Help! I’m a BLOWFISH!

By Angelique Barber
First Place Essay Winner

Blowfish are peculiar. These tiny sea creatures are elastic and, when threatened, can easily expand into a ball-like shape that’s twice their normal size. It wasn’t long after my life-giving kidney transplant that I became fascinated by the little creatures. After starting a post-transplant prescription regimen that included corticosteroid drugs, which cause increased appetite and weight gain, I began to take on peculiar attributes. Cravings for foods like cheese nachos and French fries mushroomed. Bit by bit my appetite grew until—KABOOM! So did I. Within 18 months, my size 6 frame seemed to take on supernatural elasticity and expanded into a size 12.

Cover story continues on page 4
DISCOVER THE MANY WAYS TO RAISE AWARENESS OF CKD AND SUPPORT RSN

Embrace Hope Jewelry by Lori Hartwell

Our Embrace Hope Jewelry is hand-crafted by people with kidney disease.

Visit RSNHope.org and click Embrace Hope link or see the entire line at www.etsy.com/shop/EmbraceHopeJewelry

RSN's Hope Shop

Home  T-Shirts & Clothing  Kid's Clothing  Drinkware  Car Flair  Home Decor

Customize quality merchandise from housewares to accessories & apparel with your favorite RSN graphics at cafepress.com/rsnhopeshop.

Choose amazonSmile.com or iGive.com for all your gifting needs.
Don’t Ignore the Warning Signs

by Lori Hartwell

When you have multiple health issues, it’s easy not to trust the warning signs your body is giving you. I remember when my knees started hurting: I found myself making lifestyle changes so I could ignore the problem. I avoided stairs, drove around the parking lot to find the closest space, and kept searching for that magic pair of shoes that would make my pain go away.

After many years, I decided that it was time to stop ignoring the warning signs and get help. My orthopedist worked with me to relieve the pain and prescribed physical therapy until we finally decided that it was time for a double knee replacement.

Today, 10 years later, I don’t even think about my knees any more. Recently, after one of my surgeries (and I’ve had over 40), I found myself not moving as much as I would like. I got tired after any activity but simply chalked it up to being out of shape.

I continued to beat myself up for lacking the motivation to exercise and believed that it was somehow a failure on my part. Then I was on a flight home from a business trip, and the flight attendant asked me whether I needed assistance. What? Did I look that bad? I called my doctor as soon as we landed, and we agreed that I would go directly to the emergency room.

I felt fine when I was sitting down, but got really tired whenever I exerted myself at all. My hemoglobin was good, so, again, I told myself that either lack of motivation was keeping me from recovering from my latest surgery or else I was just getting old.

As it turned out, the oxygen levels in my blood dropped significantly when I exerted myself, leaving me feeling exhausted from lack of oxygen, not lack of motivation. My team of doctors addressed the issue (Probably a reaction to a medication) and got me on a plan to improve. Voilà—I started to feel like myself again. If you don’t ignore the warning signs, you can be on the road to recovery sooner.

Warning Signs of Life Threatening Illness

Note that there’s some overlap in symptoms. Report them to your doctor; don’t try to diagnose yourself.

Blood Pressure:
- Too High or Too Low
- Blurred vision
- Chest pain
- Cold, clammy, pale skin
- Dehydration and unusual thirst
- Dizziness or light-headedness
- Fainting
- Fatigue
- Inability to concentrate
- Irregular heartbeat
- Nausea
- Pounding in your chest or ears
- Rapid, shallow breathing
- Severe headache
- Vision problems

Blood Sugar:
- Too High or Too Low
- Anxiety
- Blurred vision
- Dizziness
- Drowsiness
- Extreme hunger and/or thirst
- Frequent urination
- Irritability
- Nausea
- Rapid heartbeat
- Shaking
- Sweating
- Weakness and tiredness
- Infection
- Drainage, redness, swelling, or warmth at your incision or catheter site
- Fatigue
- Fever
- Pain

Kidney Disease
- Change in skin color (a yellowish tint)
- Changes in urination (frequency, color, foam)
- Difficulty in concentrating
- Fragile bones
- Headaches
- Increased fatigue and lack of energy
- Insomnia
- Itchy skin
- Loss of appetite
- Mental confusion
- Metallic taste in the mouth
- Nausea and/or vomiting
- Swelling or numbness in the feet, ankles, or hands
- Twitching muscles, especially in the legs

Stroke
- Confusion or trouble understanding
- Dizziness
- Numbness or weakness in your face, arm, or leg, especially on one side
- Severe headache that comes on for no reason
- Trouble seeing with one or both eyes
- Trouble speaking, walking, or keeping your balance

Sources:
- WebMD.org
- MayoClinic.org
- Diabetes.org

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 inspirational book “Chronically Happy: Joyful Living in Spite of Chronic Illness” and is a four-time kidney transplant recipient.
Help! I’m a BLOWFISH!

By Angelique Barber
First Place Essay Winner

My friend the blowfish and I seemed to have something in common: We both doubled in size. Now the cool thing about a blowfish is that once it’s rounded out, it can quickly and easily retract, returning to its normal size. But for me, losing my post-transplant weight wasn’t going to be quick or easy.

While I thought blowfish were rather cute, my post-transplant globular shape wasn’t. Mirrors don’t lie. And even though I jokingly compared myself to a blowfish when talking with family and friends, the truth is that I felt threatened and worried about the long-term effects of obesity, especially heart disease and diabetes. Driven by a strong desire to honor my organ donor, a need to stay healthy, and a bit of vanity, I made up my mind to shed pounds.

Sheer grit and determination weren’t going to get me far in a personal weight loss program. What I needed was practical help and accountability. After some research and dialogue with friends, I downloaded a fitness app. The program allowed me to set a personal weight goal, keep a food journal, and track my daily calorie intake. A bonus feature was the app’s “friends” networking capability; it provided needed support. If I didn’t log into the fitness app and track my calorie intake, my friends knew it and sent encouraging e-notes that helped get me back on track.

Keeping a food journal was a good start. However, if I was going to mimic my blowfish buddy’s size reduction, I also needed to exercise consistently.

Driven by a strong desire to honor my organ donor, I made up my mind to shed pounds.

Later, I added swimming to my exercise plan. The fitness app came in handy because it allowed me to log workouts, and it automatically deducted the calories I burned while exercising from the day’s total.

By reducing my overall calorie intake and exercising regularly, I began to see a gradual trend toward my weight loss goal. Over the course of 18 months, I lost 18 pounds and, much to my delight, my blowfish spherical shape. I replaced my size 12 clothing with size 8. More important, my cholesterol levels dropped, and diabetes has been kept at bay.

The adorable blowfish’s natural ability to fluctuate in size works to its advantage. A significant advantage to me is my body’s ability to adapt positively to a life-giving transplant, respond to a treatment regimen, and benefit from practical weight loss strategies. For this, I am truly grateful.

Since I’d enjoyed cycling before my transplant, I took up bike riding again. The tricky part was to motivate myself to ride several times a week. I started with 3-mile rides and worked my way up to 6 miles.

Angelique Barber was diagnosed with Polycystic Kidney Disease at the age of 32. In 2010, she received a life-saving kidney from close family friend, Max Bowman. Her journey through chronic kidney disease and the transplant process is not unlike that of others struggling with renal disease. She lives in Houston, Texas, with her husband, Ken.
One day while receiving my dialysis treatment, my dietitian approached me with my monthly numbers report card. Impressed by my continuous improvement, she drew little happy faces on my chart and inscribed accolades as encouragement. We continued to converse about my renal disease and how it had affected my body over the past 5 years.

After analyzing all of the information I'd given her, she asked “Sir, what is it you’re doing to improve your dialysis treatment?” Without hesitation I said, “I DRINK!”

Abruptly she exclaimed, “No, I mean what choices have you made to improve your health and how does it benefit others? Surely you can’t mean that you’ve been drinking alcoholic beverages or excess fluids?”

I said, “Neither! Please allow me to fully explain what I mean.” I asked her to have a seat and relax as I began to divulge my secrets.

D stands for Discuss
By discussing my concerns with the dialysis staff, I found out about all of the resources the center has to offer to help improve my treatment. These resources include a social worker to help me deal with some of my personal issues and people in the billing department who work diligently with my insurance company. Also, I always discuss eating habits with the staff as they teach me how and what to eat. These factors help keep my stress level low, and for this I’m thankful.

R stands for Resist
Through discipline I’ve learned to resist putting things into my body that work against my treatment, such as excessive fluids or foods high in salt. I’ve also learned to avoid fruit that has potassium (like bananas) or a high water content (like watermelon).

I stands for Interest
I continue to show interest in myself. While on dialysis, your body goes through many changes. My skin has become drier; I’ve felt frail, unattractive, and burdened at times. One’s self-esteem might start to show signs of wear and tear, or the body might just give out as mental and physical fatigue sets in. So I continue to show interest in myself by spending my free time pampering myself and indulging in my favorite hobbies.

N stands for Nutrition
Nutrition is just as important as Resist. Along with my vegetables, I treat myself to foods that are high in protein. I also have daily reminders to take my renal vitamins and other medications. And the most important letter in DRINK is K.

K stands for Keeping My Appointments. By keeping my dialysis appointments, I’m able to establish a routine and ensure that my body is functioning the way it should. I arrive on time and try to be as helpful as possible to those who are in charge of my treatment. So, the acronym DRINK explains how I choose to improve my health. I Discuss, Resist, show Interest, maintain Nutrition, and always Keep my appointments.

Arthur DeBose was born and raised in the city of Newark, New Jersey and currently resides there. Being raised in a blended family, Arthur was exposed to a vast array of music and expressionism which inspired his creativity and desire to write. Even recently publishing his first book of poems, Empathy: Book of Poetry Vol I.
“It’s only temporary.” I apply this philosophy to many facets of my health—physical, mental, and spiritual. A wise man shared this with me about 30 years ago. Applying the knowledge came much later: a simple idea that makes me laugh with appreciation.

“It’s only temporary” is enhanced tenfold when I add positivity to the mix.

Choosing to improve my all-around health by combining positivity and “it’s only temporary” creates a powerhouse of inner strength. Do you believe me?

Let’s take a little stroll through just a few of my life’s significant moments. Temporary and positivity: You’ll see. I’ll make a believer out of you yet.

I was 24 when my brother decided to end his life. I found him in his room with a belt around his neck. My heart was torn to shreds. A feeling of normality was out of reach for some time. I needed to feel the depth of my pain in order to heal.

My brother’s physical life was temporary. My injured spirit was temporary. With positivity on my side, I worked on softening the magnitude of this tragedy. I now choose to remember the joy of the heartfelt laughter I felt with Eric by my side.

Kidney disease, blood transfusions, dialysis, transplantation. Components of permanent renal failure? Separate the instances, and you’ll see temporary. Put two needles in your arm. Feel a speck of pain. The treatment starts, and the initial pain is gone.

In my mind, the dialysis treatment itself is only temporary. Using positivity, I passionately believe that each day’s treatment is really temporary. Hook up, dialyze, finish up, and voilà! Treatment is done for that day. Living in the moment affords me the ability to enjoy simple pleasures on a daily basis.

Five feet of snow collapsed the roof covering our family’s sawmill business in 2010. When I arrived the next morning, it was a devastating sight. We’d been dogged by breakdowns and economic uncertainty since 2008. When I saw the destruction before me, my only thought was, “This is it. We’re done.”

It was my Dad who used the temporary lesson that day. He quickly decided what had to be done. The mill needed to be dug out, and the debris had to be removed. With the help of neighbors, relatives, and friends, we were back in business in 10 days. This is a perfect example of how a positive mind set can make a seemingly impossible situation become a temporary one. It was a truly awesome experience to be a part of. Getting any closer to believing me yet?

Losing my father after he collapsed at the bowling alley was a shock. He was 9 days shy of his 83rd birthday. My brother Brian and my Mom rushed to Dad’s side at the hospital. I’m grateful that my memories of him don’t include his death at the hospital. When I think of him, I see him sitting in his chair as I give him my usual evening message: “I’ll see you tomorrow, Dad.” And he would reply, “I hope so.”

Physically, my Dad was with us temporarily. His positivity, determination, and stubborn resolve to face adversity with a smile will always be an inspiration to me. I find strength by including him in my thoughts every day.

On April 8, 2014, I received my second kidney transplant. Dialysis had been a part of my life for 7 years, 7 months, and 7 days—simply a temporary blip in my continuing life story. Earlier in the year, I’d started a part-time job at the library. It was a huge bonus for me. The money from the job was abundantly helpful. I received some papers to fill out regarding the time I’d be out because of the transplant. The paperwork was returned as soon as I was able. After all, I was recovering from a rather phenomenal procedure.

The final word from the dear folks at the library? “Please be advised that effective 5/1/14, your employment with us is terminated.” My first reaction was sadness. Then I opened up my lesson book: “Sandra, it’s only temporary.” I wrote the library personnel to thank them for the opportunity to be gainfully employed, temporarily. I then offered the hope that they would be blessed with kindness, understanding, compassion, and patience throughout their life moments.

By choosing to believe “it’s only temporary” and energetically activating positivity, I enhance and improve my life and health. With these habits, Lucinda, my newly transplanted kidney, and I will positively enjoy each temporary life moment we spend together.

“It’s only temporary” and positivity. Making life better one day at a time. Do you believe me now? Try it—you might like it.

Sandra L. Kisselback lives in East Berne, New York. She is married, has had 2 kidney transplants and completed the Kona, Hawaii Marathon.
Louisa May Alcott stated, “I am not afraid of storms, for I am learning how to sail my ship.” Last year, I found myself in a dark place and made the decision to confront issues from the past in order to move forward fulfilled, happy, confident, and fearless. Years of internalizing pain left me with a lack of confidence and a debilitating case of self-doubt. I was resistant to the idea of therapy because I didn’t want someone putting me on medication, psychoanalyzing me, and writing down what I was saying instead of actively listening—until I met Dr. Murphy. She told me something I’ll never forget: “It is our attitude at the beginning of a difficult undertaking that more than anything else will determine its successful outcome.” She put everything in perspective, and I was finally able to let down my guard and allow myself to be vulnerable, to be human.

I’ve met Dr. Murphy regularly since February 21, 2013, and she’s taught me how to make better decisions and set healthy boundaries. I was always afraid to be vulnerable, and I struggled to let others, including family, see this side of me; now I’m open to fully experiencing this emotion. I’ve had to fight through it and redefine my identity, my values, and my priorities. This led me to find deeper meaning in life. I recently watched a TED.com talk by Brené Brown (“The Power of Vulnerability”), where she states, “Believing that you’re enough is what gives you the courage to be authentic, vulnerable, and imperfect.” I believe that this is advice we can all apply to our lives.

Ultimately, I needed professional guidance to help me manage the fears and anxieties of the past, present, and future. Even with support from family and friends, I sometimes felt isolated, alone, and angry. I didn’t know it at the time, but it was anger that ignited my emotional healing. I thought I’d never break down my walls, but if Germany could do it, so could I! Along the way, I had a couple of breakdowns and breakthroughs. Sharing my anxieties and fears made me realize that I couldn’t avoid them; I had to go through them. Now, I’m in a healthier and happier state of mind. Therapy isn’t a cure-all; I have to work at it constantly and use the tools I was given to keep focused. Our happiness is rooted in ourselves, not in others. I believe that finding the balance of happiness requires having a positive attitude and keeping good company.

I’d like to think I’ve made tremendous progress in how I deal with adversity in my life. As long as I’m moving forward, I’m moving in the right direction. While my problems may seem small by comparison, I hope to inspire others to have a positive attitude. I firmly believe that no matter what a person experiences in life, there’s always hope—hope that things will eventually get better—and that it takes only one person to help you get there.

Sarah Tompkins is a recent graduate of University of La Verne with a Master of Science in Leadership and Management. She has had two kidney transplants and is waiting on a third. She lives in Rancho Cucamonga, California with her dogs Charlie, Jack, and Roxy.
Choose

Acceptance

By Riley B. Pummill
Third Place Essay Winner
Web ID: 951
I can't remember a day when I didn't have chronic kidney disease (CKD). I was diagnosed 21 years ago, at age 3. Until my first transplant at age 11, being and feeling sick was my normal. Though I no longer had the rigid dietary restrictions and overwhelming fatigue of my pre-transplant life, my preteen and teenage years were plagued by rejection episodes, infections, surgeries, and hospital stays. Many, many times I asked, "Why me?" I longed to be a normal teenager instead of a dialysis patient. I felt embarrassed and ashamed of this disease, and I hated the daily reminders of the unjust sentence I'd been handed.

After my second transplant at age 17, I actually felt healthy, like a normal person, and I never wanted to look back. I saw my newest kidney as a cure—like my wish had come true—and went about my life pretending I was normal. I took my medicines, had my blood work done regularly, and saw my doctors, but I didn't think about my kidney. I was fixed. I could finally live my life.

I graduated from high school, went away to my dream college, traveled across Europe, graduated with a bachelor's degree, and even got married! It wasn't until I became pregnant with my daughter that I took a closer look at my disease; I realized that it's not just about me anymore and that I needed to take a serious look at what I could do take better care of this kidney that had given me a life I'd once only dreamed I could have. I knew I had to change.

I had to make a choice: to continue ignoring my condition and passively hope I stayed healthy forever or to do whatever I could within my power to take the very best care of myself for the sake of my daughter.

It's my responsibility to take the very best care of myself possible, to look at my life as a success and not a tragedy."

The healthiest choice I've ever made was to accept my disease—to accept the fact that I'll have it for as long as I live and that it's my responsibility to take the very best care of myself possible—and to look at my life as a success and not a tragedy. It was a choice to be grateful for this gift of life and to honor my family, donors, doctors, and nurses. It was the choice that has dictated nearly every single choice I've made from that day forward. From simply choosing healthier foods to choosing to maintain healthy relationships, and from choosing to foster a positive outlook on life to choosing to maintain an exercise regimen, all areas of my life have been improved. They've improved not despite my condition, but because of it. Living with CKD has made me an active advocate for health and wellness and especially kidney disease awareness.

Today, I have a wonderful, supportive husband, a beautiful daughter, a son on the way, and the strength of a patient with kidney disease! I have the opportunity to share my story. I hope to motivate others within the CKD community to be active in their care, to engage with their doctors, to ask questions, to make healthy choices, and to share their stories as well. I also hope to inspire others to become more involved in funding research into kidney disease and offer support to patients with CKD and their families. I want to raise awareness about organ donation and to be a living example of how one's life can be completely changed by the amazing gift of life. I want to give back to this community that has saved my life too many times to count.

I know I may very well find myself back in a dialysis clinic someday, and if that day comes, I'm prepared to choose to embrace my struggle. CKD has made me a fighter, and there's a lot to fight for.

Riley Pummill lives in Virginia with her husband, Robert. She has a 14 month old daughter and is expecting a son in mid-October. She works as a caregiver at a local preschool but in her spare time she loves to cook, bake, and read.
Flu season is just around the corner. The Centers for Disease Control and Prevention highly recommends that patients with kidney disease get a flu shot, since they’re considered a vulnerable population. Besides the flu shot, other immunizations such as hepatitis B and pneumonia are beneficial as well and might be offered by your health care team. In addition to getting immunized, you can greatly decrease your chances of getting sick by learning how diseases are transmitted and incorporating safety steps into your daily routine.

Diseases are caused by either viruses or bacteria. Viruses are very small and invisible to the naked eye. They consist of genetic material (DNA or RNA) wrapped around by a protective coating of protein. They can’t multiply on their own, although they can attach to the cells of a living organism (called a host) and get inside them. Once inside, they take complete control of those cells and start multiplying. Most viruses enter the human body through the mucous membranes—such as the respiratory passages—because they aren’t covered by skin, which is the best line of defense against harmful organisms.

Bacteria are one-celled organisms that can divide and multiply by themselves without a host. They’re found everywhere: some of them live inside our bodies and are useful to us (probiotics in the gastrointestinal tract are a good example). Others are harmful and can cause a lot of damage if not treated in a timely manner. According to microbiology studies conducted in the past 20 years, Earth is home to 320,000 different viruses and 5 million trillion trillion types of bacteria. This is the number 5 followed by 30 zeroes—an impossible number to understand.

**VIRAL AND BACTERIAL INFECTIONS ARE SPREAD IN SIMILAR WAYS:**

* You shake hands with an infected person and touch your face shortly afterward without washing your hands.

* You touch a contaminated surface such as a door knob in a public place.

* An infected person (say, someone who has a cold) is close to you and coughs or sneezes.

* You touch food with dirty hands.

* You come into contact with an infected person’s bodily fluids (blood, saliva, or semen). Using dirty needles or having unprotected sexual contact can transmit dangerous viral infections such as hepatitis or AIDS.
**FIVE EASY WAYS TO AVOID INFECTIONS:**

- Washing your hands is the single best way to avoid getting a cold or the flu. Proper hand washing should last at least 15 seconds (try to sing either Happy Birthday or the ABC song in your mind). Wash your hands often: every time you come home, after you touch a dirty surface or shake hands, and before you eat. Use hand sanitizer as alternative.

- People who have kidney disease should receive all recommended immunizations, including a yearly flu shot. Immunization exposes you to a very small amount of a virus or bacteria, and your immune system responds by attacking the infection.

- If you’re on hemodialysis, wash your vascular access (fistula or graft) before your treatment. If you have a central venous catheter, make sure that at the beginning and end of treatment, both you and your nurse are wearing masks that completely cover your nose and mouth.

- If someone at home is sick, use separate dishware to keep from spreading the infection to other family members. Use antibacterial wipes to clean kitchen counters, door knobs, or other dirty surfaces, and wash your hands often.

- Handling food properly is essential: don’t leave unprepared food at room temperature for a long time. Food should be cooked or refrigerated as quickly as possible. Vegetables and meats should be stored separately and prepared on separate cutting boards.

If you do get sick, see your doctor as soon as possible and follow the medication regimen as prescribed. Bacterial infections are usually treated with antibiotics, which kill only the bacteria that cause the disease. Once you start taking an antibiotic, you might feel better in a couple of days, but don’t stop taking the medication until it’s gone. If you stop, the disease could come back with a vengeance because bacteria can not only multiply by themselves, they can also mutate into a more dangerous form if not destroyed completely the first time.

Many infections can be avoided. Being aware of how they spread and following the safety tips I’ve described could help you stay healthy and improve your quality of life.

**Lana Kacherova, RN** has been working in dialysis industry since 1993 in different capacities taking care of people with kidney disease. She started as a dialysis technician, then became a nurse, later transitioned to clinical coordinator of hemodialysis unit, quality improvement professional, and case manager. While working full-time, Lana attended California State University, Northridge, and received Bachelor Science in Nursing, and Master of Public Health in Health Education. She recently joined Kaiser Permanente of Southern California as a Renal Case Manager.
When people mention bills, we immediately think about the money that goes out every month so we can have a roof over our heads and take care of ourselves and our families. But there’s another kind of bill, one that subsequently becomes law and affects large segments of the population.

Legislative bills dealing with kidney disease can improve our lives and the lives of the many thousands of people who will face renal failure in the future. Part of the work of the Renal Support Network is to monitor and help pass legislation that affects people with kidney disease. Here are three stories that illustrate what certain types of legislation could mean to you and those you love.

Today is March 10: It used to be Vera’s favorite day, but now it’s a very sad one. Three years ago today, Vera got her kidney transplant. Over those three years, she hasn’t been able to find full-time employment, only part-time jobs with no health insurance. Today she received a letter informing her that her Medicare benefits are ending; she’s reached 36 months of post-transplant coverage. Her medications cost $600 a month; without the help that Medicare provides, she can’t imagine how she’ll pay for them. If she can’t find a way, rejection will set in, and she’ll lose her kidney.

Any one of us could be Vera. But this kind of loss is avoidable. The Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act is a bill that amends the Social Security Act to extend the Medicare coverage of immunosuppressive drugs for the life of a transplanted kidney.
Even when she was very small, Kristi loved science. Now she’s a college student who dreams of one day curing people. She’d be a great doctor, but she’s more interested in doing research on disease and treatment. When she was young, her favorite uncle died of kidney failure caused by high blood pressure and cardiovascular complications. She’d like to study the long-term effects of high blood pressure on the kidneys. As she prepares for graduation, she’s looking for an internship in the field of kidney research, but she isn’t finding many options. There are a lot of research jobs, but not many centered on renal failure. She decides to take a job with the Institute for Cardiac Health, her second area of interest, instead.

The renal community just lost a possible trailblazer. The Chronic Kidney Disease Improvement in Research and Treatment Act was introduced to provide for more renal research. The bill will ask Congress to produce a report showing the disparity between how much money is spent on caring for people with kidney failure and how much is spent on research into kidney disease. The expectation is that passage of the bill will lead to increased funding for such research.

When Luke gave his cousin Maggie his right kidney, he was just being Luke—kind, loving, and never taking no for an answer. He knew that there was no other alternative for Maggie, so he didn’t hesitate. Every single day, Maggie calls him and thanks him for the gift of life. But today’s call left them both troubled and sad. Luke just received a letter from his life insurance company stating that his policy had been terminated and that his application for long-term care insurance had been denied. The application revealed that he’s a living donor, and therefore in a higher risk category, so he no longer has life insurance and he can’t get the long-term care insurance he wanted. Luke told Maggie that he loves her and doesn’t regret what he did. But giving her a kidney means that he won’t be able to protect his family as he’d planned.

Living donors shouldn’t be penalized for saving a life. But as the laws read now, this is completely legal. However, the Living Donor Protection Act was introduced to help prevent such discrimination by making it unlawful for insurance companies to decline, terminate, or limit coverage for living organ donors or to charge them higher premiums for life, disability, or long-term care policies. The bill further clarifies that organ donors can use the time mandated through the Family and Medical Leave Act to recover from transplant surgery.

Would you like to see these bills become law? We need your help! You can share your story with members of your congressional delegation by phone, by email, or in person. Each of us is represented by a member of the House and by a Senator. These bills didn’t garner enough support in Congress to get passed in the last cycle, so all of them must be reintroduced.

If you would like to help, you need only do only a few simple things:
1. Call your elected representatives.
2. Say, “I want you to support the Living Donor Protection Act” (and/or the other bills).
3. Call them again later and reiterate it. Ideally, go meet with your legislators and tell them how important these bills are.

For more information and a sample letter, visit http://www.RSNhope.org and click on Advocacy. To help these bills become law, we need to tell our story over and over, to share this important information with our family and friends, and to ask them to share it as well. Passing these bills is the right thing to do, and if we all do our part, we will prevail.

Joanna Galeas has had kidney disease since 2009, is on peritoneal dialysis and is awaiting her first kidney transplant. She is a Board member of Renal Support Network, serves on the Network 18 Subject Matter Expert committee and the national network coordinating working group.
Renal Support Network relies on charitable contributions to provide hope to people with kidney disease. We appreciate your help!

Method of Payment for contributions:
- Check or Money Order (payable to Renal Support Network)
- Credit Card: Visa, Mastercard, Amex

Donation charge to card $__________ Billing Zip __________
Card#: __________________________
Exp. Date: _______/______
Cardholder Name: __________________________
Signature: __________________________

☐ Yes! I would like to receive a free subscription to the Live&Give newsletter
☐ Yes! E-mail me the RenAlert RSN’s electronic update.
☐ Yes! Please send me ______ additional copies of Live&Give to distribute.

Name
Address
City ________ State ________ Zip ______
E-mail __________________________
Phone __________________________ ☐ home ☐ work ☐ cell

Please check all that apply:
☐ Patient: ☐ Transplant ☐ PD ☐ Hemo
☐ Family Member ☐ Administrator ☐ Physician ☐ Nurse
☐ Dietitian ☐ Social Worker ☐ Technician ☐ Company Rep ☐ Other

Cut form on dotted line at right and mail or fax to Renal Support Network.
All Donations are tax-deductible. Thank You!

DONATE ONLINE
Go to RSNhope.org
Click on Contribute
Donate by phone: 866-903-1728
Fax: 818-244-9540

MAIL CHECKS TO:
Renal Support Network
1311 N. Maryland Ave.
Glendale, CA 91207
RSN accepts all major credit cards
Gifts are tax-deductible

Visit RSNhope.org
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!

Like us on Facebook
facebook.com/RenalSupportNetwork
Follow us on Twitter
@RSNhope
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.

Save the Date! Visit RSNhope.org for more information.

BEAT the ODDS
Celebrity Charity Poker Tournament
November 8, 2014

16th Annual Renal Teen PROM
January 18, 2015

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

1. Name one of the strategies Angelique Barber used to lose weight?
2. What does “D” stand for?
3. What education level was achieved by Riley Pummill?
4. Name five symptoms of high or low blood pressure?
5. What does Sandra Kisselback choose to believe?
6. How do most viruses enter the human body?
7. Name one of the three legislative bills introduced to Congress?
8. How many types of bacteria are there?
9. Name five symptoms of a stroke?
10. What was the TED.com lecture Sarah Tomkin’s mentions?

Send your responses to RSN (mail, fax or email) by February 1, 2015 to participate in a drawing for a $25 American Express Card. Four winners will be chosen and announced in the next issue. See RSN address on page 14.
If you have a change of address, phone number, or email address, please contact us to update it.

LiveGive is proudly supported by:

- Questcor
- Abbvie
- Astellas
- Fresenius Medical Care
- Amgen
- NRAA
- Genentech

KidneyTalk
24/7 Podcast Radio Show

Informative. Inspirational. Entertaining.

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.

- To be Young, Dating... and Living with Kidney Disease Web ID: 948
- Denied Access to Transplant Web ID: 946
- Vegan, Vegetarian, & Variety: What You Need to Know! Web ID: 941
- Transplant Quarter Century Club: The Club Recipients Want to Join! Web ID: 940
- Prepare for Surgery - Do I Have What I Need? Web ID: 947
- A Personal Renal Chef for the Weekend Web ID: 926
- Life Without Limits! Web ID: 929
- Smart Searching for Health Information Web ID: 944