Renal Support Network
RSNhope.org

Live & Give

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Helping to educate and motivate people living with chronic kidney disease.

THE SELF-DISCOVERY ISSUE

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note to self

By Sasha Couch 1st Place Essay
RSN's 14th Annual Essay Contest

They say hindsight has 20/20 vision. "If I knew then what I know now," we say, assuming we would make "better" decisions. I am surprised, impressed and continually learning from the decisions I make in the face of the adversity of living with Kidney Disease. I navigate as I go and have discovered myself in the process. No guarantees I would have made better decisions, but if Sasha 2016 could have given a few tips to Sasha 2012, they would sound something like this:

Dear Sasha,
You just turned 40, and got the shocking diagnosis of End Stage Renal Disease. You're about to enroll in the School of Hard Knocks. The lessons will be tough, but you will discover you have more strength than you thought possible and value life more than you thought yourself capable. I see that cynical look, but it's true! Besides, by 44, you'll definitely understand that furrowing your brow has lasting effects.

Cover story continues on page 7

EmbraceHOPE Jewelry

by lori hartwell

RSN's EmbraceHope Jewelry is hand-crafted by people who have kidney disease. Check out 'Lori's Collection' which is made with repurposed vintage, estate, fine, and costume jewelry. All proceeds from Embrace Hope help support our patient programs and events such as the annual Renal Teen Prom.

Visit RSNhope.org and click on Embrace Hope to find your new one-of-a-kind necklace, bracelet or earrings. Also, you will find inexpensive meaningful gifts. If you have broken jewelry or pieces that you know you will never wear, please consider donating them to RSN. Find donation contact information on page 14.

Web ID: 1060

A Phone App Can **Save Your Life**

by Lori Hartwell

We know the benefits of having a cell phone on us so we can call for help, receive a call for a kidney, or just tell someone where to pick us up.
But there may be a time when you can't speak for yourself, due to severe symptoms or losing consciousness, and a phone app can speak for you!

People who have kidney disease have complex issues. We take multiple medications and we have many medical concerns. We have a better chance of experiencing a good outcome if medical professionals know our medical history.

Most smart phones have a health app icon on their screen that allows you to enter your doctors, medications, medical history, allergies, blood type, emergency contact and any other information you believe is necessary for medical professionals to know about your health. If you cannot find it, type "health" in the search function. The iPhone app has a little "heart."

Click on MED ID and you can type in all your information, and even enter a photo. This App does a number of other things, like count your steps, measure your blood pressure, and record your sleep, etc.

Medical experts can access these smart phone apps without a password. They know to look in the bottom left corner of the screen and click an emergency icon to see the medical information.

If you can't find a preinstalled health APP, search your app store for Medical ID or ICE for "In case of emergency."

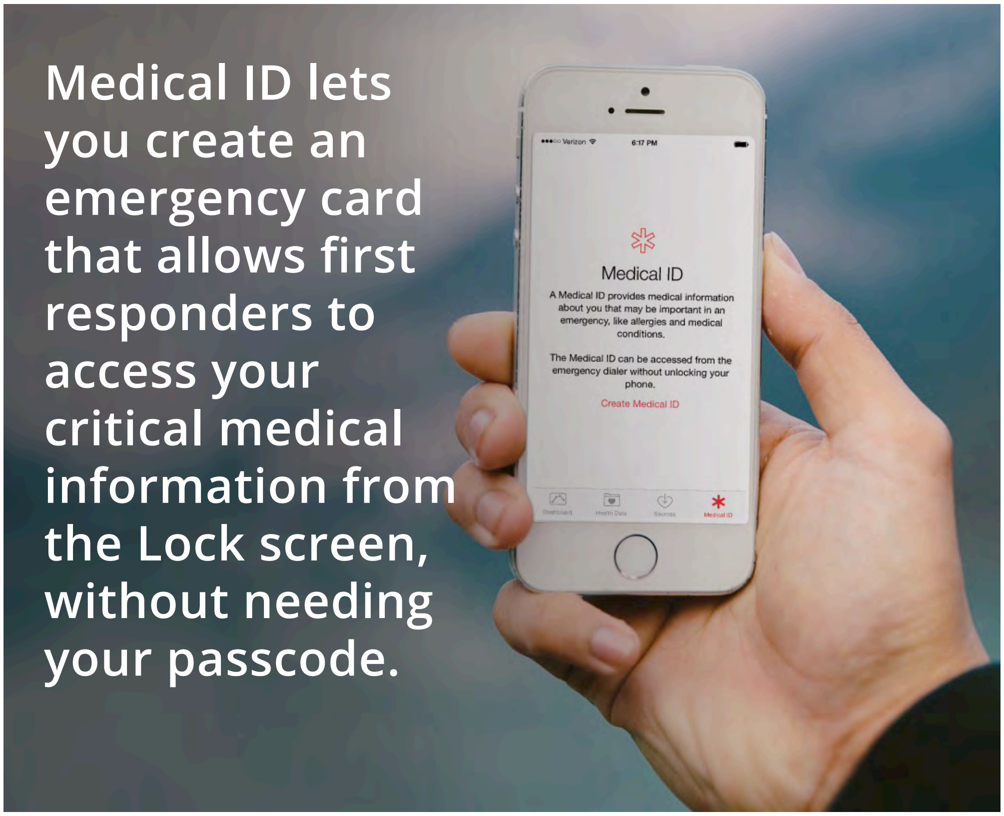
Everyone needs to learn about this feature. I have been told that emergency personnel and paramedics are aware of this app and look for a phone right away when a person is unconscious. Another great benefit of using this app; even if I'm not unconscious I might forget something important like my allergies, but the app won't!

My Medical ID is easy to retrieve and available at my fingertips! I also carry written information about my meds and my doctors in my wallet.

This is easier to hand off to a medical professional to make a copy. A Medical Identification bracelet or necklace is also a good idea; I just have never liked wearing them.

If you use this app, make sure to tell your friends and family so they can pass along important information if you can't.

Everyday technology is changing, and more apps are becoming available for health management. Make sure you understand the privacy aspect of any app you decide to download. Personally, to have vital medical facts easily accessible in any situation, I don't mind that I've lost some privacy about my health, as I believe the benefits outweigh the risks.



Lori Hartwell, Founder & President of 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.*

Receiving Adequate Iron is Essential for My Good Health

Today, there is a product that can deliver iron consistently at every dialysis treatment in place of IV iron… it's called Triferic.

Hemodialysis patients lose iron with each dialysis treatment due to the consistent blood loss that occurs. Patients lose approximately 5 -7 milligrams of iron every hemodialysis treatment. Therefore, iron is needed every dialysis treatment, to replace the ongoing iron loss that occurs during hemodialysis.

Triferic is the only FDA approved drug indicated for iron maintenance therapy.

Triferic is delivered via dialysate, simply replacing the 5-7 milligrams of iron lost during your regularly scheduled dialysis treatment. Triferic enters your blood and immediately binds to transferrin (the natural carrier of iron in the body) and is taken to the bone marrow, bypassing the liver, similar to normal dietary iron uptake. Your body will use the iron to make hemoglobin. Hemoglobin will carry oxygen throughout your body, providing energy.

Triferic is the only drug FDA approved to replace iron at every hemodialysis treatment and to maintain hemoglobin concentration.

- Iron delivered at every dialysis treatment
- Replaces the 5-7 milligrams of iron that is needed
- Maintains hemoglobin concentration
- Does not increase iron stores and inflammation (ferritin)

Triferic does not require intravenous infusion. There are no IV's or needles required to receive Triferic. Triferic is simply mixed into your dialysate and administered to you throughout the hemodialysis procedure.

The safety profile of Triferic has been demonstrated in long-term studies and is similar to patients receiving placebo treatment. There have been no severe life threatening hypersensitivity reactions in over 100,000 doses administered.

For more information, ask your doctor about Triferic or call Rockwell Medical at 800-449-3353.

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ROCKWELL
MEDICAL

THE DISCOMBOBULATED YET TOTALLY UNFILTERED KIDNEY-SHAPED CHILDHOOD

RSN's 14th Annual Essay Contest, RSN President's Pick

By Stacy Hoblitzell

An atom or two slothed off and joined a rival organ. The glomeruli may have had an issue with their nephron overlord and deserted the premises. Maybe my genetic code was wrung out like a washcloth and the remainder was frayed and useless.

These are the wonderments that keep me sane as I bask in the memories of my well-worn wisdom, earned from the tribulations of a scattered, shattered youth.

In the summer of 1980, I was ten years young, flushed with innocence, the world filtered through naïve-colored glasses. I joined my adventurous family on a whirlwind wandering of the Pacific Northwest. Near the end of our quest to enjoy the labors of Mother Nature, I started to vomit regularly and with increased vigor.

The flu was assumed. The hurling continued. The truth was rushing toward me with reckless abandon.

I wish I'd known that these early trials would embolden my self-reliance.

I relish the day when blood tests are considered barbaric. You never forget your first.

"See that little girl over there?" I nodded my head once, slowly. "She's about to have her first blood test, so I need you to show her how easy it is, okay?" Another confident nod betrayed my pulsating fear.

My mantra became clear as these continued unabated. Brace face. Hide the pain. Swallow the trauma.

I wish I'd known how detrimental this would be to my developing psyche.

Another visit to the sterile and indifferent hospital room of the week.

The tentacles of tubing reached awkwardly from the back wall, arched over my fluffy pillow, and inserted themselves purposefully into my frail, toothpick arms. Glancing over my shoulder, I saw a hovering rectangular bag of fluid whose bottom was curved nearly into the shape of a smile.

Smiles are rare currency in the economy of healthcare.

Without technological gizmos to secure boredom's extinction, my young mind decided to indulge my roommates in conversation, though they only spoke in blips, pings and alarms.

The EKG heart monitor was consistent and dependable, never wishing to be interrupted with tedious dialogue. The piercing, squawking alarm blaring from the IV pump seemed to be the only vocabulary he ever invested any energy in (though I presume he was overly entertained by striking in the absolute jackknife of the morning).

As for the blood pressure cuff, she was fresh-out-of-the-box brand new, but blatantly upset at the tiniest variation from my mathematical norms. Her saving grace was that she spoke in pleasant, reassuring tones when triggered. She was also quite needy; her musical melody becoming louder until she garnered the attention she felt she deserved.

But once my discharge papers were signed, they spoke no more.

And here I was, assuming we had become friends.

I wish I'd known that my recurring stays of loneliness would foster my perpetual imagination.

To the naked ear, glomerulonephritis sounds like a tastefully eclectic dish served in a faraway land where the mention of chronic disease causes natives' faces to scrunch unnaturally.

The tiny globes of capillaries, proudly housed inside the Glomerulus Union, decided that they were laboring far too hard, while the nephron was receiving all the credit. Thus, they went on strike. Negotiations had

continued on page 15

Web ID: 1061

TREATMENT OPTIONS

for End-Stage Kidney Disease

By Debra Hain, PhD, ARNP

James, a 64-year-old African-American male with Stage 4 chronic kidney disease, was told by his nephrologist to choose a treatment plan for end-stage kidney disease (ESKD). James knew he needed some form of treatment to survive, so he attended a kidney education class to learn more about which treatment would be the best for him. He learned that there are four treatment options: 1) hemodialysis; 2) peritoneal dialysis; 3) kidney transplantation; or 4) palliative care. The following will provide a brief overview of his options he learned about.

Hemodialysis

Hemodialysis (HD) requires a machine and a filter called an artificial kidney or dialyzer. The dialyzer has two parts: one with fibers that your blood flows through and one with the washing fluid (dialysate). A thin membrane that separates these two parts allows removal of waste products (e.g. urea, creatinine) and extra electrolytes (e.g. potassium, sodium) and fluids from your blood, but will not let protein or red blood cells come through. You need to have a hemodialysis access, and the best one is an arteriovenous fistula (AVF) in your arm, which is created in minor surgery. HD can be done at home or in a dialysis center. In-center HD is usually three times a week for 4 hours each time. One type of home HD is performed by a nurse or technician similar to in-center HD. The other type of home HD is done by you along with your designated care partner. This type of HD is done about five times a week using a machine that does not require an external water treatment system. The last type of home HD is called nocturnal HD; it occurs while you sleep for about six to eight hours every other night or six times per week.

Peritoneal Dialysis

In peritoneal dialysis the lining of your own belly acts as a filter similar to the one in HD. However, rather than having the surgeon create an AVF, the surgeon will place a catheter (soft plastic tube) into your belly. A sterile solution (dialysate) will be placed in your belly either by using a machine (automated PD [APD]) or by raising the bag of solution to shoulder height to cause it to flow in by gravity (continues ambulatory PD [CAPD]). The fluid will be placed in your belly for a prescribed time and then drained and replaced with new solution (called an exchange). You don't use a machine for CAPD but will have to perform it about four times a day, seven days a week. APD uses a machine to perform the exchanges while you sleep at night (seven nights a week).

Kidney Transplant

A kidney transplant is not a cure, but rather another treatment option. It requires surgery, and placement of a new kidney from a living related donor, non-related living donor or deceased donor, on the right or left side of your lower abdomen. The surgery usually takes about three to five hours. To be considered for a transplant, your nephrologist will refer you to a transplant center for evaluation. Any potential living donor would have to undergo an evaluation as well. You will have to take medications to reduce the chance of rejection. Rejection is when your body's immune system considers the organ from another person as foreign and begins to attack it. You will have to take antirejection medications to help prevent this from occurring. The transplant team will carefully monitor you, especially during the first year after the transplant, to try to prevent rejection. In the event of rejection, you will have another opportunity to be evaluated for a second transplant.

Palliative Care

Some people may decide they don't want one of the aforementioned treatments, and instead choose palliative care. Palliative care is specialized medical care for people with advanced chronic disease such as ESKD. The goal of care is to manage any symptoms someone may be experiencing due to advanced disease, and to improve quality of life for the individual and the family. When death is anticipated in 6 months or less, a person may choose hospice care. Hospice care is provided by a team of end-of-life care experts to alleviate suffering and provide support for the family.

Conclusion

James decided that home HD with his care partner was the best option for him as he begins an evaluation for a transplant. It is important for you to discuss the best treatment option for you with your healthcare team.

Debra Hain, PhD, ARNP, has been a nephrology nurse for about 30 years starting as a dialysis nurse. In 2002 she became a nurse practitioner seeing patients in dialysis centers and conducting kidney disease education classes at Cleveland Clinic Florida, Department of Nephrology. In addition, she has her PhD in nursing and is an Associate Professor at Florida Atlantic University, Christine E. Lynn College of Nursing.

1st Place Essay *continued from page 1*
Web ID: 1053

There is no blueprint that works for every KD or dialysis patient. It takes experimentation to figure out what works for YOU. It'll often be (truly!) miserable, but be like the student in Chemistry class who blows up a few beakers to find the best result.

You know your body best. Do your research, know your disease and always educate yourself on the latest theories, gadgets and trials. With the knowledge and power to guide your own reality, you'll fall into the swing of "living on dialysis" faster and easier.

Yes to Peritoneal Dialysis over Hemodialysis. Not even a question!

Don't stop your exercise regimen. Like a disobedient toddler, your body will not always cooperate with you. You will feel fatigue you haven't felt since listening to your 8th grade History teacher and some days you'll feel so weak you won't even want to lift a hairbrush, but it's temporary. When you regulate your dialysis routine, you'll jump right back on the horse and by 2016 you'll be working out four days a week and feeling energetic.

Start a money jar. Throw in a dollar for every time a well-intentioned person says, "You don't look sick!"

Take photos of that unblemished, flat tummy of yours, free of catheters and stretch marks because you can kiss that goodbye! "Head" shots, too: dialysis gives you face blemishes and thins your hair, so while you look 30 at 40 with luscious locks, you'll look decidedly older at 44! Once you're completely in control of your PD regimen, you go up a few pant sizes too. But you'll appreciate having an appetite and feeling well, so a few extra pounds is more of a gift than a curse. Invest in yoga pants – they stretch! And start experimenting now with high protein recipes: "Protein!" is your new mantra.

Take your phosphorus pills. Each time you don't, it'll feel like you went dancing in poison ivy, your feet will itch like nothing you've ever experienced, just your feet, but it will be that itch that can't be scratched though you try like your life depends on it. Make sure to prime your line three times when connecting to your cycler (which you name Nelson because it gives you life and freedom, the things Nelson Mandela spent his life fighting for) – otherwise you get the infamous shoulder pain which is, well, awful.

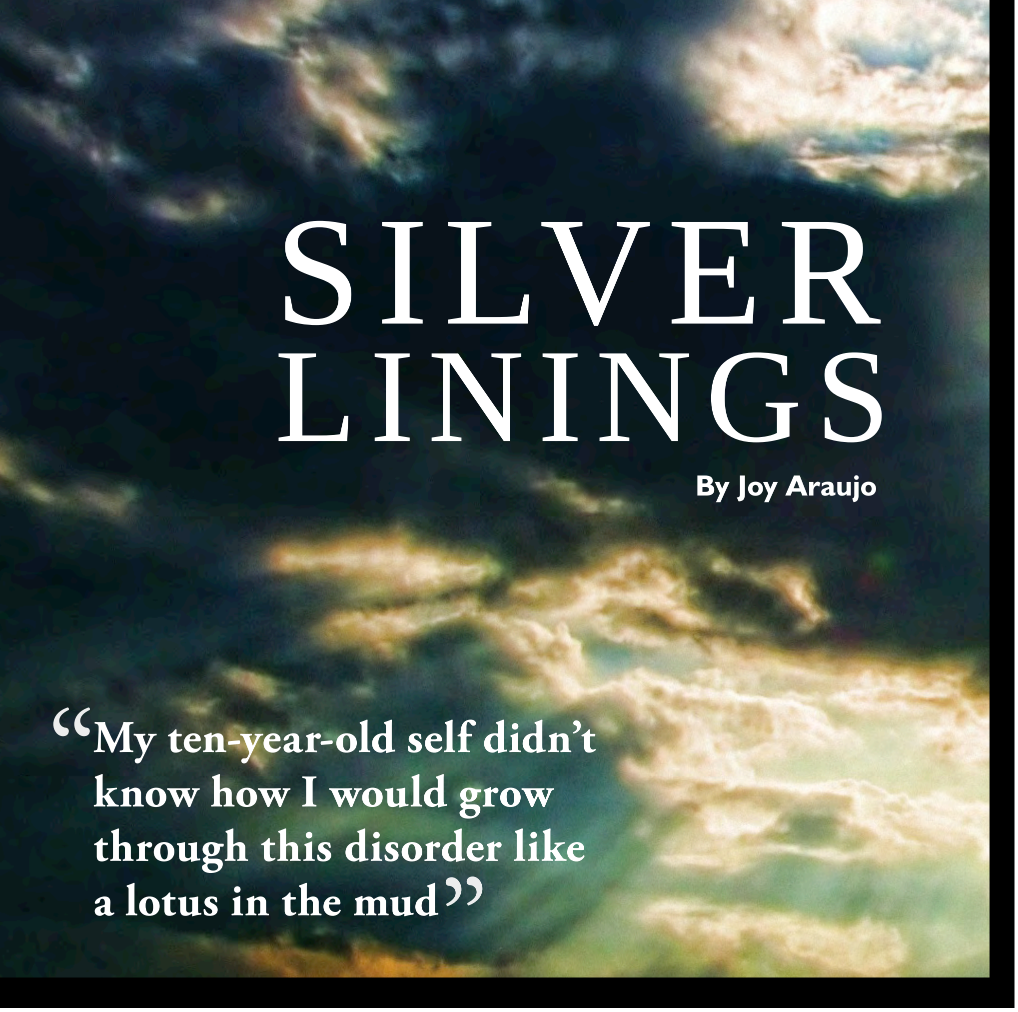
Start a money jar. If you throw in a dollar for every time a well-intentioned person says, "You don't look sick!" you'll have enough for a tropical vacay by now. If you also throw one in for every day you wake up and aren't sure if your body will conspire against you, that vacay will be ripe with caviar and massages. And you'll quickly learn that most people don't know much about Kidney Disease or dialysis and less about organ donation. Patience is key, you will eagerly disseminate the same information a bazillion times.

Most importantly, don't let this disease rule your life, fit it into your life and do what is necessary to lead a full life. You won't want to travel for a while, but know that even though it's a hassle, it's worth it. You've got the travel bug, so don't let this disease take away what you love.

"I'm still waiting for a transplant four years from now?!" you're screaming incredulously. Yes. You live in L.A., so the list is longer than Santa's naughty list, but in the hopes of having many really good years post-transplant, use these tips to get through each day and it'll be over before you know it. Trust yourself and everything will be ok.

Sasha Couch is an East Coast native who has enjoyed her last 17 years in Los Angeles. She has a BA in International Relations from The University of Pennsylvania. On dialysis for four years, she is eagerly awaiting a kidney transplant. She delights most in her volunteer endeavors, notably working with the literacy nonprofit, Reading Opens Minds. Sasha is a home Peritoneal Dialysis Patient at DaVita Mar Vista Dialysis Center in Santa Monica, CA.

RSN's 14th Annual Essay Contest
Web ID: 1054 2nd Place



SILVER LININGS

By Joy Araujo

> "My ten-year-old self didn't know how I would grow through this disorder like a lotus in the mud"

I remember the day I got acquainted with chronic kidney disease, in May of 1998, at the tender age of ten. I remember waking up with my eyes swollen shut. With no warnings, no signs, kidney disease came into my life just like that. It wouldn't leave so quickly. I would struggle with nephrotic syndrome C1Q nephropathy for six years before my doctor would look at me in a tiny room at the local pediatric hospital, exasperated and frustrated saying, "You'll need dialysis or a transplant soon." My kidneys had leaked too much protein. They were scarred and failing. It was a six-year fight until that day I knew I was dying in the back of my mother's car and would go back to the hospital to start dialysis the next day, symptomatic and sick. Eight months of daily dialysis would pass. I would miss copious amounts of high school, proms, sleepovers, and time with friends, who seemed to have run far away, scared of the word "disease."

June 8, 2005, at the age of seventeen, I got the call for a new kidney. I rushed to the hospital, full of hope and life. Adrenaline surged through my veins as I was carted off to surgery to begin a journey I had longed for since I was ten. The joy lasted eight great years, but my deceased donor kidney just couldn't keep up. It had undergone chronic rejection for about five years and I was told I needed a fistula put in. More dialysis was ordered. Eventually I did hemodialysis, until my troublesome access failed, then I began peritoneal dialysis. I still do this today.

I sit in my kitchen at this moment, typing away thinking about my ten-year-old self. She was so angry, doubtful, and bitter. "Why did this kidney disease happen to me?" I would ask. I almost find humor in that statement now. Why not me? You see, my ten-year-old self didn't know how I would grow through this disorder like a lotus in the mud. Ten year old me didn't know that kidney disease would provide the tools to make me more patient, grateful, and happy. On days when I get a tinge of, "I can't go on living on dialysis!" I find the strength within me to combat negative thoughts with a heaping dose of, "It is an honor and privilege to have a machine that can keep me alive in the midst of this disease!" I have also learned to wait patiently for my next transplant. There is no use fighting the waters: to swim, you have to go with the flow, and I know this from dealing with kidney disease. In addition, I know that life is a precious gift that has almost been taken from me more than once and that I need to treasure each breath like it could be my last. At the age of 28, I'm glad to know these truths that many people my age may not get to learn until they are much older. I'm on the fast track!

Kidney disease has also brought me to many great experiences and people. From a chaplain that helped me find myself and peace, to doctors that inspired me to attend college, to the other children at my hospital that inspire me to keep moving forward, to other volunteers of various organizations that help kidney patients and that teach me unselfishness, this ride has been a blessing!
So, what would I like to tell my ten-year-old self who was just handed a chronic kidney disease diagnosis? I would love to go back to those angry, bitter days of pulse steroids and chemotherapy and say, "This is about to be the hardest, most fantastic ride of your life!" I want that little girl to know that it's going to be difficult, but she'll learn the most valuable, important lessons about life that one can learn. She'll meet fabulous people along the way that will inspire her to become a woman. She'll cry sometimes, but get up with a renewed vigor and sense of purpose. She'll be a kidney disease warrior. I now know that the experience of chronic kidney disease is a blessing in disguise, which is the silver lining I wish I had known about when I was diagnosed eighteen years ago.

Joy Araujo is a Biblical Studies student at Anderson University in Indiana. Having battled kidney disease for most of her life, she enjoys donating her time to Donor Appreciation Network and the National Kidney Foundation of Indiana. She also likes to spend time with her dachshund, Franklin. Joy is an in-center hemodialysis patient at Fresenius in Noblesville, IN.

RSN's 14th Annual Essay Contest 3rd Place
Web ID: 1055

I NEVER KNEW A KIDNEY Was More Than a Bean!

By Debbie Sorensen

When I was a child and heard the word kidney, I always thought of the bean. You know the one I mean. The kind they put in chili or a bean salad. I never once thought I'd learn that kidneys were so much more!

When I was diagnosed with Chronic Kidney Disease, I was clueless as to what this really meant. My doctor sent me to a nephrologist (a what?) to have my kidneys evaluated. At first, they were working fairly well. My amazing nephrologist gave me great advice about what would help me keep my kidneys working at their best. I wish I had known right then the first of the important lessons I've learned: "Listen to your doctor!" I didn't follow all the advice and I didn't know what the real consequences would be. I soon learned many more valuable lessons I wish I'd known earlier.

I wish I'd known that a diagnosis of Kidney Disease does not mean you have been handed a death sentence. It was, and is, a disease that you can live with for years…and you can feel good and stay active. I wish I'd become more educated earlier about options and treatments. I wish I'd known that I could and should reach out to find more information. There are great organizations that provide valuable information.

I wish I'd known that trying to keep my family in the dark and not sharing everything that my doctors told me would only hurt me. My family members are my greatest supporters, and when I opened up after several years, they began to help me and cheer me on even at the most difficult times. I wish I'd been more open with my best friends. There were days I was feeling really sick, but never said anything or asked for help. All that this did was make them wonder why I was so aloof and didn't want to spend time with them doing the things we enjoyed. Once I opened up, I had a new group of supporters. I wish I'd known how many friends would give me their help and their hearts.

I also wish I'd known that being diagnosed would cause me to become depressed, and that realizing I was depressed would spur me to get help. The crazy thing was that once I had to go on Dialysis, the depression went away. I hadn't realized that the possibility of needing that treatment had affected me so deeply. The most amazing part is that Dialysis isn't a horrible thing…I certainly would have liked to have known that!

> *"a diagnosis of **kidney disease** does not mean you have been handed a death sentence"*

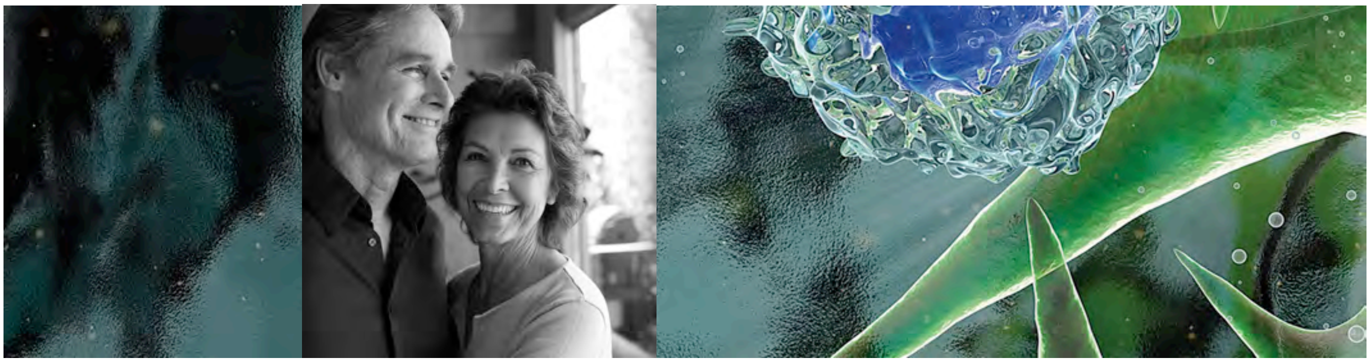
I also wish that I had known how strong I was emotionally and mentally. I wish I would have known that I would still be able to do physical activities and I wasn't going to be an invalid. I was scared of becoming "invalid" to other people; I wanted to continue to be an important part of their life. What I didn't know was that I would be able to become a patient advocate who helps others who are struggling like I did. I didn't know that I would meet a new group of friends who understood exactly what I was going through because so were they! Who knew that there were so many amazing people that would become important in my life. Talking to others who have the same disease helps a person to understand that they are not alone.

I also wish I'd known what marvelous health professionals would come into my life and how caring they would be. Doctors, nurses, technicians, dieticians, social workers and so many others who work to help me manage my lab results, my diet, my weight and who answer my questions. I wish I'd known that I will never be alone.

Looking back over the years, what I wish the most was that I had not spent time being scared. I wish I had focused more on staying as healthy as I could, planning for the future, finding an organization that would provide me with information, and being more honest with myself and others about what I was facing. I wish I could have educated myself and others more fully, but that came with time.

So, I've learned that kidneys are a lot more than beans, and I am grateful to so many people who have helped educate me so that I can educate others.

Debbie Sorensen has been a teacher for 30 years. Debbie has been married to Eric Sorensen for 25 years and is the proud mother of three sons. She has had kidney disease for ten years and has received dialysis the past year at Fresenius Dialysis Center in Anaheim.



A WELL PLANNED GETAWAY CAN Lift Your Spirits

By Leigh Anne Tanzberger
Web ID: 1062

Anticipating a getaway to visit family and friends, or to a place that you have always dreamed of seeing, can lift your spirits. I always look forward to getting away and have learned I can travel and have dialysis at most destinations.

To carry that feeling through and actually take the trip just takes great planning. You shouldn't think that you have to miss out just because you are on dialysis! It's definitely not impossible, and it's never too early to start the process.

Then, when the time is finally upon you, you can leave with great confidence and enjoy every moment. Everyone needs a break to restore their soul. Go for it!

First, remember that many regions are hot and crowded during the summer. The season in which you choose to travel and the location must suit your needs as a dialysis patient.

Next, figure out your "base camp" logistics and sightseeing. Decide where you'll be staying, for how long, and look into transportation.

After you've figured out the above, you should start inquiring into medical facilities available near your dream destination.

Your modality of dialysis will determine how you plan:

If you are on Peritoneal Dialysis, whether it is CAPD (Continuous Ambulatory Peritoneal Dialysis) or CCPD (Continuous Cycler Peritoneal Dialysis), everything can be arranged for you to travel. If you are using CCPD, you will need to speak with your nephrologist to determine whether switching to CAPD while you are traveling is the best solution for you.

If you are a CAPD patient, calculate how many medical supplies you will need during the time period you will be gone. Always plan to bring extra for the unexpected. Call your supplies delivery company, tell them the dates you will be traveling and the amount of supplies you will need and delivery location.

If you are using home hemodialysis, follow the guidelines set forth for the peritoneal dialysis. If you are using assisted home hemodialysis, you will need to speak with your nephrologist. Changing to in-center hemodialysis while you're traveling may be an option for you.

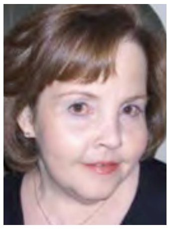
There are hemodialysis centers all over the world. If you are traveling internationally, go to globaldialysis.com. This site lists dialysis units in 61 countries!!

If you decide to stay in the U.S., go to dialysisfinder.com. This site lists all dialysis centers within a 50-mile radius of an address or zip code. You can also call the vacation spot dialysis unit and discuss your travel dates with them, or you can give your travel information to your social worker and she/he will make all the arrangements for you.

Experience has taught me, no matter the modality, you must calculate the amount of medications you will need to take with you. You can speak with your pharmacist so she/he can assist you in having enough medications with you during your trip. Most importantly, remember to carry your medications with you in your carry-on bag if you are flying. Checked luggage can get lost. Have your medications with you at all times!

Now that you have dialysis arranged, and your medications are ready to go, you can leave for your well-planned dream vacation.

Enjoy Every Moment – You've Planned for It!!



Leigh Anne Tanzberger has been a renal patient since 1978. She has had a 2 kidney transplant, was on PD for 14 years and is currently on hemodialysis. Leigh Anne volunteers with RSN and the ESRD Network 14 of Texas.

SOCIAL SECURITY, DISABILITY
and CHRONIC KIDNEY DISEASE – WHAT I'VE LEARNED

Web ID: 1063

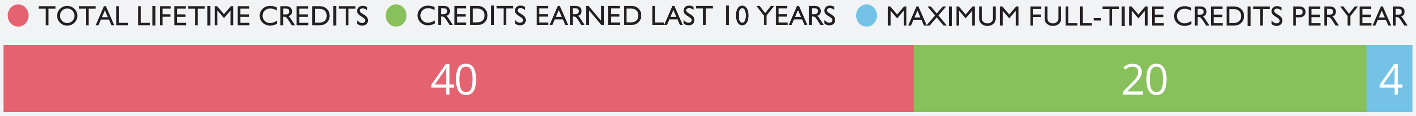
By David Ackerman, ESQ

Being on dialysis and not feeling well while trying to remain gainfully employed can be challenging. As an attorney with civil litigation cases, I could have court hearings, trials, or other matters scheduled which would be extremely difficult to cover while spending three days a week on hemodialysis. When I went on dialysis, I researched my options as far as disability payments and tried to find what was best. Here's what I've learned:

People who have Chronic Kidney Disease (CKD) may qualify for Social Security Disability (SSD). Those with CKD who are on dialysis (either hemodialysis or peritoneal dialysis) may automatically qualify.

FIRST QUALIFICATION - EARNED CREDITS

SSD pays disability benefits to those who can't work because they have a medical condition that's expected to last at least one year or to result in death. To qualify, one must have worked long enough in jobs covered by Social Security, and have a medical condition that meets Social Security's definition of disability. As for the first qualification, generally you need 40 credits, with 20 earned in the last 10 years. With a maximum of four credits being earned a year in a full time job, this means one must have worked for 20 years total, with 20 of the credits coming in the last 10 years.



(Younger workers may qualify with fewer credits on a graduated scale, but a minimum of six credits in the preceding three years prior to disability are still needed.) As for the second qualification, the disability must be total (partial or short-term disabilities do not qualify), and must be expected to last at least one year or result in death.

SECOND QUALIFICATION - PERMANENT DISABILITY

As for the second qualification, the disability must be total (partial or short-term disabilities do not qualify), and must be expected to last at least one year or result in death.

DETERMINING ELIGIBILITY:
Social Security has five questions to determine whether one is totally disabled. Answers to the first three often determine eligibility:

01 Is the applicant working? If they are and their earnings average more than $1,130 per month, they will be determined not disabled.

02 Is the condition severe? The condition must interfere with basic work-related activities.

03 Is the condition found on the list of disability conditions which automatically qualify? Here is where CKD comes into play. While there are several different CKD conditions that may be separately addressed, being on hemo or peritoneal dialysis are qualifying conditions. However, it still must be shown that the dialysis is expected to last at least one year. Even those who have had a kidney transplant will be considered disabled for only one year from the date of transplant After that, Social Security will evaluate any residual impairment(s) by considering post-transplant function, any rejection episodes, complications in other body systems, and any adverse effects related to ongoing treatment

Generally, if all three of the above requirements are met, the applicant is considered qualified. If there is still a question, Social Security will go on to determine the following:

04 Can the applicant do the work they previously did?

05 Can the applicant do any other type of work?

WAIT PERIOD FROM ONSET OF DISABILITY AND FIRST PAYMENT

Jun Jul Aug Sep Oct Nov Dec Jan

DIALYSIS BEGINS

Once the determination is made and the disability applicant is approved, the first benefit will not be paid until the sixth full month after the date of disability began, and it is paid the month following. As an example, if the date dialysis starts is June, the first month for benefits would be December, and those wouldn't be paid until January.

1ST SSD PAYMENT

TRIAL WORK PERIOD: Once approved, and after the first year of receiving benefits, Social Security will help and encourage beneficiaries to return to work. A "trial work period" allows one to "test their ability to work." For no more than nine months within a 60-month period, one can receive full benefits and have unlimited earning, as long as they report their work and continue to have a disability. In 2016, a trial work month is any month in which the beneficiary's earnings are over $810. If self-employed, it is $810 after expenses or more than 80 hours work in their business.

FOR UP TO NINE MONTHS WITHIN A 60-MONTH PERIOD ONE CAN RECEIVE FULL BENEFITS AND HAVE UNLIMITED EARNING

as long as they report their work and continue to have a disability

TRIAL WORK MONTH

earnings are over $810

SELF-EMPLOYED

$810 after expenses or more than 80 hours work

After this trial work period, whether it lasts nine continuous months or sporadically nine months over the five-year period, one must either go off SSD or cut back on the outside earnings. One can still work and receive full benefits, but only for 36 months, and the monthly earnings must not be "substantial" for any month. This amount may change each year, but for 2016, any earnings over $1,130 in any month are considered substantial. Outside expenses necessary to do this work may be deducted. If benefits are terminated because of "substantial earnings", there is a five-year period to request a restart of benefits if the applicant is again unable to work.

While SSD can help cover lost income due to CKD and being on dialysis, there are other options that may not be as stringent as Social Security's determination of total disability. Each state probably has its own version of State Disability Insurance. In California, each employee including self-employed individuals, pay into SDI. While SDI payments are limited in how long they can be paid, these payments may be greater than what SSD would pay.

In my case, I applied for SSD but was rejected because I had an office which I really didn't want to give up at that time. It was assumed by Social Security that if I had an office, I had to work to make rent payments, etc., and therefore my disability was not permanent. Although I didn't agree with this assessment, it turned out well for me in that I did go back to work and actually earned much more than I would have on SSD. I also went on SDI when I had my transplant, received more than I would have on SSD, and went back to work about four months later.

The bottom line for anyone is before making any decision about continuing to work, or applying for benefits, make sure you know and consider all your options. Discuss these with your family and/or other advisers.

David Ackerman ESQ, has been an attorney since 1976 in Maryland. After serving in the U.S. Navy JAGC, he became licensed in California in 1984, where his practice has primarily been in civil litigation. In January 2006, due to his PKD, he went on hemodialysis, but received a kidney transplant in February 2007, donated by a friend he had known since high school. He is Chairman of the RSN BOD.

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RSN EVENT CALENDAR

SAVE THE DATE!

Saturday, Nov. 12, 2016
7th Annual
Celebrity Charity Bingo
and Poker Tournament

Sunday, Jan. 15, 2017
18th Annual
Renal Teen Prom

(4th Sunday of the Month)
Monthly
Support Group

Thursday, March 9th, 2017
World Kidney Day

CHECK RSNhope.org
FOR ALL EVENT DETAILS

Live & Give

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9 AM–5 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

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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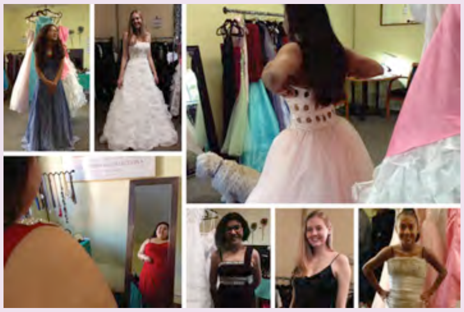
Renal Teen PROM

Prom season comes early for teens and young adults who have kidney disease with the goal of them sharing a night to remember and making friendships that will last a lifetime. This event is at no charge to attendees and their guests.

We need YOUR help to make this event a success! RSN is collecting donations of new or gently used party dresses, prom dresses, bridesmaids dresses, jewelry, purses and dress shoes for teens with kidney disease in need of affordable formals for the January 2017 Prom. Monetary donations are also accepted. To learn more about the Renal Teen Prom and how to make a donation send an email to info@RSNhope.org .



Renal teens choose a dress, accessories, and have their hair/make-up done by a professional stylist for prom at no charge.

President's Pick Essay
continued from page 5

gone horribly awry for years. Then the bureaucracy of my body began to do what all government agencies tend to do: underestimate the severity of the issue until it's too damn late, then panic.

The remaining Glomeruli that remained loyal to the cause were forced into triple overtime, pushing urinary output far past mandatory guidelines. Nutritional banks had to be lowered to minimal input as the stomach was used as a waste management backup.

My septic system was flailing, drowning in its own toxic fluids. Oxygen was scarce as my lungs unwillingly caved. Then the nothing overwhelmed the everything.

Nothingness is rather peaceful. Peaceful and pain-free.

Consciousness greeted me with the sting of an invasive tube protruding from the side of my neck. My streaming blood abandoned my tainted system, desperate for a second chance. Dialysis saved my fragile life. No one told me it would ask for shards of my soul in return.

I wish I'd known how lucky I would be to endure this as a child. Future ailments would be easier to conquer because of my fateful youth.

(Stacy Hoblitzell couldn't be here for this quickie quick bio due to his infatuation with the blissful art of slumber. Thus, we've asked his best friend Filbert the Kidney to speak for him. It's okay Filbert. Squash the fear like we spoke about.)

"Stacy's kinda weird. Silly and funny and awkward and weird. And, like, really sleepy. We don't go on many adventures cuz of that. When I woke up I was really scared and confused because there were four other kidneys in here just like me, but, um, well...not like me at all. Two were born ready, but Stacy said they gotz sick. So his Mom's kidney is over there and his sisters' is right near me. I talk to them, but they never talk back. It's kinda lonely. Stacy makes me sad sometimes because he doesn't feel like he deserves any of us. And sometimes, on the good days, we have lots and lots of fun together.

I think I'm done now. Did I mention he's kinda weird?"

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- *Reaching 100 on Dialysis: Tips for a Long Joyful Life* Web ID:1045
- *Transitioning Pediatric Patient to Adult Facility* Web ID:1043
- *For the Love of Nursing and Patient Care* Web ID:1041
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