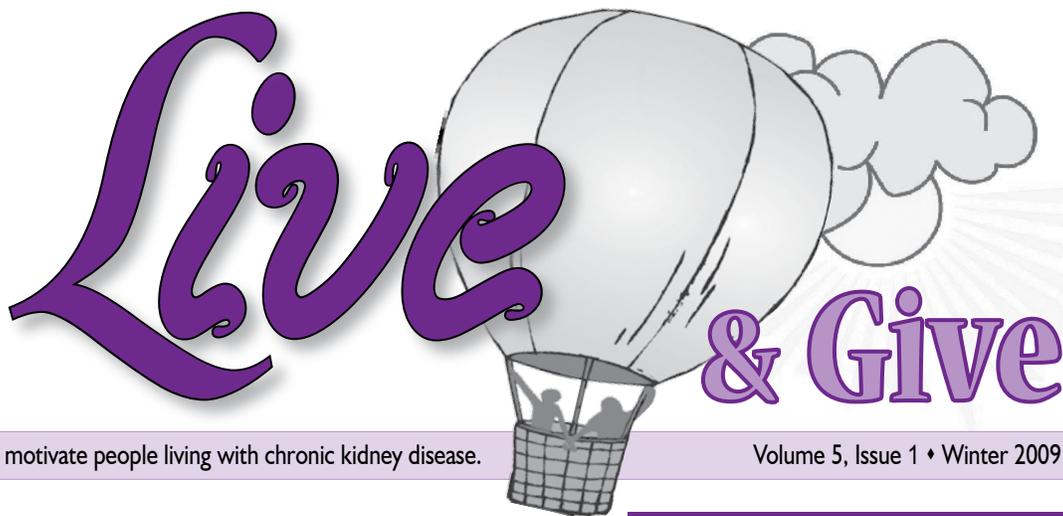




A PROGRAM OF
RSN
Renal Support Network



The quarterly update helping educate and motivate people living with chronic kidney disease.

Volume 5, Issue 1 • Winter 2009

RSN Report



Kidney Times 6th Annual Essay Contest Winners

by Heidi Lesemann

If you found a \$100,000 cashier's check in your mailbox one day, what would you do to improve the lives of people who have kidney disease? That was the challenge thrown down to anyone whose only qualification to enter the Renal Support Network's KidneyTimes Sixth Annual Essay Contest was to have been diagnosed with chronic kidney disease.

The nearly one-hundred essay entrants shared their personal stories and showed compassion for the conditions of people on waiting

lists for kidney transplants or who are on dialysis. Written on the theme, **"Funding a Dream: Giving Back,"** and sponsored by the Renal Support Network (RSN), the essays of 750 words or less covered a wide variety of possibilities and provided valuable insights into how the writers cope with kidney failure in a spirit of courage, strength, Health, Happiness, & Hope.

"We appreciate the effort of everyone who participated and did such an excellent job," said RSN President Lori Hartwell.

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KidneyTimes Essay Winner



Mentors Make a Difference

First Place

by Demmie Raysor

First, let me introduce myself. I was diagnosed with end-stage renal disease (ESRD) in the summer of 1999, and typically for me, I went into denial. But that has never stopped me from doing what I do best: moving on. While the disease was taking control of my body, I began to read up on kidney disease. The more I read, the more I realized that I was going to be in for the fight of my life, a fight which—I am

here to tell you—I was not going to lose. But even now, when I look back on how far I've come, I realize I have a ways to go.

Growing up in a family of ten with our father as the only bread

"It's important to have affirmation from someone who has already been where I still have to go."

winner, we kids all knew how to dream, how to imagine and how to improvise. Let me begin with my quest, or my adventure, about what I would do to inspire or to help fellow kidney patients if I found a check in the amount of \$100,000 in my mailbox.

First, I would educate them. Once a person has been diagnosed with renal disease and will need to begin dialysis, I would have a

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Telling Your Story – One Person at a Time

by Lori Hartwell



Everyone has a story. Unfortunately, not everyone tells their story for fear of being judged, shyness, or the belief that

other people are not interested. I have learned that telling my story can save lives.

I have grown up telling my story of how I survived with chronic kidney disease. I always receive responses like “you are so young to have kidney problems” or “are you okay now?” These comments remind me of the lack

of education among the general public of CKD and what causes it.

Looking back, I missed opportunities to educate people about how to prevent CKD and the importance of organ donation. Today, I take every opportunity to tell my story and use my experience to help educate the public.

For instance, recently I was returning a pair of shoes. The sales lady asked me why I was returning the shoes. I replied that because I had a kidney transplant, sometimes my feet swell and the shoes feel too tight. She said “my aunt is on dialysis and waiting for a transplant.”

I asked her if she knew the cause of her aunt’s kidney failure and she replied, “I don’t know.” I told her the two main causes of kidney failure are diabetes and high blood pressure and that she and her family are at greater risk because a family member has kidney disease. I asked her if she has ever been tested.

“No I haven’t. So how would I know if I am at risk?” she asked. I told her when she has a check-up that she should ask for a glomerular filtration rate (GFR) test. Also, she should ask her doctor about whether her blood pressure is in a normal range, if she has diabetes and whether she maintains normal blood sugar levels.

Since I had a captive audience, I furthered my spiel... “Over 26 million adult Americans have CKD (1 in 7) and many don’t even know it. Over 100,000 people are on the transplant waiting list. It is important for everyone to discuss organ donation with their family and let them know their wishes. Also, many states have websites (California’s is www.donatelifeca.org) that will allow you to register your decision to be a donor.”

KNOW
YOUR
NUMBERS!

Blood Pressure
120/80

Blood Sugar
80-120

Protect your kidneys.
Get tested often!
Tell a friend.

She was hungry for information, so I happily handed her my business card and told her she could find out more at our website. All this over a pair of returned shoes! We never know who our story will help educate, encourage, or empower.

In this issue of Live & Give we are exploring ways you can tell your story to help others. But remember when you tell your story, use it as a platform to help educate your audience with ways they can help themselves and their loved ones.

We need to serve the kidney community by instilling health, happiness, and hope through education, advocacy, and awareness... one person at a time.

Chronically Yours,

Lori Hartwell
President & Founder
of the Renal Support Network

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

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

Newsletter Staff

Editor-in-Chief

Lori Hartwell

Managing Editor; Layout & Design

Jodie Younse

Editorial Coordinator

Dawn Dungun

Distribution

Renal Support Network

Contact Information

Renal Support Network

866-903-1728 Toll Free

9 AM–5 PM Pacific Time

Submissions, Newsletter Business

info@RSNhope.org, or mail to RSN

Address Changes & Distribution

Live & Give Distribution Dept.

Renal Support Network

1311 N. Maryland Ave.

Glendale, CA 91207

info@RSNhope.org

Web Version (PDF files & archives)

www.RSNhope.org

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EIN#95-4672679

Essay Contest Winners

Continued from page 1

Following is a list of the winning essays and their authors:

•**First Place Winner:** Demmie W. Raysor, Bamberg, SC. Demmie composed an inspiring essay about establishing a mentorship with newly diagnosed patients who are about to start dialysis to guide them through the maze of information, struggles and emotions they will experience. Read the full story on page 1.

•**Second Place Winner:** Kevin Reynolds, Florence, KY. Kevin looked at the “Opt-In” tradition of organ donation and decided that it was falling far short of the need for organs, turning it around to “Opt-Out,” where everyone is considered an organ donor unless they say otherwise. Read the full story on this page.

•**Third Place Winner:** Mountray Oliver, Orlando, FL. Mountray offered her \$100,000 to the research and development of a portable, implantable, artificial kidney that would help alleviate the lack of donor kidneys, relieve the need for anti-rejection medication (immunosuppressants), maintain proper balances in the system, and broaden the patient’s variety of food choices. Read the full story on page 7.

•**Best Essay in Spanish:** Sonia Miranda Matos, Ponce, PR. Sonia would create a renewable funding source to contribute towards faster transplantation, assist low income patients who need help to get to distant transplant centers, help with the cost of medications, increase nurses per patient, and renovate medical equipment. Read the full story online at www.kidneytimes.com. 

KidneyTimes Essay Winner



Opt Out: A Donor Option Second Place

by Kevin Reynolds

There it is.
A check for \$100,000,
from out of nowhere, sitting
in my mailbox.

Only one caveat... do
something good with it for other
kidney patients.

Oh... is THAT all? Really, I
would need 1000 times that
amount to even make a dent
in accomplishing all that I
would like... improving centers,
earlier kidney education, better
physician awareness of ESRD, and
of course, donors all around!

But as we kidney patients all
know, you do the best with what
you have. So that’s what I’ll do
with my hundred grand.

I’m going with the theory that
you start at home, make changes
in your own neighborhood, city,
or county then, like a pebble
dropped in a still pond, you
wait for the ripples to spread
the message. That’s how I am
going to use these funds to try
and move my state towards
an opt-out
program of
organ donation.
What’s that,
you ask? Well,
instead of asking
residents to sign a
donor card on their
driver’s license, they
would be asked if
they DON’T want to be a donor
and sign that. This then begins
the process of re-educating the
populace to believe they are
considered an organ donor unless
they say otherwise.

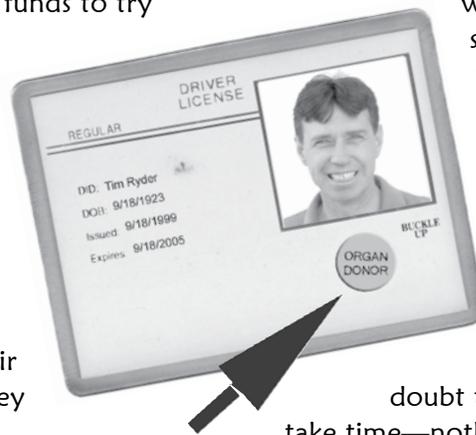
While it sounds like a simple
change, it’s actually a complex
process involving various state

departments, rules and regulations,
and, most importantly, the verbiage
used on the actual driver’s license.

Step one would be sponsoring
a statewide meeting of all the
key stakeholders in this effort:
transplant hospitals and doctors,
health organizations, patient groups,
United Network for Organ Sharing
(UNOS), government agencies and
the state transportation department.
Information regarding the critical
need for organ donors and the
miniscule percentage of those who
agree to be donors will be stressed,
with an emphasis on the need for
greater donor education. An action
plan to change the current state
policy would be created by the end
of the meeting so that specific steps
and assignments would be in place
to begin the process of changing the
current regulations.

A part of the \$100,000 would
be used to contract with a
knowledgeable lobbyist to assist
with the effort in the
state capital. Knowing
the right legislators,
their staffs and
government officials
will be critical
to pushing this
movement along
in a quicker-than-
normal rate.

There’s no
doubt this process will
take time—nothing moves quickly
in state government. However,
while the wheels of legislature
grind slowly, rallying public support
can move more quickly. Using
an aggressive online and e-mail
campaign, and with the assistance
of the stakeholder groups from the
statewide meeting, a coordinated
advocacy effort will begin to help



Continued on page 9

2009 KidneyTimes Essay Contest

“What Helps You Live a Joyful Life In Spite of Kidney Disease?”

Announcing the 2009 KidneyTimes Essay Contest.

Accepting submissions March 1st - August 31st 2009. To submit an essay you must have been diagnosed with chronic kidney disease (CKD). Essay length should be between 400-750 words. Please include your full name, mailing address, phone number and e-mail address at the top of the essay. Essays must be typed and may be submitted via e-mail MS Word document attachment (preferred), mail, or fax—see addresses below. Submissions will be judged on their relationship to the contest theme, originality, creativity, and technical expertise. Essays may be submitted in English or Spanish. All essays become the property of the Renal Support Network. For more information and contest rules visit RSNhope.org or KidneyTimes.com.

Send essays to:
essay@rsnhope.org
KidneyTimes Essay Contest
c/o Renal Support Network
1311 N Maryland Ave
Glendale, CA 91207
Fax: 818-244-9540

For questions call (toll free):
866-903-1728

KidneyTalk™

Listen to Diana Headlee-Bell's story online

Hemo for Night-Owls: What One Person Discovered Two Transplants and 34 Years Post Diagnosis

Aired August 9th 2008
Go to RSNhope.org and
click on the KidneyTalk logo.



Perspectives

Connecting with Fellow Patients

by Diana Headlee-Bell

Times have changed and so has technology. When I was diagnosed with kidney disease 34 years ago, we merely had telephones, televisions, and radios. Today, we have a new way of communicating via cell phones, text messaging, e-mail, and the Internet. No matter which method of communication you prefer, connecting is a useful tool to help learn about ways to live successfully with kidney disease.

Today, we rely on the Internet to learn about kidney disease and have on-line friends from around the world. We share our personal experiences with others throughout the world about chronic kidney disease (CKD).

The Renal Support Network has developed a web-based bulletin board called KidneySpace.com that has opened up many doors for connecting people living with kidney disease. It's easy to join—you simply register at www.kidneyspace.com, create a username and password, and shortly thereafter an e-mail will be sent to you indicating your acceptance to the site. You can start sharing your personal experiences and concerns, and gain insight from fellow members.

Kidneyspace is a tool for reaching out to others who are experiencing the same things we are. It allows us to share our deep personal stories and many experiences that come with this disease. Some posts are positive, while some posts are negative; however, they all include our need to convey our thoughts and feelings. We also share about our home lives and how the disease has affected our families. There is a close, family feeling on the site that unites us together. Corresponding about our day-to-day experiences gives us the encouragement, support, and help you would expect from a loved one.

Kidneyspace is also a place to meet others for support through our online chat group. The support groups meet twice weekly and a variety of topics are covered. It's a great place to educate yourself about kidney failure and all the issues that go along with it as well as meet others in real time conversations.

Thanks to the improvements in technology, a whole new world has opened up for those of us living with CKD. It is so important for people like us to connect with each other, make new friends, and realize we're not in this disease process alone. Come join us—'your CKD family'—at www.kidneyspace.com. We're online and can't wait to meet you! ☺



Diana Headlee-Bell went into end-stage renal disease (ESRD) in 1978 at the age of 15 as a probable result of glomerulonephritis due to strep throat. She has received two transplants, her second in 1981, which lasted for 18 years. Her present modality for treatment is in-center nocturnal hemodialysis. Diana is active in her state ESRD Network, serving on the Rehabilitation Committee and the Board of Directors, as well as co-chairing the Patient Advisory Committee. She currently works with RSN as a PEPP speaker, HOPEline operator, and KidneySpace moderator.

For more information about RSN and RSN's programs, visit our website:

RSNhope.org

"KidneySpace has been of such support to me and I love how fast I get answers on even the most mundane questions without any flack. Rules are not too strict and everyone is so friendly and welcoming. It has quickly become my favorite place out of the few CKD sites I visit."

-Angie of Ontario, Canada

"KidneySpace is a great place for people to get support from others in the same situation as them, or for people to give something back to the kidney community. I have learned so much from others on the site and feel I have offered my support and understanding to them."

-Julie from Missouri

"When I was told that I had renal failure I was completely devastated, it felt like I had been given a death sentence. After doing a search for support groups I came across KidneySpace.com and for that I'll forever be grateful. Its members were so caring and supportive. They took the time to answer any questions I had, provided me with links to various websites that gave me information from everything about the disease to diets and most importantly they showed me that renal failure is just an inconvenience and not the end of the world."

-Marc from Michigan

To join the KidneySpace community, log on to www.kidneyspace.com. You do not need to register to read the posts on each message board. If you would like to post your own question, comment, or story you will need to register. To do so click on the *register* link at the top left of the KidneySpace home page and fill out the form. You will be required to have a valid e-mail address.

Mentors Make a Difference

Continued from page 1

fellow dialysis patient who has had the procedure—catheter, life-site or graft—assigned to the new patient. Let them share their personal story about the surgical process, the healing period, and what the incision will look like once it has healed. Although my brain knows this procedure will not only save my life but give me a better quality of life, as a woman, my heart tells me that I will have a scar that will be unattractive and might limit my wearing of certain clothing. To some this might seem superficial but to a female, especially a young female, this is a very real concern. It's important to have affirmation from someone who has already been where I still have to go.

Once the patient has decided on the dialysis center they will use, I would have the manager of that center or his designee contact the patient to set up a personal tour of this particular center. During the tour the manager can explain to the patient what they can expect and assign them a mentor.

The mentor will share his or her own personal story, answer any questions the new patient might have, invite the new patient to visit with other patients while they are being dialyzed, and talk about food choices. The mentor can also help prepare them for the emotional experiences they are going to go through that are common in all illnesses. We all do a balancing act between regulating our blood pressure, fluid gain and high potassium and phosphorous levels. While dieticians and the medical staff will counsel a patient and give them all the necessary information they will need to add years to their life, a mentor will give them what they need to add life to their years.

Alcoholics Anonymous (AA) has built a very successful treatment program based on the idea of assuring that each new person has a mentor. There are things that we will share on a one-on-one basis with a person who has walked or is walking in our shoes that we will not share in large groups or even ask

a medical professional.

At least monthly, have people who are on dialysis and working share their stories. Or have a transplant recipient come in and share their story. Sometimes when a person starts dialysis, they are not interested in a transplant, but as time goes on they become more amenable to the idea.

The scripture Hosea 4:6 states, "My people perish for lack of knowledge." Let's not perish, let's educate! My desire is that all of my fellow kidney patients be proactive about their health. Whether you have developed kidney disease because of life choices or genetics, it's important that you arm yourself with all the knowledge at your disposal. 



Demmie Raysor briefly attended South Carolina State College in Orangeburg, SC. During that time she worked in the Bamberg School District One School System in Bamberg County SC, as a paraprofessional and bus driver before taking an early retirement. Ms. Raysor was diagnosed with end-stage renal disease (ESRD) during the summer of 1999. She is currently awaiting a kidney transplant.

A Family Affair

by Robert Ziegler

Kidney failure has been a whirlwind experience. I knew I was someday going to need dialysis and even had an access put in three months before needing treatment. I had never been to a dialysis unit, so I didn't know what to expect. After receiving treatment for two months, I realized I would be able to manage the requirements of dialysis. I didn't take much time to consider the impact this would have on my family. After all, I was sitting in the chair for almost four hours three times a week. But, I came to learn that it impacted my family more than I was aware.

I know an illness can either bring a family together or tear it apart.

My illness was making me see that my family cared about me and was willing to do anything to improve my quality of life. After I was able to comprehend that my family was willing to give me a kidney, I just had to be willing to accept it. My daughter, Jennifer, had a hard time seeing me rely on dialysis to live. My 7 year old granddaughter, Destiny, was my constant strength and would sit by my chair at dialysis and wasn't fazed by it. She thought this was just a normal way of grandpa staying healthy.

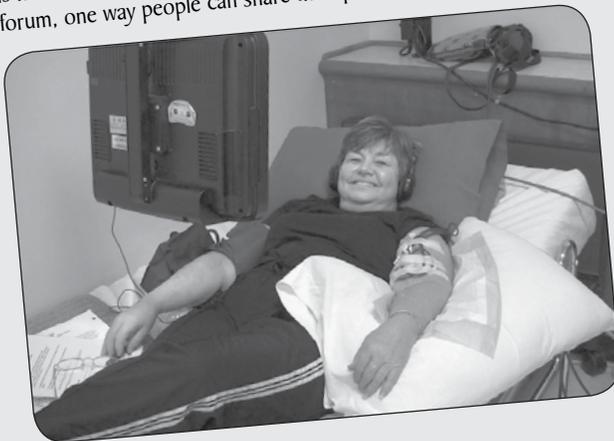
I understood the extent of my family's concern after my first transplant clinic visit. My doctor had signed me up to be a candidate

for a transplant. I received a letter in the mail from UCLA about the clinic. The letter was very specific, telling me they would be taking a LOT of blood, that I might get called for a transplant as soon as my labs cleared, and I got an okay from the transplant doctor. The letter also stated to bring any concerned family members. I called to confirm my appointment and my family readily agreed to go.

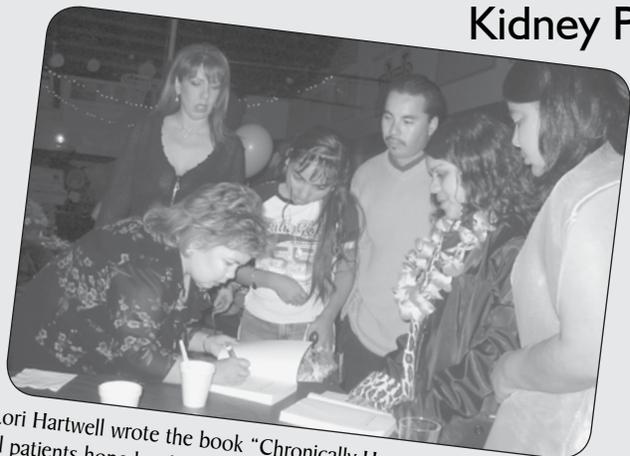
I had no idea what to expect because I was still trying to understand the impact of being on dialysis. Transplant was such a new concept to me. At the clinic, they told us it could be a seven year wait for a deceased donor

Continued on page 11

Diana Headlee-Bell does in-center nocturnal hemo dialysis. No, she is not watching television. Diana is moderating RSN's KidneySpace forum, one way people can share their personal experience.



Kidney Patients Share Different



Lori Hartwell wrote the book "Chronically Happy" to give chronically ill patients hope by sharing her story. Here, Lori signs books for young kidney patients at RSN's Renal Teen Prom.

1965. For Gabriel and others, it's dialysis or death – but there aren't enough machines.
Now an anonymous citizens committee must decide...

March 12-29, 2009
Thursdays, Fridays, and Saturdays at 8 p.m.
Sundays at 2 and 7 p.m.

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Los Angeles CA 90064

I WHO LIVES?

a play by Christopher Meeks directed by Joe Ochman

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www.RSNhope.org

presented by The Renal Support Network



My Best Friend Arty

Third Place

by Mountray Oliver

If I found a check in my mailbox for \$100,000, I would be very surprised and happy.

My first thoughts, after the initial shock, would be to make life easier for patients with kidney failure and who are on dialysis. My \$100,000 check would be spent on research and development of a portable artificial kidney.

The portable artificial kidney, "Arty," would be similar to a pacemaker. The Arty would be to the kidney what the pacemaker is to the heart. The artificial kidney would be a small machine about the size of a woman's fist. A patient would only need one artificial

urinary bladder until it is full. The urine would then exit the body through the urethra.

In addition to removing waste and toxins, the Arty would maintain proper balance of water, electrolytes, and acids in body fluids. The Arty would also help to regulate and lower high blood pressure. Patients that have an Arty installed would no longer have to be concerned with their potassium, calcium, and phosphorus levels. Patients would have more variety of food choices.

Unlike a transplanted kidney, anti-rejection drugs would not be needed for the Arty since it is

nurse would hold an electrical wand over the body where the artificial kidney's battery is located. The electrical charges from the wand would charge the artificial kidney's battery. Because the Arty has a lot of micro fibers that act as filters, for optimum performance the Arty would need to be replaced every ten years.

The Arty would be another treatment option for patients with kidney failure. It would be moderately priced and insurance companies would cover the cost of the machine, surgery to install it, and the cost of recharging the battery. This portable device will give kidney

Share Their Story in Different Ways



Actor Stephen Furst, diagnosed with kidney disease in 2006, cohosts KidneyTalk and often shares stories of his 35 years living with diabetes. You can hear his anecdotes on KidneyTalk podcasts at www.kidneytalk.com.



WeKAN member and PEPP speaker, Sherai Onibasa shares her experience with peritoneal dialysis while dining with RSN employee Jessica Garcia.

kidney that would be placed inside the patient's body through a small 2-inch incision in the area where one of the kidneys is located. The artificial kidney would consist of a soft, pliable type of material that has a lot of micro fibers similar to a natural kidney's nephrons. It would also take over the functions of a diseased kidney by filtering nitrogenous wastes and toxins from the blood and produce urine. The urine would then be stored in the

not made of living tissues and cells. If an infection occurs at the site where the Arty is placed, antibiotics will be given. The only pills the patient will be required to take while using the Arty will be hormone pills, vitamins, and medications for pre-existing conditions.

The Arty would be powered by a tiny battery that will need charging every five years. To charge the battery a doctor or

patients another chance at living a relatively uncomplicated life. Like the convenience of a kidney transplant, traveling will be easier for patients who have an Arty. 



Mountray Oliver began dialyzing on Nov 4, 2007. She worked for 20 years with her husband at their family business. In 2004 she changed careers and became a high school teacher where she taught for three years. Mountray often educates family and friends about kidney disease. She currently resides in Florida with her husband and three children.



A Time to Speak

by Shari Gilford

As a little girl I loved being the center of attention. Whenever my father got out his camera, I would dance happily around him begging, “Daddy, daddy, take a picture of me!”

In my teen years, my piano performances put me on stage often—a place I enjoyed immensely. Speaking in front of people didn’t scare me either. In fact, the few times I spoke publicly I felt energized. I knew the stage was for me.

Fast forward to 2004 when I met Lori Hartwell, the founder of the Renal Support Network. She proudly attributed her speaking abilities to her long-time involvement in a Toastmasters club, and encouraged me—and everyone she knew—to try it.

In case you’re wondering, Toastmasters is not where you learn the fine art of making toast for breakfast (though a lot of clubs meet at that early hour). Rather, it’s a training ground for learning the fine art of public speaking.

After visiting a few Toastmasters clubs in my local area, I decided this would be a beneficial investment of my time. I chose a club and became a member.

For three years now, I’ve regularly attended weekly club

meetings. Many people tell me they’ve seen a big improvement in my speaking ability. My involvement in Toastmasters has also enhanced my ability to listen—an asset in all aspects of life!

Toastmasters keeps me sharp because I have the opportunity to practice, practice, practice. “Stage time” is the best way to get more comfortable in front of an audience, and Toastmasters guarantees that club members get lots of it!

Opportunities to practice both



speaking and listening skills abound at every club meeting in the form of various speaking and evaluating roles. Members are challenged to lead the meeting, give a short speech, tell a joke, speak without preparation, listen for filler words (um, uh),

and evaluate others.

Instructional manuals guide members in preparing a speech. In the first speech manual, ten speech projects focus on practicing skills such as gestures, visual aids, or vocal variety. After completing the ten projects, a member can continue with more advanced speech manuals. Leadership manuals help members learn and practice leadership skills.

My favorite part of the meeting is the evaluation portion, which I find both inspiring and helpful.

Read another article by Shari Gilford on KidneyTimes.com

Enrich a Life—Share Your Knowledge
EasyLink Access #: 151

You can also hear Shari discuss fitness on KidneyTalk

Overcome the Exercise Excuses!
Aired July 31, 2007
Go to RSNhope.org and click on the KidneyTalk logo

Evaluators highlight positive aspects of each speech along with constructive suggestions for improvement. I always look forward to the feedback I receive—it’s been instrumental in my growth as a speaker.

I have a story—a story that encompasses the experiences, victories, heartaches, hope, and determination of living with kidney disease for over 30 years. As a result of Toastmasters training, I’ve learned to share my story with greater clarity, emotion, skill, and confidence. Toastmasters made the difference!

Toastmasters clubs are located in almost every city and in small towns as well. Clubs are visitor-friendly and welcoming. To find a club near you or to learn more about Toastmasters International, go to www.toastmasters.org.



Shari Gilford has lived with kidney disease for over 30 years and received her third transplant in March of 2006. She was the managing editor of the Renal Support Network’s Live & Give newsletter for almost three years. As a PEPP speaker, she has spoken to patient and professional audiences of over 200 people.

Opt-Out: A Donor Option

Continued from page 3

influence our state leaders. Using the tag line “Feel Great: You’re a Donor,” the campaign will be upbeat, positive and present this new concept as one that is easier and will save thousands of lives each year. Recognition will be given to religious beliefs that do not embrace this, but for the majority of residents, this idea will be shaped as the easiest way to provide life-saving organs to those of us who desperately need them. As this campaign gains speed, a coordinated outreach to state media outlets—television, radio, newspaper, etc.—will be undertaken to provide stories

of local individuals waiting for donations and the simplicity of this new opt-out plan.

Our old way of opting in for organ donation just isn’t working. Too many people are dying each day awaiting kidneys or lungs or hearts. The process that has been implemented is being presented in a backwards way, and often, in the crunch at the DMV, is probably only being mentioned briefly, if at all. A new thinking and new philosophy about organ donation needs to begin, and if it begins here, it could easily spread throughout the country.

I believe this is the greatest,

long-range effort that we can undertake to assist as many kidney patients as possible, now and in the future. Yes, we need new drugs and new technology, but we have got to find more donors to help keep us alive. That’s why “opt-out” is my \$100,000 effort. 



Kevin Reynolds was diagnosed with renal cancer in both kidneys in 2006 and had both removed in 2007. He, with his wife, Susan, began home hemodialysis in May 2007. He works full time as the Community Relations Director for Cincinnati Public Radio (90.9 WGUC and 91.7 WYXU) and enjoys spending time with his beautiful wife and daughter and their new puppy, Sophie.

“I think everyone is born with a story. If you believe in a divine power, which I do, you learn to open your mind to the doors that open around you.”

—Judith A. Beto, PhD, RD, FADA

To Your Health

Phosphorus: What is it and why is it important?

by Judith A. Beto, PhD, RD, FADA

Phosphorus is a major mineral found throughout the body. Phosphorus is controlled as part of normal, healthy kidney function. When the kidneys do not work effectively, the level of phosphorus accumulates in the body. Your dialysis clinic measures the amount of phosphorus in your blood during the monthly laboratory tests.

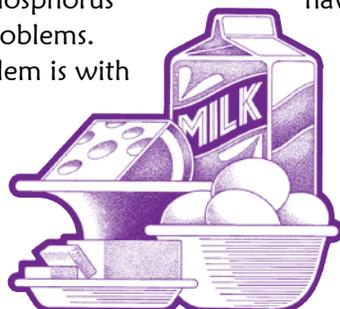
High serum (blood) phosphorus levels can cause many problems. The most common problem is with your bones. When your phosphorus is too high, it may encourage the calcium in your bones to move. The calcium moves from

the bones to match the level of phosphorus in the blood, like two people holding hands. This process can cause the bones to have less calcium than they need to stay strong. Many other things may be happening when your blood phosphorus is too high. Most of these things you cannot feel and may not know about until you have problems several months, or even years, later. By then, the problems cannot be easily fixed.

Phosphorus is found in many foods. The most common foods are dairy products or

foods that contain milk. Examples are cheese, milk, yogurt, and ice cream. Phosphorus is also found in legumes, and in dried peas and beans. Phosphorus is often also found in protein products like liver and meat. It is often difficult to follow a low phosphorus diet.

To help keep the blood phosphorus to a normal level, you may be asked to take phosphate binders. These binders are medications that remove the phosphorus from the food as it’s being digested. The phosphorus is then moved through your system in a “bound form.” Think of it as putting the extra phosphorus in a clear sandwich bag. You can see



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Low Phosphorus Food Substitutes

Macaroni and cheese	INSTEAD	Pasta noodles, margarine, garlic & basil
Peanut butter	INSTEAD	Jam, jelly or honey
Frozen yogurt / ice cream	INSTEAD	Sorbet
Nuts	INSTEAD	Unsalted popcorn or pretzels
Cola (soda)	INSTEAD	Ginger ale or root beer

Check with your dietitian before changing your diet.

Phosphorus

Continued from page 9

it, but it cannot get out of the bag. The phosphorus in the “bag” or the “bound state” now moves through your intestinal system without being absorbed. It leaves your body through your stool. It does not go into your blood stream.

You must take your phosphate binders at the right time to “grab” the phosphorus in the food you are eating. Your phosphate binder won’t work right if you don’t take enough binders or don’t take them at the right time. There are many binders on the market so ask your health care provider what binder choices are right for you.

It is very important to know about phosphorus. If you need more information, ask your dietitian or

health care provider. They can often help you learn more about the foods you are eating and how you can protect your bones. Strong bones help you remain active and healthy.

Keeping your blood phosphorus in the normal ranges each month is a good step you can take to keep you healthy and feeling good while on hemodialysis. 



Judy Beto has over three decades of hands-on renal nutrition experience as one of the earliest renal dietitians. She was the first editor of the Journal of Renal Nutrition. Currently she manages clinical trials for hemodialysis patients at Loyola University Medical Center and is a professor in the department of Nutrition Sciences at Dominican University.



weKAN: Wellness & Education Kidney Advocacy Network

A national group of people with kidney disease who advocate on behalf of fellow patients. *Live & Give*—weKAN’s quarterly newsletter for patients—informs, inspires, and educates patients, family members, and healthcare professionals.



PEPP: Patients Educating Patients & Professionals

PEPP patient-speakers are trained to give educational presentations about kidney-related issues to patients and professionals. To learn about the presentations offered or to schedule a PEPP speaker for a meeting of patients or professionals, go to RSNhope.org and click on Programs, then PEPP.



KidneyTalk

Online radio talk show hosted by Lori Hartwell & Stephen Furst, covering a wide variety of kidney-related topics. Listen at RSNhope.org or download podcasts from iTunes.



RSN Renal Teen Prom

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



HOPEline

A toll-free call-in line offering patient-to-patient encouragement and support from operators who have lived successfully with chronic kidney disease. Call **800-579-1970** Monday - Friday, 10:00 a.m. - 8:00 p.m. (Pacific Time).



Regional Patient Lifestyle Meetings

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



KidneyTimes

An online resource with articles written by kidney patients and professionals on medical, social, nutritional, and lifestyle issues. Home of the annual “*KidneyTimes Essay Contest*.” KidneyTimes.com



KidneySpace

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

Give the gift of health, happiness & hope!

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

Name _____

Address _____

City _____ State _____ Zip _____

E-mail _____

Phone _____ home work cell

METHOD OF PAYMENT FOR CONTRIBUTIONS:

- Check or Money Order (payable to Renal Support Network)
- Credit Card: MasterCard Visa American Express
- Total billed to credit card \$ _____ Billing Zip _____
- Card #: _____ Exp. Date: _____ / _____
- Cardholder Name (as on card): _____
- Signature _____ Date _____

All donations are tax-deductible. EIN#95-4672679

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

Enclosed is my gift of:

\$ _____

Please check all that apply:

- Patient—I have experienced:
 - transplant PD hemo
- Family Member Administrator
- Physician Nurse
- Dietitian Social Worker
- Technician Company Rep
- Other _____

Cut form on dotted line and mail or fax to the Renal Support Network. Thank you!

Renal Support Network

1311 N. Maryland Ave.
Glendale, CA 91207

toll free 866-903-1728 ♦ 818-244-9540 fax

A Family Affair

Continued from page 6

transplant and living donation was an option. They spoke about the pros and cons of donation and provided a phone number if someone wanted to donate a kidney. I still get choked up when I say this, but all three of my children made the call. My wife, Cindy, didn't think she would be a match because we are not blood relatives, so she didn't call. She always claims she was going to call! We've been happily married for 31 years and

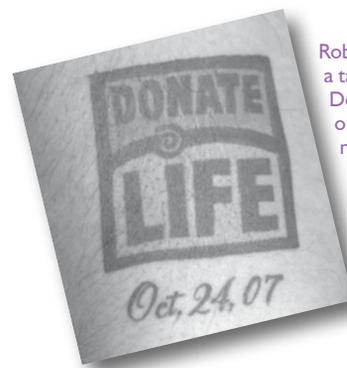
she's still the love of my life.

The transplant doctor called a meeting for my whole family and told us that since I was AB positive, I was easy to match and they were all possible donors. So who would donate? The doctor helped us make a decision. My daughter was not the top choice because she might still have more children, so he suggested my oldest son, Robert, be tested and my other son, Michael, be the second choice.

Robert went through a lot of testing, including a psychological test to make sure that he was sure about his decision to donate. Six months later, on October 24, 2007, I received the most incredible gift from my son. He was out of the hospital within 24 hours; I was in for a week.



From left: Robert Ziegler senior and his son Robert who donated a kidney to his father.



Robert senior got a tattoo of the Donate Life logo on his arm to memorialize his one-year transplant anniversary.

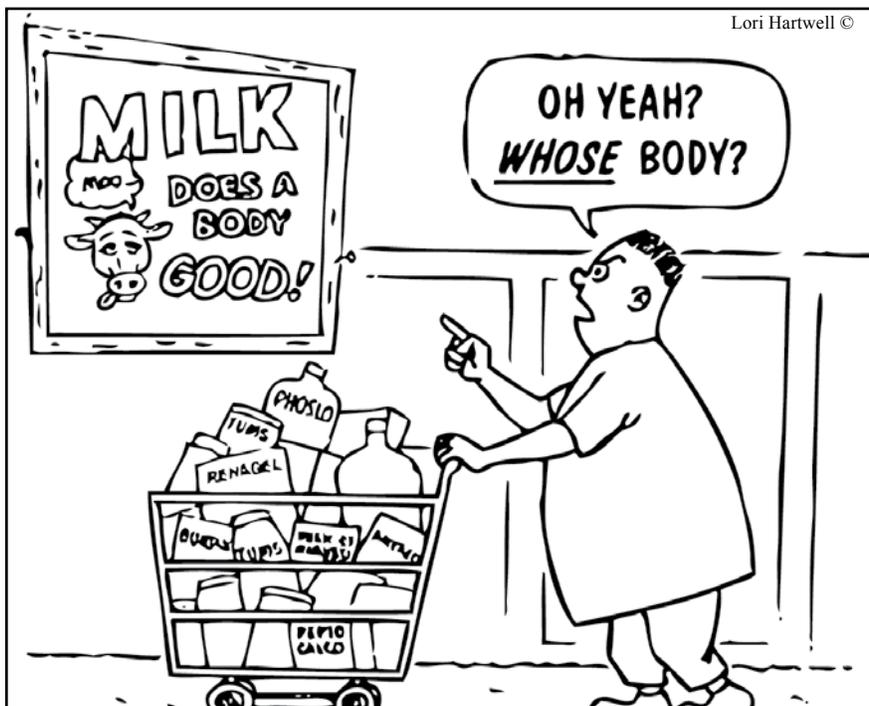
Today, my son and I are doing great and to memorialize my one-year anniversary, I had a tattoo put on my arm to remind me of the special gift I received. I thank my family and especially my son for all of their love, encouragement, and support. I'm the luckiest man alive. Dealing with my kidney disease has indeed been a family affair. 



Robert Ziegler is a Los Angeles native who worked for Courtaulds Aerospace in Glendale, CA, for 17 years. He has three children and one granddaughter who consistently beats him at the game Sorry. Robert enjoys volunteering for the Renal Support Network on a regular basis. For 31 years he has been married to his wonderful wife Cindy. They currently live in Glendale, CA.



*In this issue of Live & Give...
The Importance of Telling Your Story*



Read Judith Beto's article about phosphorous on page 9.

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Calendar

RSN Renal Teen Prom

January 18, 2009 (Sunday)
Sherman Oaks, CA
10th Anniversary Theme:
Somewhere over the Rainbow

World Kidney Day Celebration:

**RSN Presents the Play
Who Lives?** by Christopher Meeks
Opens March 12th 2009
Performances March 12-27

Patient Meetings to be announced soon.

Go to RSNhope.org to check the latest calendar listings, download flyers, or register online.

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