



A PROGRAM OF
RSN
Renal Support Network

Live & Give

Volume 7, Issue 1 ♦
Spring/Summer 2011

The bi-annual update helping to educate and motivate people living with chronic kidney disease.

RSN Report



Making the Magic Happen

by Malia Langen

Michael Grasso's life has been filled with magic. Not only has he been a professional magician for nearly two decades, but he has experienced the "magic" of transplantation three times over. On Sunday, January 16th he shared his talents and the lessons he has learned as a kidney survivor with 400 young kidney patients and their guests who gathered for RSN's 12th annual Renal Teen Prom held in Sherman Oaks, California.



Fans of *America's Got Talent* will remember Michael as a finalist in last season's competition. During the show he shared that he had received three kidney transplants, all from living donors. As Michael's story was shared with a national audience, new opportunities

arose. Professionally, the show took Michael's career to a new level. Within the renal community, we realized there

.....
Magic Happen; Continued on page 5



Jack Black once again graced us with his presence at the 12th annual RSN Renal Teen Prom. He gave a fun filled performance on stage and made all of the young people feel special. Here he is pictured with Rebecca Soto (Las Vegas, NV), on the left, who is on dialysis, and her friend Taylor Jackson.

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We're Bringing Pasta Back

How it Works



How the Transplant Waiting List Works

by Jacqueline Harris, RN, BSN, CCTC

The kidney transplant waiting list is a list of transplant candidates maintained by the United Network of Organ Sharing (UNOS). UNOS holds the contract to operate the Organ Procurement and Transplant Network (OPTN).

How do I become eligible to be placed on the waiting list? A referral is needed from your physician in order to be evaluated by a transplant program as a potential transplant candidate. Your next step would be to select a transplant hospital, with factors to consider including location, compatibility with your insurance program and financial arrangements. Once you have selected a hospital, schedule an appointment for an evaluation to find out if you are a candidate for transplant. During the evaluation, ask questions to learn as much as you can about that hospital and its transplant team. If the transplant team members determine that you are a suitable transplant candidate, they will add you to the national list of all people waiting for a transplant. Your transplant center will be requesting laboratory tests from your dialysis facility to keep your blood samples up to date.

How long is the wait for a kidney? The average wait time for a kidney

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Transplant Waiting List; Continued on page 7



Managing Multiple Medications

by Lori Hartwell



I have taken enough pills in my lifetime to choke several horses! (I am sure you have taken your fair share, too.) At this point, I believe that my 42

years of pill taking have qualified me for a PhD in pillology, so I thought I would share a few tips that I have learned along the way. There are a lot of issues that I could cover, but for now I will limit my comments to two general categories—medication safety and medication adherence.

It is always important to check your medications when you get them to make sure the pharmacy didn't inadvertently give you the wrong prescription. This has happened to me on more than one occasion and is a definite safety and health concern.

Once you have the right medications, you need to decide where to store them. The bedroom (not the bathroom medicine cabinet) is one of the best places to keep medications because it is likely that the temperature and humidity will be more constant. Changes in temperature, humidity, and exposure to light can sometimes cause medications to become ineffective or dangerous.

When deciding where to store your medications, you also want to make sure to consider the safety of others in your household. If you have children or pets, make sure that the medications are out of their reach (remember that for children the definition of "out of reach" changes with age). If you have houseguests, you may want to consider whether you should temporarily put your medications in a different location.

Adherence to the prescribed medication schedule is also vitally important. Taking the right medication at the right time at the right dose is

an acquired skill. Adherence ensures transplant and dialysis success!

Right now, I have 14 bottles of medications on my bedroom dresser (I obviously have no children or pets that can reach them). For me, having the meds visible reminds me to take them. To help me organize my prescription bottles, I label the top of my medications with colored happy face stickers. For example, I use green for morning, yellow for lunch, and red for nighttime. I use an additional orange sticker to identify blood pressure medications, and a purple sticker to identify "as needed" medications.

It is vital to know the correct time to take each medication, and each medication can be different. For example, phosphate binders need to be taken with meals and snacks. If a medication makes you sleepy, ask your doctor if it is possible to take it at bedtime. Some meds may also need to be taken on an empty stomach. Transplant meds must be taken at the same time each day to maintain constant levels in the bloodstream. Oftentimes the directions on prescriptions are not very clear. For example, the label



may simply state "take twice a day" without providing guidance about the best time of day. If you have questions about when to take your medications, you should check with

“Taking the right medication at the right time at the right dose is an acquired skill.”

your doctor.

I take most of my meds either in the morning when I get up or at bedtime, so I have not found a need to set an alarm for those times. I do set my phone with an alarm to remind me when to take my lunchtime medications. It may be a good idea for you to set an alarm for all medication times if you are new to the whole pill popping game. Taking phosphate binders with every meal can also be a challenge, but I have found that the key is to have them everywhere—I have them on the dining room table, in my purse, and on my desk.

Learning to order medications properly is another necessary skill. Often medications have different refill dates, so you may feel like you are continuously ordering prescription refills.

Consider the following when managing your refills. For each medication, you should ask yourself questions such as: How many refills do I have left? Do I need to get any blood tests before ordering my refill? Do I need to talk things over with my healthcare team before ordering refills? How long does it take to get my medication?

For example, my insurance company requires me to get many of my medications by mail order, which can take up to 10 days. Be on the ball to make sure you aren't paying

HOPEline

If you have chronic kidney disease
and don't know what to expect call

Si tiene enfermedad renal crónica
y no sabe que le espera

English
1-800-579-1970

Español
1-800-780-4238

Support from someone
who's been there.

Monday-Friday 10am-8pm (PST)



alguien que ya estuvo ahí
le ofrece su apoyo.

Lunes-Viernes 10am-8pm (hora del Pacífico)

overnight shipping fees.

When calling in a mail order refill and dealing with the frustration of an automated system you may need to play soft music and have a puppy on your lap to pet and calm your nerves. On many occasions I have found myself yelling “operator” like a mad woman in the receiver, hoping that their voice recognition system would understand my words, only to be prompted back to the very beginning. I have learned that, for the mail order house I use, using the term “representative” instead of “operator” is the key to talking to a human being. Although mail order pharmacies are a reality for many of us, I like going to the corner drug store whenever possible. Besides being easier, you can have face-to-face contact with an actual pharmacist, and you can check your meds on the spot.

I always keep a medication list in my wallet and in my Smart Phone. It is not only impossible to remember all the names, times and doses, but I also impress healthcare professionals when I whip out the list. I also have given this list to my family in case of an emergency. A great website called MyMedSchedule.com has helped me create, update and print my list of meds—it also provides some pictures of the medications.

Finally, if you have any questions about your medications at any time, don't be shy about asking your doctor. There are undoubtedly many more tips that I could provide on medication safety and adherence, but my time has run short—I need to go take my meds!

What is EasyLink Access?

KidneyTimes.com has a simple way to locate articles and podcasts.

With an EasyLink Access number you can simply go to the KidneyTimes.com homepage and type the number into the EasyLink Access box, pictured on the right. Once you click GO it will quickly bring up the article you are requesting. This makes it easy to recommend specific articles to others.



MEDICATION RESOURCES

Medication Financial Assistance

Go to RSNhope.org/resources and click Learn More under Medication Assistance Programs.

KidneyTimes.com

Medication Safety—Get it Right!
by Denise Eilers
EasyLink Access #: 525

Medication Reconciliation: A
Practical Guide For Dialysis and
Transplant Patients
by Matt Schonder, RPh, MBA,
and Kristine S. Schonder,
PharmD
EasyLink Access #: 289

Tips on Adhering to a Medication
Regimen For the Dialysis and
Kidney Transplant Patient
by Tiffany Strohmeyer, PharmD
EasyLink Access #: 162

Generic Medications: Are They
Right for You?
by Kristine S. Schonder, PharmD
EasyLink Access #: 264

Medication Tips
KidneyTalk podcast with Michael Josbena, MS, RPH
EasyLink Access #: 355

Why Kidney Patients Need a Primary Care Doctor

by Mandy Trolinger MS, RD, PA-C

When someone asks who your primary doctor is, do you think of your nephrologist or primary care physician? If you are a kidney patient you most likely see your nephrologist more than your primary care physician (PCP). You might ask “Why do I need a PCP?” PCPs not only treat acute illnesses, but also provide preventive medicine as well. As a kidney patient and healthcare provider I have learned over the years why I need BOTH, my PCP and nephrologist.


Kidney patients are at increased risk for certain diseases and conditions, which is why preventive medicine is important. The leading cause of death in kidney patients is cardiovascular disease; for example, heart attacks and peripheral vascular disease. Other risks in the kidney patient population are bone health, immune system function, cancer, depression and polypharmacy (use of multiple medications). Most of these conditions can be managed by your PCP, however, there are a few cases where your nephrologist might treat you instead, such as bone disease. Bone disease in a kidney patient can be influenced by several factors that could be related to kidney disease. There are screening tests, lifestyle changes and medications that can manage and even prevent these medical problems. Your PCP can coordinate your medical care, consulting with your nephrologist when necessary, and make sure you undergo medical screening when appropriate, along with managing your medications.

Preventive medicine not only helps you live a longer and healthier life but it also keeps your medical costs down. The United States Preventive Services Task Force (USPSTF) is a panel of experts (internists, family physicians, pediatricians, health behavior specialists, etc.) that review scientific evidence on clinical preventive services and creates recommendations (See Table). These recommendations are written for the “general” population and are updated as needed, so it is important to discuss with your PCP which recommendations are most appropriate for you. In addition, PCPs can make sure you are up to date on immunizations. The Centers for Disease Control and Prevention (CDC) provides an immunization schedule to

guide practitioners (www.cdc.gov/vaccines). This is especially important for kidney patients, as complications from the flu or pneumonia can be fatal.

Not all health events are directly related to kidney disease, but require the medical specialty of another branch of medicine (i.e. cardiology, oncology, etc.). To prevent and manage other health events, optimal communication between various medical specialists is essential. Your PCP can serve as your liaison or “home base” for your healthcare. Any time you see a specialist make sure they have your PCP’s contact information, so they can send a copy of your records to your PCP. It is also a good idea to get copies for yourself at every doctor appointment and keep your “own” medical file. PCPs practice in internal medicine or family practice. Family practitioners see patients from birth to geriatrics, where internal medicine physicians focus on adult medicine only. Both of these physicians can provide primary care medicine and

preventive health care services.

Remember YOU are the most important part of your healthcare team and open communication is necessary to receive quality healthcare. Having a healthcare provider that can help you coordinate your healthcare among multiple specialists and who is knowledgeable/current on recommendations for overall health is of great benefit. Below is a listing of some of the guidelines by USPSTF; keep in mind other organizations’ recommendations might differ slightly and you need to discuss with your PCP which ones are best for you. It can be difficult coordinating care when you have several providers, conditions, and medications, and having a PCP can make it manageable. It has certainly helped me. 



Mandy Trolinger MS, RD, PA-C worked as a renal dietitian before becoming a physician assistant. She has been on hemodialysis, and is a two-time kidney transplant recipient. In her spare time she volunteers, exercises and spends time with her husband and pets. She resides in Highlands Ranch, CO.

Topic	Description/ Recommendation
Aspirin to Cardiovascular Disease(CVD): Men	Aspirin for men 45-79 years old when the potential benefit due to a reduction in heart attack outweighs the potential harm due to an increase in stomach bleeding.
Aspirin to Cardiovascular Disease(CVD): Women	Aspirin for women 55-79 years old when the potential benefit of a reduction in blocked artery outweighs the potential harm of an increase in stomach bleeding.
Blood Pressure Screening	Screen adults aged 18 and older.
Breast Cancer Screening	Mammogram for women, with or without clinical breast examination, every 1-2 years for women aged 40 and older.
Cervical Cancer Screening	Women who have been sexually active and have a cervix.
Cholesterol Abnormalities screening: men 35 & older	Screen men aged 35 and older for lipid disorders.
Cholesterol Abnormalities screening: men under 35	Screen men 20 to 35 years old for lipid disorders if they are at increased risk for coronary heart disease.
Cholesterol Abnormalities screening: women 45 & older	Screen women aged 45 and older for lipid disorders if they are at increased risk for coronary heart disease.
Cholesterol Abnormalities screening: women under 45	Screen women aged 20 to 45 for lipid disorders if they are at increased risk for coronary heart disease.
Colorectal Cancer screening	Screen using fecal occult blood testing, sigmoidoscopy, or colonoscopy, in adults, beginning at age 50 years and continuing until age 75 years.
Depression screening: adults	Screen adults for depression when staff-assisted depression care supports are in place to assure accurate diagnosis, effective treatment, and follow-up.
Osteoporosis screening: women	Screen women aged 65 and older routinely for osteoporosis. Routine screening begins at age 60 for women at increased risk for osteoporotic fractures.

was an inspirational story to be told about following their dreams.

A resident of Philadelphia, Michael Grasso moved to Los Angeles in 1993 at the age of 18 in order to realize his dreams of becoming a professional magician. A year after the move he found himself not feeling well, prompting a visit to the emergency room where he was diagnosed with IgA Nephropathy. Soon after, he received his first kidney transplant back in Philadelphia. Michael didn't let the new obstacles he faced with his health stand in the way of his professional goals. In fact, he returned to LA and was able to continue working as a magician through the ups and downs of dialysis and losing two transplants, due to a return of his disease. Three years ago he received the gift of life again from his cousin.

With his health stable and his career on the rise, there seems to be no stopping Michael Grasso. And this was precisely the message he came to share with the excited teens on their magical night. "I'm here to tell you that I've lived with kidney disease for 19 years and I haven't let it stand in the way of pursuing my dreams." He went on to state that he is not defined by his kidney disease, but by his magic, his talent. And he encouraged the young, energized crowd gathered at the foot of the stage to do the same, to not let their disease stop them from realizing their passion.

Michael performed illusions that wowed the crowd and if only for that reason, everyone in attendance was in awe. But by sharing his story with fellow patients, he gave teenagers, many of whom were about the same age as he was when he was diagnosed, inspiration and hope that they too can make a magical life for themselves by pursuing their dreams. ☞



Malia Langen is a Renal Support Network board member and volunteer. As a teenager, she spent over 5 years on both peritoneal dialysis and hemodialysis and has been enjoying a successful kidney transplant for the past 15 1/2 years. A native Californian, she resides in Los Angeles and works in the television industry.

To see more photos and
a video from

January's prom go to
RSNhope.org/RenalTeenProm

Renal Support Network

Who are we and what do we do?

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

Chronically Happy: Joyful Living in Spite of Chronic Illness

Written by Lori Hartwell, this is an upbeat, motivational book that helps people living with chronic illness create joyful, fulfilling lives. **Available on Amazon.com for Kindle or in paperback. Audiobook available on CD from RSN and for download from ChronicallyHappy.com.**

HOPEline

A toll-free call-in line offering patient-to-patient encouragement and support from operators who have lived successfully with chronic kidney disease.

English **1-800-579-1970** Spanish **1-800-780-4238**

Monday - Friday, 10:00 a.m. - 8:00 p.m. (Pacific Time).

KidneySpace

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

KidneySpeak

This program provides tools, resources and presentations to inform people on chronic kidney disease and organ donation. Developed patient speakers through the PEPP (Patient Educating Patients and Professionals) program can also be requested for healthcare and patient meetings.

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**.

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**

Patient Lifestyle Meetings

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

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.

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 biannual newsletter for patients—inform, inspires, and educates patients, family members, and healthcare professionals.

All of this information and much more can be found on our website

RSNhope.org

In honor of April being Organ Donation month Live & Give highlights different topics in

Transp

Perspectives



Becoming a Living Donor

by John J Pitney Jr.

A few years ago, an in-law of mine was in rapidly declining health. He had been diabetic since his teen years, and now the diabetes was causing his kidneys to fail. He needed a transplant. For a variety of reasons, his blood relatives were not able to donate, so I volunteered. My friend Virginia Postrel had written about donating her kidney, and from her article I knew a couple of important things. First, although any major surgery involves risk, kidney donors usually fare quite well. Second, new surgical techniques have made things much easier for the donor.

We were able to schedule the transplant for early summer, which smoothed the path even further. I teach college, and as the old joke says, the three best reasons to go into my line of work are June, July, and August. I didn't have any teaching responsibilities until fall, and recovery from surgery would not hamper my writing. Most academic research is not exactly strenuous, especially in the era of the Internet. So for a minimal amount of risk, pain, and inconvenience, I could help somebody in trouble. It was not a hard call.

So far, so good. Most of my family members supported my decision right from the start. Not surprisingly, my mother was a tougher sell. But just before the surgery, when she joined me at the hospital and saw how sick my in-law looked, she turned to me and said, "You're doing



HOW TO BE LISTED AS AN ORGAN DONOR

Laws that oversee donation vary from state to state. Sign up through the Donate Life website to ensure your wishes are carried out.

DonateLife.net/CommitToDonation

If you are interested in becoming a living donor like Mr. Pitney, check out the web resources on page 10.

the right thing."

Although I had never undergone major surgery before, I was not especially nervous. The operation took place at Stanford, a world-class hospital that had never lost a kidney donor during a transplant. They put me under, and I woke up a few hours later. Once the anesthetic wore off, the incision was uncomfortable, but not unbearably so. (I've had worse pain from greasy French fries.) I was on my feet the next day, and out the door three days after that. It helped that I had prepared for the surgery as if I were training for an athletic event: losing weight and stepping up my existing workout regimen. The doctors told me that this approach hastened my recovery.

The surgery was a success. Though my in-law's recovery was much rougher than mine, he regained his health and went back to work. He

has to take medication to prevent his body from rejecting the kidney, but it doesn't limit his activity. And I don't have any serious restrictions as a result of the surgery. There are certain pain relievers that I should avoid, but I never used those particular products in the first place. I should drink plenty of fluids, but then again, so should everyone else. There is a faint scar on my lower belly – which is no big deal. At my age, I don't aspire to be an underwear model.

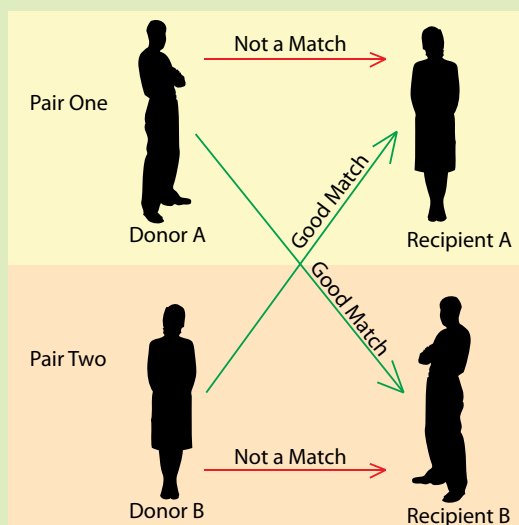
My in-law and I had always been close. The surgery brought us even closer, as if we were blood relatives. In a way, the transplant made us so.



John J. Pitney, Jr. is the Roy P. Crocker Professor of Government at Claremont McKenna College. He is coauthor of *American Government and Politics: Deliberation, Democracy, and Citizenship* (Cengage). He has also written an article on organ transplants for the forthcoming reference work, *Governing America*.

Transplantation

How does Paired Kidney Donation work?



Read Gareth Hil's article and listen to his podcast episode about how he created the National Kidney Registry and his own experience with finding a donor for his daughter.

KidneyTimes.com

The National Kidney Registry by Gareth Hil, EasyLink Access # 485

The Kidney Matchmaker with Gareth Hil, EasyLink Access # 529

Visit the National Kidney Registry website at KidneyRegistry.org.

To learn about EasyLink Access turn to page 3

Transplant Waiting List

Continued from page 1

transplant can vary from two to ten years, depending on several different factors:

ABO Blood Type - The kidney needs to come from a donor with a compatible blood type.

Antibody Level - Your antibody level measures the strength of antibodies within your system. A high level of antibodies makes it more difficult to find a compatible donor for you. If you've had multiple transplants, multiple pregnancies, blood transfusions, etc., you most likely will have a higher antibody level than transplant candidates who have not.

Organ Availability - Some OPO's (Organ Procurement Organizations, also known as organ allocation "regions") have higher wait times than others. Discuss with your transplant coordinator the average wait times for your particular area. They can vary greatly across the country. You can look into multi-listing; this means you can list at more than one transplant center, including one outside of your primary OPO. However, be sure that you can reasonably get to the center even during the middle of the night, should an organ become available then. You cannot list at two transplant centers located within the same OPO. Say you live in Los Angeles, you couldn't list at both UCLA & USC. However, you could list at UCLA and UCSF; or Cedars-Sinai and UC Davis.

How does an offer from the waiting list work? When a donor organ becomes available, the transplant coordinator will call you & discuss specifics about the donor organ. They do not reveal the donor name or personal specifics. They will discuss with you any issues or concerns regarding the organ, or let you know if it is a great offer. You will always have the right to decline an organ. However, should you decline, you do not automatically move to the top of the list for the next available organ. You would need to wait until another becomes available that matches you, is compatible and if you're in line to receive it based on

matching. Carefully consider all of the issues before you decline an offer.

While you're on the waitlist, please make sure that the coordinators have all of your contact information, especially if you change phone numbers, address, dialysis schedule/location, insurance, etc. If they can't reach you, or your insurance hasn't been updated, you could lose out on an offer and be denied the transplant. If you have an infection or a cold you may not be able to receive the kidney so it is important to stay as healthy as possible. Hopefully that call is just around the corner! ☺



Jacqueline Harris is a Senior Executive Healthcare Specialist with the Immunology division of Astellas Pharma US. She is an RN, Clinical Nurse Specialist & former transplant coordinator at Cedars-Sinai Medical Center & UCLA Medical Centers. She has over 20 years of ICU, critical care & Nephrology experience. She is a board member & volunteer with RSN. She is also a private pilot & enjoys flying whenever able. She lives in La Canada, CA.

Listen to Jacki Harris' podcast *Preparing for a Kidney Transplant* EasyLink Access # 392

2011 KidneyTimes Essay Contest

Call for submissions for the 9th annual KidneyTimes Essay Contest.

“What hobby helps improve your quality of life and helps you forget the many challenges kidney disease presents?”

Accepting submissions April 1st - August 1st, 2011. To submit an essay you must have been diagnosed with chronic kidney disease (CKD). Essay length should be between 350-750 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 as a 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 Renal Support Network. For more information and contest rules visit RSNhope.org or KidneyTimes.com. Send essays to:

Email: essay@RSNhope.org

Mail: 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

Legislative Update



Forget Uncle Sam, WE Need You!

by Kathe LeBeau

It's a very important time to be an informed and active kidney patient; we have a lot of work ahead of us. With the advent of bundling we know that there are changes to be aware of and the unintended consequences they may cause in the provision and quality of our care. There are a number of issues arising at both federal and state levels that could greatly impact access to necessary treatments and medications for the nation's renal patients. State budget crises across the country are resulting in proposed cuts that could threaten access to quality care for the most vulnerable patients. With everything on the table, from the coverage of transplants under Medicaid programs, to moving protected drug classes for anti-rejection meds out into the managed care realm, and eliminating the “prescriber prevails” language in a statute that keeps a patient and doctor in control of that patient's care, we won't know what final changes will remain in the final budgets until the dust settles. It's important to check into our weKAN advocacy pages and see the status of the budget measures where you live and let your voice be heard on any impending cuts.

On a federal level, with some factions in Congress looking to roll

“State budget crises across the country...could threaten access to quality care for...patients.”

back the historic health care reform of last year, even Medicare is on the proverbial chopping block. Again, you sharing your experiences with your representatives as a kidney patient, and the importance to you of their continued support for the ESRD program needs to be heard loud and clear. Please go to the RSNhope.org website under “weKAN” to connect with the information you need to do this effectively.

Many changes are happening in the regulatory world as well. Following six years of ongoing work and some hindered efforts, the United Network for Organ Sharing (UNOS) is working

towards a Kidney Allocation Policy that could radically alter the process and criteria under which transplantation occurs in the U.S. UNOS is actively seeking comments from those who would be most affected by this policy – patients. You can be part of it too by linking to the UNOS Public Comment procedures through our website.

A number of other issues are soon to be changing as well, and will be up for debate. You don't have to get involved in every issue, but there is something that resonates with each one of us and what is most important to us, and we can speak to that with our experience and our passion. I urge each of you to identify that issue for yourself, and get involved...we need you now, more than ever.



Kathe began home hemodialysis in April of 2007 after being diagnosed in 2004 and is currently on the transplant waiting list. She is the Project Manager for RSN's weKAN group, and a HOPEline operator. Kathe lives in the Capital Region of New York State.

Find your local representative, **join weKAN**, and learn more by visiting

RSNhope.org/weKAN



Got Antibodies?

by Kristen Cisneros

Have you had a prior transplant? Multiple pregnancies? Blood transfusions? If you are on a transplant list, has your transplant center reported to you that you have high levels of antibodies?

If you answered “yes” to any of these questions and are not sure what this means or what you can do about it, here is some information to help you out. If you have high levels of antibodies, you may have been told that it will be hard to get a donor match or that there isn’t any treatment out there to help you. Here is a bit of good news; leading hospitals such as Cedars-Sinai Medical Center, Johns Hopkins Hospital and The Mayo Clinic have published studies that show there is hope and that you can increase your chances of a successful transplant. This treatment is called desensitization.

A person can become sensitized as a result of exposures to other human tissues such as blood transfusions, pregnancies or prior transplants. If you have elevated antibodies, know that you are not alone. Approximately 3 out of 10 people on the national waiting list are sensitized. As of February 15, 2011 the United Network for Organ Sharing (UNOS) reported that there are 87,939 people waiting on the national waiting list for a kidney transplant and approximately 25,000 of those people have antibodies high enough to be a problem matching with a donor.

Antibodies are proteins the body makes to defend itself, like an army in our body that fights off foreign tissue; for example: a new kidney. An army is good for fighting

enemies like infections but not so good if you need a transplant. This army can attack and reject a kidney transplant immediately (this is called acute rejection).

You may have heard of treatment called Intravenous




Immunoglobulin, referred to as I.V.I.G, that helps with antibodies. If you were to look up this medication you would see that it can also be given to people with autoimmune diseases or people who have a lot of infections. That is because IVIG has antibodies in it to help people fight off infection. This is not why we use IVIG in transplant. IVIG can help decrease the ability of the army of antibodies your body has made to engage and fight off foreign tissue, like a kidney transplant. In simple terms, IVIG can weaken the reaction of the antibodies (soldiers in the army) that would fight off a kidney transplant.

This is considered the standard of care for antibody treatment. Dr. Stanley C. Jordan from Cedars-Sinai has been studying IVIG for over 20 years and has published its effects and how it can help improve the chances of a successful transplant for people who have high antibodies.

IVIG modifies the immune system without suppressing it. In addition to IVIG at Cedars-Sinai, we add a drug call Rituxan which blocks cells which produce antibodies (or soldiers that are part of this army that fight off foreign tissue).

Plasmapheresis can also be used for treatment. This is a procedure where your blood goes through a machine and the plasma where these antibodies are circulating is removed.

These treatments can be used if you are on the national waiting list or if you have a potential living donor who wants to give you a kidney. IVIG and other desensitization treatment options have also lead hospitals such as Cedars-Sinai, to be able to perform blood type incompatible transplants. That means that if your living donor is not the same blood type or is incompatible with your blood type, you may be able to get your transplant with the use of medication like IVIG, Rituxan and Plasmapheresis.

If you are wondering if you have antibodies, ask your transplant center what your PRA (panel reactive antibody) level is. If it is above 30, ask if you need treatment such as IVIG or desensitization. 



Kristen Cisneros, RN, BS, CCTC is a Kidney and Pancreas Transplant Coordinator at Cedars-Sinai Medical Center. Kristen currently specializes as their Transplant Immunotherapy Program Nurse Coordinator. Kristen has worked in transplant for over 10 years, including ICU, critical care at Johns Hopkins Hospital and UCLA Medical Centers. She is an active triathlete and is scheduled to do the LA Marathon in March.

Tips to Remember



Questions to Consider When Being Evaluated for a Transplant

Questions Submitted by weKAN Members

- How long will it take to be evaluated for a transplant?
- When I am offered a deceased kidney, will I be told about the background of the donor?
- If I decline a kidney because I do not think it is suitable, will I lose my place on the wait list?
- How long after the transplant before I can return to work?
- If I need to travel a few hours to get to my transplant hospital, will the hospital have a place for my family to stay when I have my transplant? If so, for how long, how many people and how much?
- How long until I can drive a car?
- Do you participate in paired donation or kidney chain swaps? If so, which ones?
- Is there a weight restriction? How much weight will I need to lose?
- If I have a suitable donor, can I be transplanted before going on dialysis?
- When someone expresses an interest in being my donor, what do I tell them?
- Does this center allow multiple listings at other transplant centers?

WEB RESOURCES

Organ Donation Organizations

UNOS.org
KidneyRegistry.org
LivingDonorsOnline.org
KidneyLink.org
OrganDonor.gov

Transplant Stories

Go to KidneyTimes.com and listen to the following podcasts, EasyLink Access # follows the title:

Eyewitness Account of Kidney Donation 492
Cartooning Around 387
Living on Both Sides of the Knife 341
High Antibody Count—What to do 433
Celebrating 35 Years and Counting 382
How do You Ask for a Kidney 497

Live & Give is a publication of the Renal Support Network's weKAN program.

weKAN Patient Activists serve to educate, and empower fellow chronic kidney disease survivors to advocate for themselves and for one another.

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EIN#95-4672679

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If you have a change of address, phone number, or email address, please contact us to update it.

Thank You.

Renal Recipe



We're Bringing Pasta Back

Prepared by Ed Robinson

There is no arguing that pasta is a staple of the busy American's life. And there is no one busier than a working professional who spends around 10 hours every week on dialysis.

Pasta is cheap, quick, and easy... and normally topped with tomato sauce, usually from a jar. The problem is, of course, that tomatoes are high in potassium and not healthy for someone on dialysis, and the other options aren't any better. Jarred alfredo sauces are high in phosphorous and packed with sodium, and jarred pesto is made with pine nuts, which are high in phosphorous and potassium.

So I set out to find a few dishes you can make at home that are still quick and easy, and renal-friendly. I was able to come up with several recipes, and the good news is that they taste better than those jarred sauces, too!

My first goal was to find an

alternative to tomato sauce, but still be a red sauce. The answer lay in roasted red peppers. With a few simple steps, jarred red peppers that can be found at most grocery stores (and very affordably at Trader Joe's) can turn into a red sauce. You can make it in large batches and store it in your refrigerator or freezer.

I also tweaked Chicken Piccata and Shrimp Scampi recipes to keep them low sodium, but still delicious. The trick is to find ingredients, like lemon and garlic, that are so full of flavor that no salt is necessary.

I hope you enjoy preparing and consuming these dishes as much as I enjoyed creating them. Cheers! ☺



Ed Robinson has been a self-taught home chef since he was tall enough to reach the counter. He recently hosted and created the cooking show "Five \$ Feasts." Ed runs his own catering business and is the food stylist for the latest season of "Fed Up!"

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Chicken Piccata

Serves 2

2 boneless skinless chicken breasts, pounded flat to a ½ inch thickness (this step can be skipped for ease by buying “thinly sliced” chicken breasts or chicken breast “cutlets” commonly sold in stores)

pepper

flour for dredging

½ cup olive oil

½ cup dry white wine

juice of ½ lemon (about ½ tbsp.)

½ lemon, sliced

1 tsp. capers, drained

4 oz. (about 1 cup dry) farfalle (bowtie) or other favorite pasta

1. Season the pounded chicken breasts (or cutlets) with pepper on both sides. Coat the chicken breasts well with flour.

2. Boil the water for the pasta and cook as directed by the package. Do not salt the water; the lemon sauce and capers will provide plenty of flavor.

3. Heat olive oil in a large pan on medium heat until shimmering. Add the floured chicken breasts and cook, uncovered, 3 to 6 minutes per side, until the chicken breasts are golden brown. When done, remove the chicken breasts from the pan and transfer to a plate.

4. Add wine to the pan and bring to a simmer. (Be careful, this may cause some minor popping) Add the lemon juice and capers. Adjust the amount of lemon juice to taste. Do not overcook; the lemon juice will become bitter if cooked too long.

5. Return chicken to the pan and top with lemon slices. Cover the pan and reheat the chicken, no longer than two minutes. Serve immediately over the pasta, passing extra pan sauce as desired.



Calories 690 | Protein 45g | Potassium 583mg | Fat 38g | Carbohydrates 35g | Sodium 159mg | Phosphorus 400mg

*In this issue of Live & Give...
Transplant: Know Your Options*

Thanks to our sponsors!

Roasted Red Pepper Pesto



Photos by Jodie Younse

- Serves 2
- 2 garlic cloves, cut in half
- 1 jar (about 7 to 8 ounces) roasted red bell peppers, drained
- ¼ cup olive oil
- ¼ cup fresh basil, torn
- 1 tsp. balsamic vinegar
- pepper to taste
- 1 Trader Joe’s Lobster Ravioli, or

- another meat filled ravioli.
 - 1. Combine all of the ingredients except the pasta in a food processor and blend 30 seconds until it has reached your desired consistency. Taste, and adjust flavors to your preference.
 - 2. Prepare the ravioli or stuffed pasta according to the directions on the package. Do not salt the pasta water; there is plenty of sodium inherent in the sauce and ravioli.
 - 3. Top the hot ravioli immediately with room temperature pesto and enjoy.
- NOTE:** This recipe can also be made with freshly roasted bell peppers.

For instructions on how to roast fresh bell peppers, the recipe for Garlicky Shrimp Scampi (photo to the right) and other renal friendly recipes visit...

KidneyTimes.com/recipes

Calories 526 | Protein 17g | Potassium 394mg | Fat 37g | Carbohydrates 31g | Sodium 487mg | Phosphorus 186mg

Recipe Disclaimers: Due to variations in ingredients, the nutritional analyses should be used as a guideline only. A renal dietitian reviews all recipes, but we cannot assure that all values are accurate. Remember to consult a renal care provider with respect to any specific questions or concerns you may have regarding proper renal nutrition or before making any changes in your renal diet.

Garlicky Shrimp Scampi

