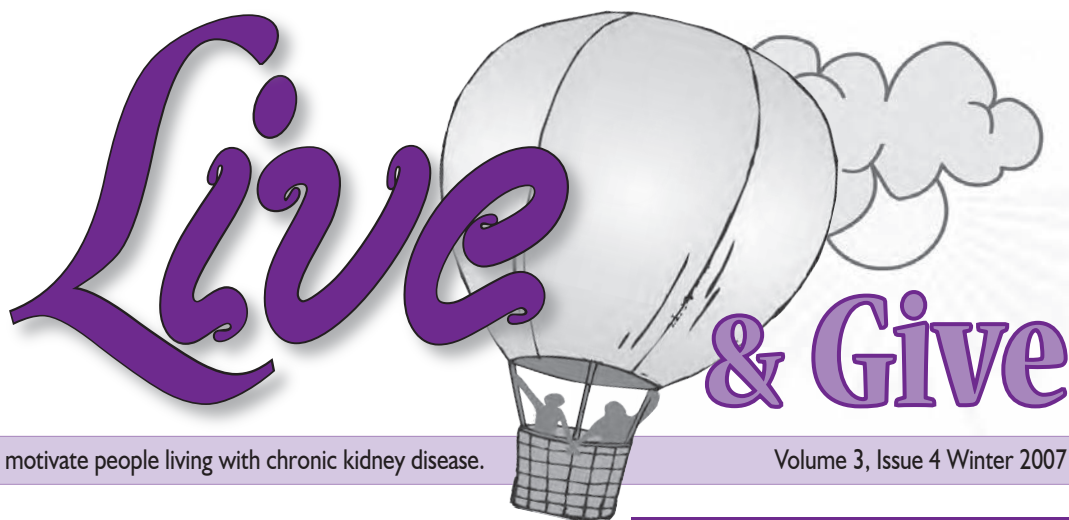




A PROGRAM OF
RSN
Renal Support Network



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

Volume 3, Issue 4 Winter 2007

Headline News

You Can Make a Difference!


During March and April there are two events that give you the opportunity to raise awareness about kidney disease.

On March 13, 2008, World Kidney Day will be observed around the globe. The purpose of World Kidney Day is to raise awareness about the importance of our kidneys and that kidney disease is treatable.

Last year celebrations occurred in 66 countries. In the United States, many members of weKAN—the Wellness & Education Kidney Advocacy Network—notified their city mayors and took part in public events. For more information, visit www.worldkidneyday.org.

April is National Donate Life Month during which people across

the United States make a special effort to celebrate the tremendous generosity of those who have saved lives by becoming organ, tissue, marrow, and blood donors, and to encourage more Americans to follow their example. To help spread the word about organ donation, you can find materials and information at www.donatelifeamerica.org or www.organdonor.gov.

The Renal Support Network encourages you to get involved. Please let us know how you are promoting World Kidney Day and organ donation in your city or state! Contact us at info@rsnhope.org or post your ideas on KidneySpace.com. 

RSN Report

KidneyTimes Essay Contest Winners

Proving that there is a large, untapped reservoir of innovative literary talent among people with kidney disease, more than 200 essays were submitted for the KidneyTimes 2007 Annual Essay Contest entitled “Aspirations for the Future: What Gives You Hope.” The essays—some serious, others humorous and clever, and all heartfelt—covered a wide variety of subjects and provided valuable insights into how

these special people coped with kidney failure in a spirit of courage, strength, and hope.

“The essays showed some remarkable talent,” stated Lori Hartwell, RSN Founder and President. “Some were so funny we fell out of our chairs laughing while others were thought-provoking and spiritual. The stories reflected remarkable people writing about how they overcame the

First Place Winner

“Hope Moments”
by Sherai Onibasa

Read it on page 8!


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Are You Prepared for a Pandemic?

challenges of their chronic illness. Narrowing these essays down to six winners was a real challenge.”

The first, second, and third place winners received checks for \$500, \$300, and \$100 respectively.

Winning essays and EasyLink Access numbers are listed on page 8. To read the essays, go to KidneyTimes.com and type the EasyLink Access number in the EasyLink Access search bar, or just go to the Hope section.

We appreciate the effort of everyone who participated! 

The Resilience of the Human Spirit

by Lori Hartwell, RSN President



I grew up believing that the blind could see. My grandfather taught me that. For instance, he could hear the ice cream truck

long before I could, and he always knew who was in the room. He would walk around the neighborhood by himself for hours, knowing exactly where he was and what was around him. The only difference between him and other people was that he carried a cane.

In the 1960s, knowledge about

diabetes and how to treat it was limited, and it led to my grandfather's blindness. He was healthy until his mid-50s, when he suddenly became very ill and lapsed into a diabetic coma. He did wake up, fortunately, only to discover that his sight was permanently gone. I can only imagine the shock and despair he must have felt.

Forced to embrace a new life, my grandfather became involved with the Blind Center. The people there helped him adjust to his new lifestyle and remain independent. He learned how to read Braille and "see" with a cane. Most important, he learned how to live again.

He was introduced to other blind people who became his friends and with whom he shared stories. He also learned to make beautiful ceramics, some of which I still display proudly on my mantel. My friends are surprised when I tell them that my blind grandfather made them.

These beautiful works of art remind me of how resilient the human spirit is. Tragedy can strike overnight or creep in over time, but I don't remember my grandfather ever complaining about his misfortune. He seemed very grateful to be alive, and he enjoyed

what life still had to offer. I'm sure he must have been frustrated, angry, and depressed at times, but he never showed these feelings to me.

To be resilient, people need to believe that they have a future and that they're valued. Healthcare professionals and my grandmother helped my grandfather take care of his medical needs, but it was the Blind Center that played a vital role in providing peer support. The center helped him develop a renewed sense of purpose, a reason to get up in the morning.

When our kidneys fail, we have to embrace a new life and learn how to live with the challenges we face every day. We never know when we'll serve as an example to others or witness an example of extraordinary courage and resilience. So much of my grandfather's spirit is manifested in RSN's mission. We provide support to fellow patients and believe that one friend can make a difference.

As a child, I had it right after all: my grandfather *could* "see!"

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.

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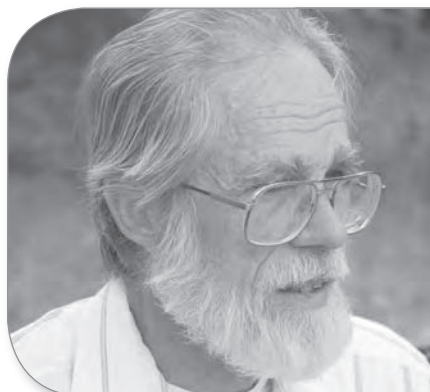
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Do you know someone with kidney disease who is an example of extraordinary courage and resilience?

Please let us know and we may feature him or her in a future issue of Live & Give!



If Only We Had a Crystal Ball

A Look Back and Ahead

by Kathe LeBeau, weKAN Project Manager

Advocating for legislative and regulatory issues has made this past year a very busy one for the kidney community, and 2008 promises to be equally challenging.

With all of the attention focused on the End-Stage Renal Disease (ESRD) Program by Congress and the Centers for Medicare and Medicaid Services (CMS), it is evident that change will occur in the coming years. It would be nice if we could look into a crystal ball to learn the outcome. However, if we're proactive and vocal on our own behalf right now, we might not need that crystal ball.

By the time you read this, the fate of the Kidney Care Quality and Education Act (KCQEA) of 2007, which we've worked so hard on all year, should have been decided. Find out what the verdict is by going to the Advocacy Pages at RSNhope.org.

Another very important piece of legislation, introduced in both the House and the Senate, is the Comprehensive Immunosuppressive Coverage Act (H.R. 3282 and S. 2320). We need to make sure Congress understands that it doesn't make sense to pay for a kidney transplant and not continue to pay for the medication that keeps the kidney viable. Returning to dialysis when a transplanted organ fails is more expensive than continuing the immunosuppressive medication required to maintain it. Let's help move this bill forward by encouraging our legislators to support it.

On the regulatory side, the Food and Drug Administration (FDA) held a hearing concerning the use and optimal dosage of erythropoiesis-stimulating agents, or ESAs, used to manage anemia. They established that patients with kidney disease should

maintain hemoglobin levels between 10 and 12 g/dL. In addition, an FDA advisory panel was also favorable to the use of phosphate binders in pre-dialysis patients.

Finally, CMS is redefining the

interpretive guidelines for the ESRD Conditions of Coverage, which will be released in final form

.....
Things are changing by the moment it seems, so we encourage you to get informed and get involved.

at the Annual CMS/ESRD Network Meeting in February.

These are the criteria that healthcare providers must meet in order to receive funding from the Medicare and Medicaid programs. These health and safety standards are the foundation for improving quality and protecting the health

and safety of beneficiaries.

Things are changing by the moment it seems, so we encourage you to get informed and get involved. While we can't predict exactly what the future will look like without a crystal ball, we can help move things in the right direction. Visit the Advocacy Pages at RSNhope.org for updates on these and other legislative and regulatory issues. And please, as a person with kidney disease, or as a family member or friend, become proactive now! ☞



Diagnosed with kidney disease in 2004, Kathe LeBeau began home hemodialysis in April of 2006, and is presently on the kidney transplant waiting list.

She is the Project Manager for Renal Support Network's weKAN group, and is also a PEPP speaker and HOPEline operator. Kathe lives in the Capital Region of New York State with her husband of 11 years, Loren Fadding.

Few will have the greatness to bend history itself, but each one of us can work to change a small portion of events, and in the total of all those acts will be written the history of this generation.

— former U.S. Senator Robert Kennedy

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Bonnie Was Chosen

by Sharon Pahlka, weKAN Patient Activist, PEPP Speaker

Bonnie (Parks) Markuson knew something was wrong when she started wetting the bed in first grade. Her parents did everything they could to help her, but the doctor said she was just lazy and didn't want to get up. No one had any idea that her kidney function was almost gone.

In 1966, Bonnie was referred to the University of Washington

Hospital in Seattle and diagnosed with renal reflux. At age 13, surgeons tried to protect her kidney function by repairing her ureters, but two

years later she started experiencing many of the classic signs of kidney failure. She needed dialysis.

A few years earlier, in 1961, the first "artificial kidney center" in the world was under construction in Seattle, but it didn't have enough kidney machines for the people who needed them. And so that summer, a lawyer, a minister, a banker, a housewife, a state government official, a labor leader, and a surgeon were selected to help choose the best candidates to use these few machines. This group became known as the "Life or Death Committee."

These anonymous volunteers served without pay and few of them knew each other. They didn't meet any of the candidates for dialysis and instead based their decisions mostly on paperwork and input from doctors. With no moral or ethical guidelines except for their own consciences, their

job was to choose who would receive dialysis and who wouldn't—quite simply, who would live... and who would die.

None of the committee members had ever heard of Bonnie Parks, on whose life they would have such an enormous impact. She was chosen to live.

These were the first years of dialysis, and everyone was learning.



Bonnie started peritoneal dialysis (PD) under Dr. Henry Tenckhoff, using his newly invented catheter and a machine on loan from the University of

Washington. Bonnie dialyzed for 24 hours that first time, and her parents were shocked at how much better she looked afterward.

Bonnie continued use the PD machine at home three times a week for nine to 12 hours. She did most of the hookup herself with some help from her mother, and even ordered her own supplies. "I felt empowered by this," Bonnie remembers, "and my parents wanted me to be independent."

Other challenges arose. "Bonnie Parks Needs Donations for Machine" was a sign you would have seen all over the Seattle-Tacoma area in 1969. The machine she was using was on loan, but now she needed to buy one of her own. The newspaper clippings Bonnie and her family saved tell of the many fund drives that took place; even the convicts at McNeil Island joined the effort. Everyone wanted to help.

Bonnie was on dialysis for a little


over four years before receiving her first transplant in 1972. It functioned for 26 years, and a few days before she was scheduled to initiate dialysis again she got a call for her second transplant. Both were a "perfect match," and the second one has been working well since 1998.

Bonnie has been through a lot, but feels very fortunate to be living at a time when medical progress is so rapid. It's never occurred to her to ask, "Why me?"

She's worked since she was 18 and will retire in a few years. She says, "When I retire, I'd like to visit and encourage patients who need help and feel alone. Today's patients seem to be isolated and don't understand the experiments and sacrifices that went into keeping us alive. They don't know the price that was

paid so we could live."

Bonnie doesn't think of the Life or Death Committee very often or of what would have happened if

she hadn't been chosen. She just knows the importance of making the most of her life and of giving back to others. After all, she was chosen to live. 



Sharon Pahlka has lived with kidney disease for over 30 years—19 on dialysis and the last 14 with a transplant. As a Certified Life Coach, she specializes in coaching people with chronic health challenges to fulfill their dreams (www.lifeisagift.com). Sharon also helps caregivers maximize their effectiveness, speaks nationally, and writes for various publications. She fills her spare time with travel and adventure.

The Early Days of Dialysis

by Richard F. Drake, MD

Today there are many dialysis centers, and many patients receive intermittent dialysis. Although it might seem that those with kidney failure have always been able to get treatment and live, before 1960 most had no option other than to die. A few patients—very few—received transplants.

It was in this setting that Dr. Belding Scribner, of the University of Washington Medical School in Seattle, decided to use a new treatment called dialysis on five patients with permanent kidney failure.

That's when medical advances in the Northwest began to play a major role in treating patients with end-stage renal disease.

Many felt that Dr. Scribner's treatment wouldn't work. Everything about it was a learning experience, and many questions needed to be answered: For example, how long should a patient be on the machine? How could phosphorus be prevented from accumulating in the body? Although questions still remain, we've learned a great deal since the early 1960s.

During this time, I met an inventor named Charles Willock. Together, we designed a hemodialysis machine that solved some

of the problems with the existing equipment. The machine was first used in Oregon at Portland's Good Samaritan Hospital in 1963. This pioneering piece of equipment allowed patients to perform dialysis at home, and made it easier to administer dialysis in a hospital as well.


Within a year, we'd started a home dialysis training program at Good Samari-

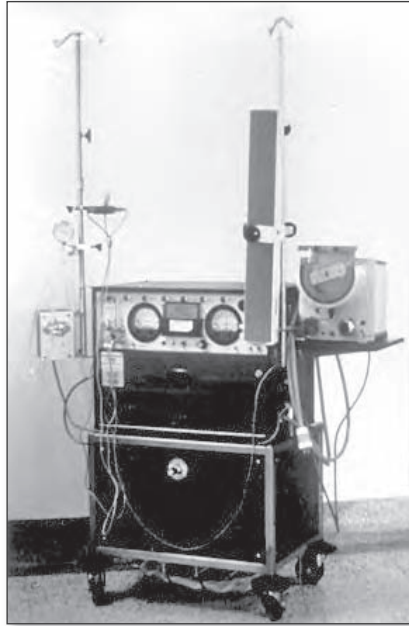
tan. Between 1963 and 1975, the Drake Willock machine, manufactured in Milwaukee, OR, set the standard for hemodialysis equip-

ment and came into world-wide use. Company employees played a key role in maintaining contact with patients as far away as Australia.

Many people—such as the home training staff and the people who raised the funds that were needed—helped dialysis patients during this period. But then, as now, patients themselves played a major role in their care.

Home dialysis patients learned a great deal about the influence of diet and would dialyze extra runs if they became overloaded with fluid. The knowledge they gained from their own experiences helped improve the care of others. Incidentally, according to studies done in Europe, home dialysis patients had the longest survival rates of any chronic dialysis patients at that time.

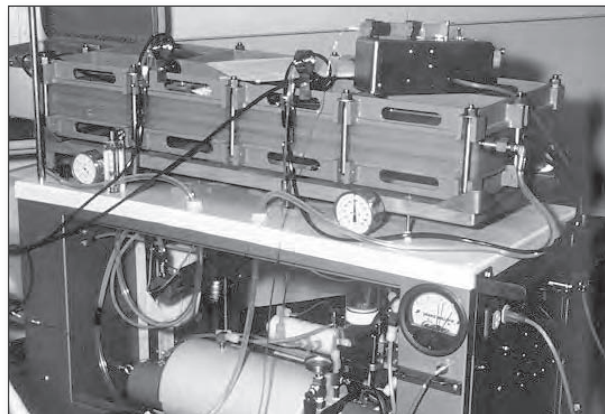
Dialysis and transplantation continue to advance, but it's still essential that patients learn about their condition and become involved in their care for treatment to be successful. 



This Drake Willock machine, the 4015 model, was widely used throughout the world from 1965 through the '70s.

From 1967 to 1975 the Drake Willock machine became the principal dialysis delivery system used in the United States, Canada, Australia, New Zealand, and Europe. The company provided machines for Tito of Yugoslavia, Marcos of the Philippines, General Song of Korea, and possibly Andropov of Russia (no information was given to the company once the machine entered Russia).

Below: Early model Drake Willock machine using a Kiil dialyzer (1963-1964).



Dr. Richard F. Drake practiced nephrology in Oregon for over 30 years after receiving his medical degree in 1959 from the University of Oregon Medical School. In 1964 he was co-inventor of the Drake Willock dialysis machine and also launched the first home dialysis training center in Oregon. Dr. Drake is now retired but remains involved in the kidney community.

A Timeline of Dialysis

Remember the days when aluminum phosphate binders made you cough white “smoke” or when peritoneal dialysis solution came in glass bottles? Maybe your hemodialysis bath was made with acetate, not bicarbonate, or you had a Scribner shunt sticking out of your arm or leg. Perhaps a relative or friend died because there weren’t enough dialysis machines to treat everyone.

Dialysis has come a very long way in a short time, and many people who dialyzed during the 1960s and 1970s are still alive today. Machines and procedures have improved rapidly over the past few decades, and there are many physicians, inventors, researchers, and fellow patients to thank for their perseverance and hope. Someday you may be able to tell your grandchildren about “those old-fashioned computerized machines” and “the big needles that poked my arm,” while a kidney created from your own cells keeps you healthy.

Be thankful for dialysis now, and keep dreaming about the future!

Read more dialysis history at KidneyTimes.com. Click on For Hope, then Treatment Advances.

Early “Dialysis” Treatments

Blood letting, hot baths, and sweating therapies are used to remove toxins from the blood

1825 - 1845

In England, Richard Bright, MD—dubbed “Father of Nephrology”—is the first to study kidney problems

1861

The term “dialysis” appears for the first time in a paper written by Thomas Graham, a Scottish chemist

1913

John Abel, MD, develops the first artificial kidney for animals at Johns Hopkins University in Baltimore, MD, and publishes the first description of the process

1923

First successful peritoneal dialysis treatment performed by Georg Ganter in Germany

1928

George Haas, a German doctor, is the first to use heparin as an anticoagulant instead of Hirudin (extracted from leech heads); he is also credited as the first to dialyze a human patient

1940s and 1950s

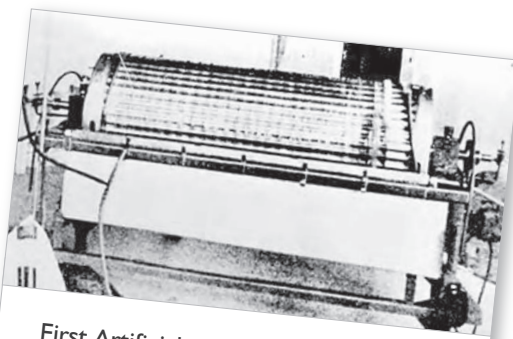
Throughout Europe, Canada, and the United States, interest in dialysis increases and researchers develop many new dialyzers and machines, building on past successes and learning from failures

1942

In the Netherlands, Willem H. Kolff, MD—known as the “Father of Dialysis”—develops the first artificial kidney, a rotating drum

1945

First patient successfully dialyzes with Dr. Willem H. Kolff’s Rotary Drum Machine



First Artificial Kidney - Rotating Drum
Designed by Dr. Willem H. Kolff, 1942



Dr. Willem H. Kolff, 1950s
Brigham-Kolff Rotary Drum Machine



First Home h
of the Seattle A
Using “Mini-Mo

1975 and beyond...

Technology continues to evolve, outpatient dialysis clinics become the norm, dialysis is more effective than ever, home dialysis gains popularity, and machines continue to become smaller and more portable.

The next breakthrough is just around the corner!

1975

Willem H. Kolff, MD, introduces the Wearable Artificial Kidney

1973

Congress passes a bill establishing the Medicare End-Stage Renal Disease Program to provide access to treatment for all patients in the United States

1968

Henry Tenckhoff, MD, improves an existing peritoneal dialysis catheter; the Tenckhoff catheter continues as a commonly used catheter today

1966

James Cimino, MD, creates the first internal arteriovenous (AV) fistula

1962

The "Life or Death Committee" is formed in Seattle, WA, to choose who will be able to use the few dialysis machines available

1960

Fred S. T. Boen, MD, invents the first automated peritoneal dialysis machine

1960

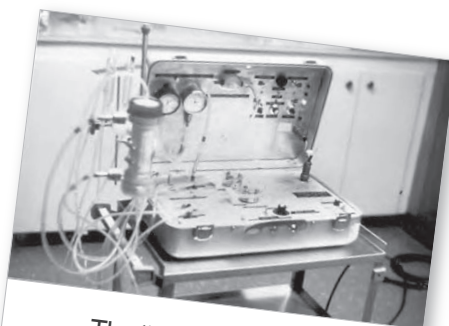
Belding Scribner, MD, invents an external shunt from non-stick polytetrafluoroethylene (PTFE) that could remain permanently in the patient

1959

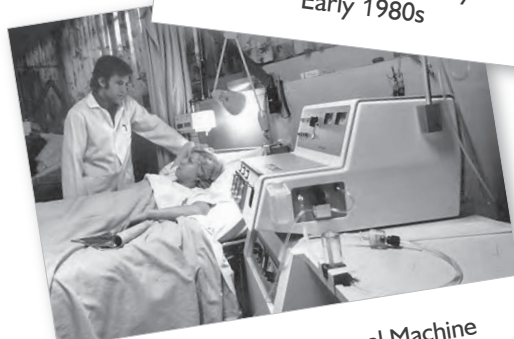
Fredrik Kiil of Norway develops a parallel plate dialyzer which could be used without a blood pump; the Kiil Dialyzer remained in use for many years

1952

Arthur Grollman, MD, publishes a book that describes the intermittent method of peritoneal dialysis which is still used today



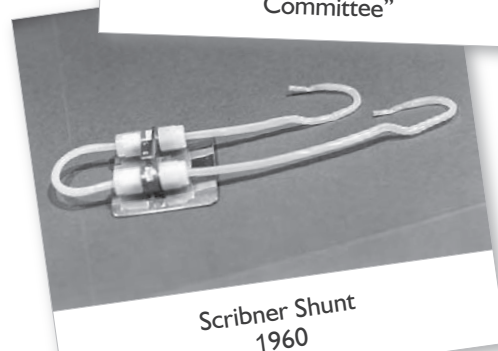
The "Suitcase Kidney"
Early 1980s



Physio-Control Peritoneal Machine
Early 1970s, Seattle, WA



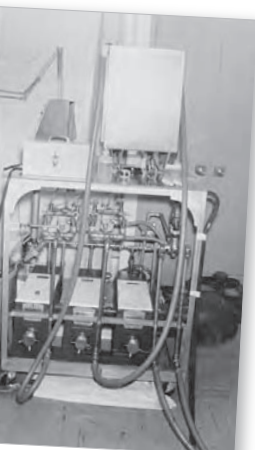
The "Life or Death
Committee"



Scribner Shunt
1960



Kiil Dialyzer Being Built
Early 1960s



"The Monster" Dialysis
Machine, 1963



Hemodialysis Patient
Artificial Kidney Center
"Monster" and Kiil Dialyzer

2007 KidneyTimes Essay Contest 1st Place Award

Hope Moments

by Sherai Onibasa, PEPP Speaker

There's hope
It doesn't cost a thing to smile
You don't have to pay to laugh
You better thank God for that.

- India Arie

The R & B artist, India Arie, caught on to the essence of "hope" when she created the above lyrics. It's the simple things in life that give me hope: smiles from infants, laughter, nature's beauty, dew in the morning, the sun shining brightly on a summer day, or the sound of the waves crashing against some rocks. You can't place a price on these things. They are precious, and the joy I experience from these things gives me hope because I can allow myself to bask in the moment and simply enjoy life.

I like to explain this experience as an identified moment that lodges itself in the midst of a deep breath. Think about it... inhale... exhale. It's that split second that nestles between inhale and exhale that I call my "hope moment." These "hope moments" give me the energy that I need to help me achieve the goals that I have in life despite my kidney disease.

The "hope moment" can be described as that moment of silence where there is nothing happening ex-

cept you and your thoughts. It's that moment that temporarily suspends life and brings you an inner peace. It allows you to forget about your troubles, relax, and even think about what is going to come next. It represents potential. Specifically, it gives me permission to focus on tomorrow.

Yes, in that split second... Think about it... Inhale... Exhale... I believe it's the tomorrow factor within the "hope moment" that allows me to continue to participate in life rather than to simply observe it. It's the participation in tomorrow that fuels my aspirations for the future. So, what does the future hold? I don't know, but I do know that, if I don't look forward to tomorrow, then I won't have any hope for today.

Tomorrow represents opportunity. It's another chance to have a "do over." With tomorrow, I can make amends. With tomorrow, I can try it again. With tomorrow, maybe that



Sherai Onibasa is a graduate from UC Berkeley. She began peritoneal dialysis four years ago and is presently on the transplant list. She holds a Master of Arts in Psychology and currently manages a non-profit agency that works with youth in the community. She lives in Carson, CA, with her husband Richard.

laugh that I didn't get to have today will come. With tomorrow, the possibilities are endless, and just thinking about those possibilities in that "hope moment" gives me what I need to press on. Go ahead... inhale!... exhale!... Are you getting it yet?

I believe that my "hope moments" have a lengthening effect on my life because they allow me to be grateful for the things that I have today. This is so important because, in spite of my circumstances and all that I go

through, the simple truth is many people don't have "hope moments" because they don't get another

tomorrow. So as long as I am still around, I will smile, laugh, observe the beauty of nature, and enjoy all of the "hope moments" that life has to give me!

As a dialysis patient, you can experience many not-so-good days. A day that is filled with lengthy doctor appointments, multiple needle sticks, and/or chronic pain can really put a damper on your mood.

However, for me, that thought of, "if I can just make it to tomorrow," gives me that little glimmer of hope that I often need to make it through the rest of the day. The idea of looking forward to something rather than focusing on the unpleasantness that I may be experiencing is what tomorrow is about.

So, when the challenges are abundant in a day, I simply inhale... exhale... and enjoy that "hope moment."

Doesn't that feel better? ☺

To read other winning essays:
Go to KidneyTimes.com
Click on "For Hope"



KidneyTimes™
Health Information Beyond The Ordinary

Home of
the Annual
KidneyTimes
Essay Contest

Essay Contest Winners:

First Place: "Hope Moments" by Sherai Onibasa *EasyLink Access #236*

Second Place: "Celebrate the Day" by Beverly Betts *EasyLink Access #235*

Third Place (tie): "A Man Named Mr. Black" by Elizabeth Churilla *EasyLink Access #233*

Third Place (tie): "Hope is Love" by Margaret Sewell *EasyLink Access #234*

Special Prizes:

Most Inventive: "The Big D" by Michael Doyle *EasyLink Access #232*

Junior Achievement: "Hope is Harmony" by Raul Lozada *EasyLink Access #231*

KidneyTimes.com is made possible with support from Roche.



A Healthy Heart

by Allan H. Sklar, MD

Hearts. We see them everywhere as Valentine's Day approaches. But the heart you can't see is much more important and needs your attention every day of the year.

Heart disease represents the greatest threat to the health of Americans, and those with kidney disease—

.....
There are steps you can
take to reduce your risk
of heart disease.
.....

especially if they have diabetes mellitus—appear to be at highest risk. The well-known risk factors include hypertension, diabetes,

high cholesterol, and tobacco products. In patients with kidney disease, fluid overload and anemia also weaken the heart.

There are steps you can take to reduce your risk of heart disease. As you read the following list, think about how you can apply each item to maintain good heart health, then discuss your plan with your doctor.

Blood Pressure

First and foremost, understand that your blood pressure needs to be kept under control with predialysis and postdialysis levels to be determined by your doctor. Home blood pressure readings are probably a better indicator of control than in-center measurements.

Fluid

Minimize your weight gain between dialysis treatments to below 1% to 2% of body weight per day and achieve as close to dry weight as possible. Limit your salt and fluid intake to the bare minimum in order to accomplish this.

Blood Hemoglobin

Maintain a hemoglobin level of 10 to 12 g/dL with the use of erythropoietin and iron products.

Blood Sugar

Keep your blood sugar under good control. Your hemoglobin A1C, an important measure of long-term control, should be less than 6.5%.

Cholesterol

Maintain your blood lipids in a safe range with proper diet, exercise, and (possibly) medication.

Phosphorus

To minimize arterial calcification, keep your phosphorus under control by limiting the amount of phosphorus in your diet and using (primarily non-calcium containing) oral phosphate binders.

Inflammation and Infection

Whenever possible, reduce chronic inflammatory or infectious conditions—for example, by correcting gum disease. If you develop a fever, be sure to notify your healthcare team immediately.

Aspirin Therapy

Talk to your doctor to see whether aspirin therapy is a good option to reduce the chance of blood clots.

Vitamins

It is essential for dialysis patients to replace essential vitamins. The jury is still out on whether supplementing with antioxidants—such as vitamins C and E, as well as with high doses of B6, B12, and folic acid in an attempt to decrease potentially harmful levels of homocysteine—is valuable in diminishing the risk of cardiovascular disease in those with kidney failure.

Diet

Adhere to a heart-healthy diet by limiting your intake of calories, saturated and trans-fats, and refined carbohydrates.


Exercise

Since moderate exercise is always beneficial to heart health, ask your doctor which types of exercise would be safe for you.

Stop smoking!

This is of utmost importance. If necessary, use aids such as the nicotine patch and nicotine receptor blockers.



Give yourself a Valentine's Day gift by taking care of your heart. It's a gift that will give you life! 

Excerpted and adapted with permission from *The Kidney Bean* (Binghamton, NY), Spring 2004.



Allan H. Sklar, MD, graduated from McGill University School of Medicine in 1976. He is a solo nephrologist in Blacksburg, VA, and has a teaching affiliation with Virginia Tech. He has published several articles on dialysis subjects, including hemodialysis prescription and postdialysis fatigue.

*It is only with the heart that
one can see rightly; what is
essential is invisible to the eye.*

— Antoine de Saint-Exupéry

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Tips to Remember



Are You Prepared for a Pandemic?

by Wendy Funk Schrag, LMSW, ACSW

What's a pandemic? Are you prepared for one?

A pandemic is a flu outbreak that occurs after the appearance of a new type of influenza virus that people have not been exposed to in the past. The virus spreads quickly from person to person.

States and the federal government are working on local and national pandemic preparedness plans, and the dialysis industry has implemented a national pandemic response team of its own. This team is part of the Kidney Community Emergency Response (KCER) Coalition, which was formed in 2006 in response to Hurricane Katrina.

Currently, the coalition includes nine teams—one being the pandemic response team—that are working to improve the emergency preparedness response of the dialysis industry. The Renal Support Net-

work has two representatives on the pandemic response team—Kathe LeBeau and John Garcia. Information about this team's activities and the coalition as a whole is available on the KCER website at www.kcercoalition.com, along with a host of other resources. Of specific interest to people with kidney disease is the patients' pandemic preparedness checklist at www.kcercoalition.com/pdf/pandemicfluplanningchecklist.pdf.

What can you do to prepare for a pandemic?

First, educate yourself. In addition to the coalition's website, some good resources are www.flustar.com,

which has user-friendly information about flu outbreaks in the United States, and

www.pandemicflu.gov, which monitors outbreaks around the world.

Second, to keep your body strong and able to fight disease, see that all your normal vaccines are current.

Third, contact your local health department and make sure staff members know about the unique needs dialysis and transplant patients may have (such as transportation to dialysis and special dietary requirements) during a pandemic or emergency. Offer to serve as a resource for them.

Finally, be proactive. Watch for more information from your dialysis clinic staff, and be prepared so that you can inform others.



Be Prepared

Blizzard, flood, fire, earthquake!

Basic Emergency Preparations

- ✓ Carry important medical information with you at all times.
- ✓ Ask your facility about how to find out about alternative arrangements for treatment.
- ✓ Pack an emergency stock of supplies, food, and medicines to bring with you if you have to leave your home quickly.
- ✓ Know what diet to follow if your dialysis must be delayed.
- ✓ Check your regular prescription drugs to make sure you have at least a two-week supply at home.

To learn how to be prepared for *any* emergency as a dialysis patient, ask your dialysis facility for a copy of "Preparing for Emergencies: A Guide for People on Dialysis" published by the Centers for Medicare and Medicaid Services. It's also available on our website. Go to RSNhope.org and click on Resources.



Wendy Funk Schrag is the Director of Advocacy and State Government Affairs for Fresenius Medical Care North America. She also worked as a dialysis social worker for 16 years.

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Glendale, CA 91207

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Searching for a Solution

Continued from page 12

I was so excited. What could possibly go wrong?

I've probably lived most of my life keeping an eye out for the other shoe to drop; it did. We were ready to go after innumerable blood tests and examinations. There was only Marla's final MRI (magnetic resonance imaging) scan before the scheduled surgery. Plans abruptly halted as the test showed a small growth on one of her kidneys.

The surgical team was astonished but adamant: no transplant. The growth was cancerous, and the kidney was removed. Who had saved whom? Of course, I was glad that Marla's cancer had been discovered and treated, but saddened that I was no closer to a solution.

The following year, I got an e-mail from a former student, Marco, who offered me one of his kidneys, despite being fearful of being "cut." There were more tests, blood work, and appointments and finally another trip to Baltimore in 2004. The tests included a liver probe that raised my liver enzymes way beyond normal. The

operation was scrubbed.


For the next two years, I continued to deny that my body was showing the effects of failing kidneys. I was pale and listless, but still determined to avoid dialysis. The toxicity increased, making me itch constantly and take long naps. I found my energy, appetite, and passion for life dwindling and finally agreed to dialysis on May 22, 2006. I still hoped for a transplant, though I finally admitted it might not be an option for me.

Then a friend in California sent me an article explaining that "extended-criteria" kidneys that may have been damaged by the medical condition of the donor are often given to people who have few transplant options. Although these donor kidneys may not last as long as healthier ones, they have proven a viable option for many recipients. I discovered that the Presbyterian Hospital in Albuquerque, NM, had just such a list and I applied, thinking that it was a last chance to get off dialysis.

Everything came together seam-

lessly on February 18, 2007. To everyone's surprise the extended-criteria kidney ended up being very healthy.

Having a working kidney has transformed my life, my attitude, and my mission. I'd been given a miraculous second chance and knew what I had to do with it. Though I can't personally thank my donor, I *can* do my best to make sure that others have the same opportunity. I'm committed to spreading the word about donor registration, live donors' "gift of life," and getting a simple test to detect possible kidney disease.

Approximately 70,000 people are awaiting kidney transplants. I'll do whatever I can to reduce their wait. 



After less than a year on dialysis, Mary Lou Newburn received a kidney transplant. She keeps busy in her community—increasing donor awareness, teaching social studies to GED students, and helping at church-sponsored charitable activities. She loved a recent hot-air balloon ride, and continues to fly high on life.



*In this issue of Live & Give...
Timeline of Dialysis History*

Perspectives



Searching for a Solution

by Mary Lou Newburn, weKAN Patient Activist

When I was 22, I thought of myself as a college hotshot. That changed when I was diagnosed with Type 1 diabetes (formerly "juvenile diabetes") and told to follow a new lifestyle revolving around rules and restrictions. My reaction was to deny what I saw as weakness. I didn't tell anyone that I had diabetes.

Things changed as the years and



Mary Lou enjoys a hot air balloon ride after her transplant.

decades passed. The disease began to command my full attention. A nephrologist first mentioned transplantation in 2001 because my clearance level (the amount of waste filtered by my kidneys) was dropping quickly, but even this wasn't enough to pull me out of denial. It took a sterner nephrologist to note an 18% clearance rate and offer me two options: transplantation or dialysis. I decided to concentrate on finding a living donor.

In 2003, my good friend Marla was searching the Internet and found that Johns Hopkins Hospital had a program facilitating incompatible organ donors. Through plasmapheresis, my type O blood could accept her type AB blood and she would become my donor.

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Fresenius Medical Care



Calendar

Renal Teen Prom

January 20, 2008 (Sunday)

Sherman Oaks, CA

Theme: Winter Elegance

RSN Regional Patient Lifestyle Meetings

March 30, 2008 (Sunday)

Iowa City, IA

Go to RSNhope.org to register online for a meeting, check the latest calendar listings, or download a meeting flyer.