below the threshold required for filing federal income tax
  - People who would have qualified for Medicaid if their state had expanded the program
  - People who qualify for religious exemptions
  - Members of Indian tribes
  - Undocumented immigrants
  - People who are incarcerated

## ***Is financial help available for people who can't afford to purchase a health insurance policy?***

Someone who enrolls for a health insurance plan through a state marketplace will be notified if he or she qualifies for financial aid to help pay the insurance premium. This is basically a tax credit and is paid in advance. The subsidy will reduce the amount a person owes up front, and the state marketplace will send the money directly to the insurer every month. Consumers can also choose to receive their credit in one lump sum annually when they file their taxes the following year. Those who are late in paying their premiums will have a 90-day grace period to catch up before their subsidy is discontinued. Once the grace period has passed, there will be no opportunity to enroll in a plan until the annual fall open enrollment period (Andrews).

The Henry J. Kaiser Family Foundation has a premium subsidy calculator on its website. It asks for basic information on income and family size and then calculates the approximate subsidy that can be expected. To access the online calculator, go to <http://kff.org/interactive/subsidy-calculator/>.

# UNDER THE AFFORDABLE CARE ACT

By Wendy Schrag

## **Can health insurers charge different premiums? Can health insurers continue to reject a person because of a pre-existing condition?**

Premium rates may not vary based on health, claims, genetic information, or any other health-related factors. Rates can vary only by age (within limits), tobacco use, geography, and the number of family members covered.

Starting in 2014, all health insurers are required to sell coverage to people without taking into consideration their medical history or health status. At that time, insurers will not be allowed to make those with pre-existing conditions pay more, nor will they be able to exclude coverage of those conditions from the insurance plans they sell (The Henry J. Kaiser Family Foundation, Frequently Asked Questions).

## **Where can I find more specific information about my state plans?**

The Centers for Medicare and Medicaid Services manages the official government website for the ACA's Health Insurance Marketplace (<https://www.healthcare.gov/>).

People called "navigators" will be available in each state to help applicants understand and enroll in marketplace insurance plans. Watch for public service announcements and information in your local newspaper, or contact local libraries or Departments on Aging for more information.

A website sponsored by the U.S. Department of Health and Human Services (<http://www.hhs.gov/healthcare/facts/timeline/timeline-text.html#2014>) provides a timeline for key aspects of ACA implementation.

View references on website version:

## **References**

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The Henry J. Kaiser Family Foundation. Health Reform: Subsidy Calculator: Premium Assistance for Coverage in Exchanges. <http://kff.org/interactive/subsidy-calculator/>.

The Henry J. Kaiser Family Foundation. Health Reform: Frequently Asked Questions. <http://kff.org/health-reform/faq/health-reform-frequently-asked-questions/>.

U. S. Department of Health and Human Services. Key Features of the Affordable Care Act by Year. <http://www.hhs.gov/healthcare/facts/timeline/timeline-text.html#2014>.

## **ADDITIONAL RESOURCES**

**National Association of Insurance Commissioners.**

*Health Care Reform Frequently Asked Questions (FAQ).*

[www.naic.org/index\\_health\\_reform\\_faq.htm](http://www.naic.org/index_health_reform_faq.htm).

**State Reform:**

**An Online Network for Health Reform Implementation.**

[www.statereform.org](http://www.statereform.org)

Wendy Funk Schrag is the Director of Advocacy and State Government Affairs for Fresenius Medical Care North America. In her role, she monitors and develops advocacy responses as needed for state policies and legislation related to kidney disease.



# Staying Active makes for a Happier and Healthier Life



by Nancy Spaeth



Let me tell you a little about myself. I'm a 65-year-old nurse and grandmother. I was diagnosed with chronic kidney disease (CKD) in 1959 and began dialysis in 1966. I finished college and worked while I was on dialysis. I was chosen for dialysis by the Admissions and Policy Committee at the Seattle Artificial Kidney Center (now the Northwest Kidney Centers) before Medicare began paying for treatment. I had three brothers and a mother who supported me and encouraged activities such as going to school, snow skiing, traveling, and helping around the house. I had to stop water skiing when I started dialysis because of my Scribner Shunt (we called it a cannula). I've been on four different modes of dialysis; nocturnal dialysis, which is all we did in the 1960s, both in-center and at home from 1966 to 1972; in-center and at home dialysis for 4 hours three times a week from 1979 to 1981, and again from 1986 to 1989; and continuous ambulatory peritoneal dialysis from 1995 to 2000. In between, I've had four kidney transplants.

It's important that you find fun, active things to do because, as the old saying goes, "Use it or lose it." The longer you sit around without

doing any physical activity, the more deconditioned you'll get. The more hours of dialysis you have, the better you'll feel, and that makes it even easier to be active. Yes, CKD and dialysis can tire you out, but it's important to get back on your feet after you start dialysis! Physical therapy can help you get stronger and function better. It's the same after you receive a transplant

**It's a great feeling when you realize that hard work really does pay off!"**

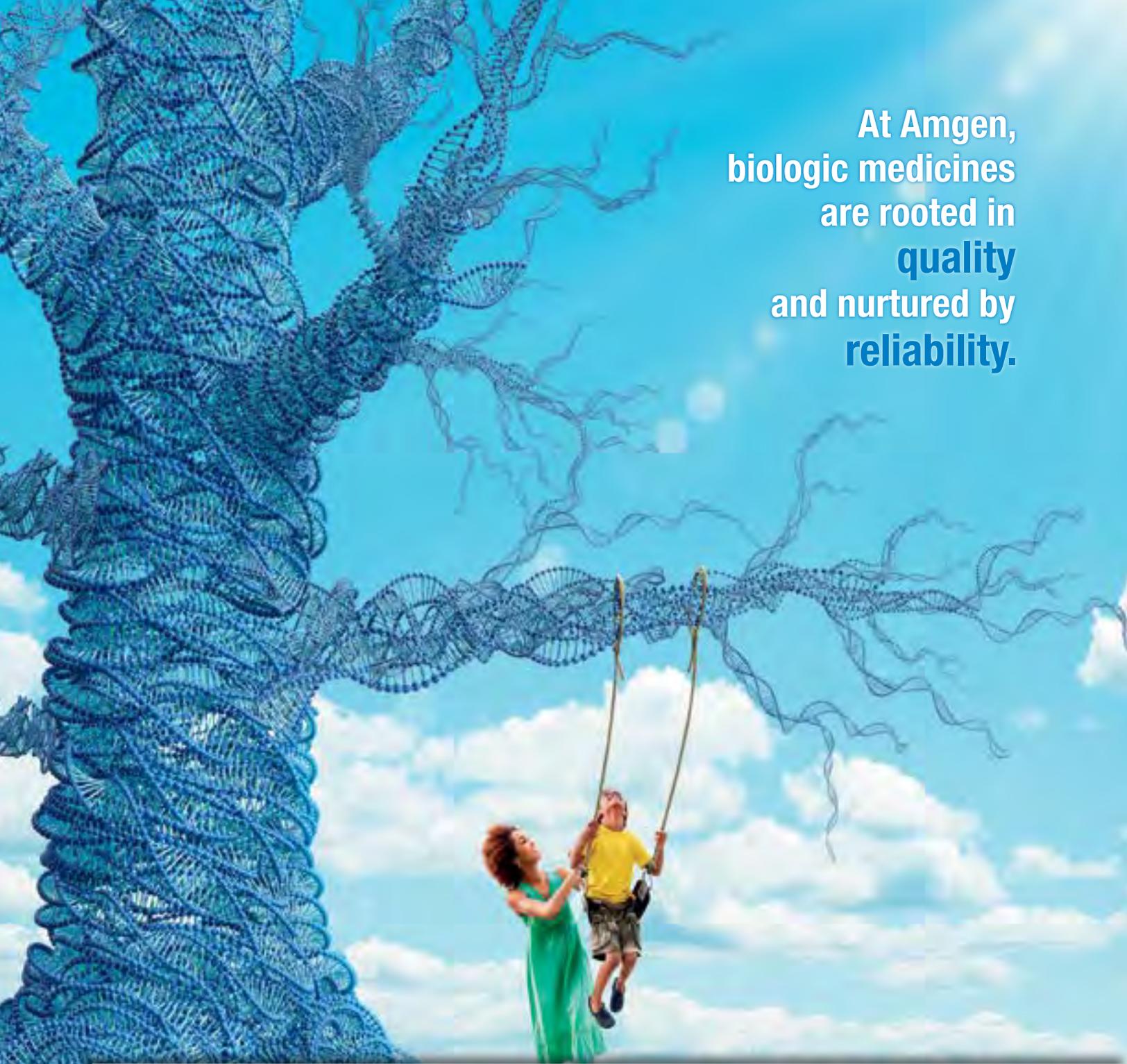
I worked as a physical rehabilitation nurse for many years and saw physical therapy and exercise help lots of people get their lives back. Your doctor can write you a prescription for physical therapy aimed at strengthening and endurance. The therapist can assess your needs and start you on

exercises, with cards to remind you of what to do. You can start slowly, doing more as you gradually get stronger. It's a great feeling when you realize that hard work really does pay off!

Today, I'm retired but still help out in a pediatric office and in my local school district. The things that I enjoy are taking care of and playing with my grandchildren, volunteering, gardening, weeding, pruning, and planting flowers. I also serve on committees and give talks. My dog and I love to go on walks together, and my grandchildren like to have me pull them around the neighborhood in a wagon. What do you love to do? It's time to get moving!

*Nancy Spaeth is a pioneer in the kidney world and is dedicated to helping her peers understand they can live a long life. She lives in Seattle, WA.*





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#### CONTACT INFORMATION

Renal Support Network  
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Glendale, CA 91207

[info@RSNhope.org](mailto:info@RSNhope.org)

866-903-1728 Toll Free  
818-543-0896 Local  
9 AM-6 PM Pacific Time  
Monday-Friday

*If you have a change of address  
or other information,  
please contact us.*

#### LIVE & GIVE ONLINE

Current issue, printable version,  
articles, and archives can be found at:  
[www.RSNhope.org](http://www.RSNhope.org)

#### MISSION

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

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Sign up to receive  
RSN's e-newsletter  
or to get *Live&Give*  
at your home

Connect with RSN  
Tell us your story of hope!



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## What is RSN?

Renal Support Network (RSN) is a nonprofit, patient-focused, patient-run organization that provides non-medical services to those affected by chronic kidney disease (CKD). Through a variety of programs RSN strives to help patients develop their personal coping skills, special talents, and employability by educating and empowering them (and their family members) to take control of the course and management of the disease.

## HopeLine

If you have questions relating to chronic kidney disease Call (800)579-1970 toll-free 10:00am to 6:00pm and connect with someone who can offer EXPERIENCE, STRENGTH and HOPE.

**Are you concerned about policies and news affecting people with kidney disease?**

Become an  
**EDUCATED ADVOCATE**

Join Renal Support Network's weKAN Program  
weKAN promotes self-advocacy and self-determination by showing patients how to become actively involved in medical, regulatory, and legislative decisions affecting their lives.

**For more information e-mail  
wekan@rsnhope.org or  
call 866-903-1728**



**Where the Kidney  
Community  
Connects**

Got Questions?  
Need someone to talk to?  
Log on and join the conversation!

Kidneyspace.com is a program of RSN

**What did you  
learn from this  
issue of  
Live&Give?**

**Take  
our Quiz  
and find out.**

*Send us your completed  
quiz to be entered into  
our prize drawing.*

**Let's give a shout out to  
the lucky Quiz winners  
from last issue.**

Janice Vickery, Wa, Mountrey Oliver, FL,  
Debra Rasberry, TX, Sally Walker, FL,  
Cheryl Potts, OK, Clemente Villanueva, CA,  
Joann Hall, PA, Wendy Bright, NY, Cynthia  
Perkins, NY, Frank Townsley, KS

1. How much potassium is there in a glass of red wine?
2. What is one quick way to feel joy?
3. What did Risa name her kidney?
4. How tall is Mary Wu?
5. Is periodontal disease reversible?
6. Who loves to walk with Nancy?
7. How much does Medicare pay for hospital bills?
8. Where can you find more specific information about state insurance plans?
9. Can insurance companies deny health insurance to individuals because of a pre-existing illness?
10. What does Lori say can damper the Holiday season?

**Send your responses to RSN** (mail, fax or email) by February 1, 2014 to participate in a drawing for a \$25 American Express Card. Ten winners will be chosen and announced in the next issue. See RSN address on page 14.



Service to those affected by chronic kidney disease

1311 N. Maryland Ave.  
Glendale, CA 91207

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Tune in for free to RSN's online bi-weekly podcast talk show on iTunes or RSNhope.org

**iTunes:** Enter "KidneyTalk" into the search tool at the iTunes store to access or download any show 24 hours a day.

**RSNHope.org:** Enter the Web ID listed below in the search box in the right hand corner located on RSNhope.org to stream.



*Laugh and Sing Your Pain Away (200th Show!) Web ID: 888*



*But You Look Good! Invisible Disabilities Explained Web ID: 886*



*The Long Haul - 36 Years on Dialysis Web ID: 883*



*Anxiety and Panic Attacks: When is it Time to Get Help? Web ID: 857*



*Back on Dialysis Again: Surviving the Transition of Losing a Kidney Web ID: 471*



*Kidney Transplantation: Understanding the Match Web ID: 446*



*Adequate or Optimal Dialysis? Web ID: 495*



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