



RENAL OUTREACH

ESRD Network 9/10

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The Robert Felter Memorial Award

The Renal Network, Inc. is offering patients the opportunity to apply for **The Robert Felter Memorial Award**. Robert Felter was a gentleman who touched the hearts and minds of patients and staff with his courage, knowledge, self-sacrifice and devotion to patient care and quality of life. With this focus, Mr. Felter taught us to value and celebrate the patient experience and point of view.

Applications for The Robert Felter Memorial Award will be sent to dialysis facilities in January, 2010. There are two awards given to patients who are involved in volunteering in their community and educating others about kidney disease. The winners attend an approved educational conference on kidney disease and write an article for this newsletter about their experience. Talk to your social worker in January if you are interested in receiving an application for this award. You will need to include a letter of recommendation with your application.

The application and recommendation letter must be received no later than: February 15, 2010. The winners will be notified in April, 2010.

There's Always Something to Learn

By Jim Dineen, the Patient Leadership Committee and Medical Review Board

The American Association of Kidney Patients (AAKP) is an organization dedicated to providing patients with the education and knowledge necessary to ensure quality of life and quality of health. As one of The Renal Network 2009 Robert Felter Memorial Award winners, I attended the AAKP conference in Denver, Colorado in September. The theme of the conference was "Going the Extra Mile." My goal was to attend as many sessions as possible and to learn what I could to share with patients back home.

One of the first things I learned at the AAKP meeting was that we are all just people, dealing with a common problem and making the best of life as we know it. We are actually no different than we were before this kidney business introduced itself to us except that we are united in our efforts to help ourselves, each other and all those dealing with all of the many issues that are a part of kidney disease.

Of interest to me was a session about the different types of disasters, including flu outbreaks, fire, and snow storms. Although we might not be directly involved in one of these disasters, we

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always need to be prepared and to know what to do. As kidney patients, we have to understand how to get dialysis treatment and have our medication with us in an emergency. We need to discuss how to be prepared for an emergency with our families and caregivers.

[Editor's Note: For more information on emergency preparedness visit <http://www.kidneypatientnews.org> and click on the Emergency Preparedness link.]

One of my favorite sessions concerned how to participate in our own care. I have been dealing with this disease since 1998 and have always stayed as involved as I could be in my own care and treatment. I'm a strong believer in inspiration and motivation. Shad Ireland, one of the speakers, is an inspiration himself. Shad has lived with kidney disease most of his life and has inspired countless people to move beyond the negatives of kidney disease and "press forward." He has bicycled across the United States and has spoken with countless patients on never giving up.

There were even presentations for caregivers. As patients we often forget how valuable and necessary our caregivers are to our well-being. It was encouraging to see so many family members and professionals attending educational sessions.

From talks about self-cannulation to talks about paired and altruistic kidney donation, the conference was packed with information about dealing with chronic kidney failure. I learned that we are an important part of our treatment. I learned that education is vital to leading a productive and happy life and that the more we give, the more we receive. The people I met, the information I brought home and the inspiration I received will stay with me for life.

My Trip to Boston

By Dadi Ding, the Patient Leadership Committee

I was extremely honored to receive the 2009 Robert Felter Memorial Award from The Renal Network. With this award, I was able to go to Boston to attend the annual American Transplant Congress in May. I work in a renal transplant center managing post-kidney transplant patients. The conference presented cutting-edge technologies in basic research in transplantation and the most up-to-date practices in transplant surgery and post-transplant management. The new knowledge and information that I gathered will help me in my everyday work in post-transplant patient care.

There were many sessions devoted to expanding the donor pool so that more patients on the waiting list can get a transplant. Topics included strategies to increase recipient tolerance, improving donor organ preservation, incentives for organ donation, desensitization in highly-sensitized transplant candidates, new developments in stem cell research, and xenotransplantation (transplant using animal organs).

As always, the main goal for organ transplantation of all types is to prolong the life of a transplanted organ. This five-day conference focused on sharing the experience, strategies, and new findings in post-transplant patient management. Practitioners discussed post-transplant patient care, including immune monitoring strategies, delayed graft function, recurrent diseases in kidney and liver transplantation, infection prevention, and cancer prevention.

Many internationally recognized scientists presented their advanced research work in organ transplantation. These findings will help clinicians to have a better understanding of human immunology, which will lead to better outcomes in transplantation of all organ types.

I am most appreciative of the recognition and the award. Attending this esteemed educational event in the field of basic research and clinical transplantation enabled me to listen to many outstanding practitioners and researchers worldwide. It provided me with a great opportunity to learn and see the world outside of my everyday life in Chicago.

The Journey of Dialysis

By Fayton Hollington

How did we get here? It's a question that has plagued each and every one of us. In some cases, the answer is self evident, while in others, it's due to unforeseen circumstances. No matter the journey, race, religion, social background, or financial status, we are a unit of people striving for the same end result...another chance. Unique in our individual dreams, we still control that ability. Let us not forget how powerful dreams can be, and how inspiration can keep dreams alive. I had lived my life on dialysis for eight long years before my prayers were answered, and I received a kidney transplant. I have written a book about my experience called **Conception of a Dialysis Patient (The Untold Truths)** which has recently been published. In addition, a CD of my poetry (the spoken word) titled: **By My Words I Stand**, is also available. Through my publications, I look forward to sharing my story and poetry with you...Keep dreaming.

ESRD Prospective Payment System

In June 2008, Congress passed the Medicare Improvements for Patients and Providers Act (MIPPA). Several provisions of this act will have a significant impact on dialysis patients and for all of the nephrology community.

On September 15, 2009 the Centers for Medicare and Medicaid Services (CMS) released their proposed ESRD Prospective Payment System or bundled payment system, as it is more commonly known.

The draft ESRD Bundled Payment System could affect how your dialysis is provided. Some of the areas impacted by the proposed payment system include: out of pocket expenses; access to medications and Epogen; home dialysis training; and population treatment disparities.

CMS has requested written comments from the public on the ESRD Prospective Payment System. This is only a proposed rule and none of the changes have been made to the current payment system.

Patients have the opportunity to provide comments to CMS on what they think about the new payment system and to voice any questions or concerns about the proposed changes. The deadline for comments is December 16, 2009.

To learn more, visit The Renal Network, Inc. online at www.therenalnetwork.org. and check on the ESRD Prospective Payment System links.

Commonly Prescribed Medications for Kidney Transplant Patients Part I – Immunosuppressive Drugs

By Dadi Ding, the Patient Leadership Committee

After kidney transplantation, you are prescribed a few new medications in addition to the medications you were taking before the transplant. What do you need to know about these medications, why are you taking them, how do you take them in order to be most effective, and what are the side effects? We will discuss these questions in two short articles. This article is about anti-rejection medicines and part two will discuss other routinely prescribed post-transplant medications.

Anti-rejection medications are also called immunosuppressants. You will need to take these medications as long as you have the transplanted kidney.

In the United States, the most commonly prescribed immunosuppressants are: Tacrolimus (prograf), Cyclosporine (Neoral, Gengraf), Mycophenolate mofetil (Cellcept) or Mycophenolate acid (Myfortic), Sirolimus (Rapamune) and Steroid (Prednisone). You may be prescribed a combination of two or three of the above drugs depending on your transplant center's protocol.

As suggested by their group name, "immunosuppressants" or "anti-rejection medications," suppress your body's immune system, preventing the transplanted organ from being rejected. Since the transplanted kidney is foreign to your body, your immune system tries to protect you from the intruder by destroying it, just like destroying a bacteria or virus during an infection. The immunosuppressive drugs weaken the body's defenses, making it incapable of getting rid of the new kidney.

This is why you have to take these medicines as long as you have the transplanted kidney. Any time you stop taking them, your immune system will kill the transplanted organ. You may still have rejection of your kidney while taking these medications, but it is rare (about 10% chance) and usually reversible with treatment. Now you know why your transplant team always emphasizes the importance of taking anti-rejection medicines and strictly following the directions given by the team. Never skip or stop taking them without checking with the team. Interruption of these medications can cause severe rejection of the transplanted organ.

Your transplant team orders laboratory tests for you on a regular basis to monitor your kidney function and the level of the immunosuppressive drugs. The medication doses are adjusted to keep the level therapeutic. Too much or too little medication in your system is harmful.

Another important aspect to keep in mind regarding immunosuppressive drugs is the drug-drug and/or food-drug interaction. There is a list of medications known to have interactions with immunosuppressants. It is very important to only take the medications prescribed by your transplant team. If you need to take something over-the-counter or a medication prescribed by a physician outside of your transplant team, check with your team member before taking it.

Never use any herbal medications. Although the herbs may offer certain health

benefits, they may interact with the immunosuppressants you are taking and can cause severe side-effects. Since there are so many herbal medications on the market, and most of them have never been studied to determine the interaction, the principle rule is to avoid all herbs. The interaction between food and the immunosuppressive drugs is not completely understood. However, we know that any food containing grapefruit can raise the immunosuppressive drug level. This is why, at the time of the transplant, you were told never to eat grapefruit or drink grapefruit juice.

Most commonly consumed foods in the U.S. are safe to eat while you are taking immunosuppressive medications, but some of the exotic or ethnic foods have not been studied. To be safe, if you are not sure about the new food you have added to your diet, call your transplant team and check your immunosuppressive drug level to see whether the dose needs to be adjusted.

Each immunosuppressive drug has its own side effects. Please see the chart below for an overview. The most common side effect

of this group of medications is that they make you more susceptible to infections. This group of medicines “suppresses” your immune system and makes it more difficult for your body to recognize and fight bacteria and viruses. To reduce the risk of infection while taking these medications, you should maintain good hygiene, avoid direct contact with people who have active infection, and follow the recommended vaccination schedule. You will also be given medications to prevent certain infections post-transplant for a period of time.

A “suppressed” immune system also increases the risk of cancer development. We advise all the transplant patients to wear sun screen and to follow a cancer surveillance protocol including ultrasound of the native kidneys, colonoscopy, mammogram, pap smear and prostate-specific antigen levels at regular intervals.

Not all of the side-effects, listed in the table below, will occur in every patient who is taking these medications. If you experience any of these symptoms, report them to your

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Name of the drug	Side effects
Cyclosporine	hair growth, tremors, high blood pressure, fluid retention, high cholesterol, high potassium, gum swelling
Tacrolimus	hair loss, tremors, headaches, diarrhea, high blood pressure, nausea, high potassium, diabetes (20% risk)
Sirolimus	rash, acne, joint pain, low potassium, anemia, diarrhea, high cholesterol/triglycerides, high blood pressure, mouth sores, lung infection
Mycophenolate mofetil &/or Mycophenolate acid	diarrhea, nausea, vomiting, decrease in white blood cells, anemia, mouth sores
Steroid	insomnia, acne, moodiness, night sweats, high blood pressure, fluid retention, easy bruising, joint pain, muscle weakness, high blood sugar, high cholesterol, vision changes, osteoporosis, increased sensitivity to the sun

The Comfort of Food at a Time of Stress and Illness

*By Janet Schueller, RD, LD
and Patient Leadership Committee*

Mmmm, there is comfort in food at a time of stress and illness. There is also a need to limit foods which can harm your health. These ideas can be hard to mesh for many people and can become a real puzzle for people with kidney failure. It is tempting to just “forget” about the diet especially when there are only a few foods which you find appealing enough to eat. Quality of life IS important! Your renal dietitian has worked with many new and experienced dialysis patients facing these problems daily. Let’s look at some of the solutions that these nutrition professionals have found to work for real people.

One of the major goals for you and your dialysis team is to make sure that you maintain good nutritional health once dialysis treatments begin. Your team will speak to you about having adequate protein stores, which we measure with a lab called serum albumin. Ask your dietitian how you are doing with this goal. Weight goals may vary – some may need to lose weight, while others may need to gain weight. In either case, weight changes should be gradual and planned. Losing weight rapidly can cause loss of important muscle mass, leading to weakness and infections. Rapid weight gain often is due to extra fluid and extra fluid can put strain on your heart and lungs.

So...you definitely need enough protein and calories in your daily diet to keep your body healthy. Of course, you can get calories from that “junk food” that many of us reach for when stressed. But in fact, protein sources such as beef, pork, chicken, fish, seafood and eggs should be the centerpiece for each meal.

People getting dialysis usually require 8-10 ounces of protein per day. This can be challenging when some of these foods taste and smell a little strange. You would be making a mistake to avoid protein and fill up on starches and sweets. What to do then?

First, think about eating softer, bland main dishes that don’t have strong cooking smells. Some people choose to grill meats outside or purchase them already prepared to avoid the odor. Cold foods like chicken salad, egg salad or tuna are popular with many dialysis patients. Cottage cheese with fruit and various egg dishes such as custard or quiches are also good options. Although cheese is high in phosphorus, you can check with your own dietitian to see if it will fit into your diet plan. If you are not eating well, macaroni and cheese or grilled cheese sandwiches with lower sodium cheese may be allowed. Make yourself a favorite sandwich but definitely avoid the processed lunch meat. Bologna, salami and ham often contain poor quality protein and add large amounts of salt to your diet. Most delis have lower sodium versions of turkey and beef which can be piled high on your sandwich. Remember – you should be aiming for at least 3-4 ounces of protein with lunch AND dinner!

Another common complaint about meats is the effort required to chew thick cuts of meat. Many people resort to casseroles due to their fatigue. But your favorite casserole may actually have little protein in it after the pasta, rice or bread is added. Think instead about buying thin cutlets of pork, turkey or chicken to prepare your recipes. Interesting sauces can be made with lemon, wine, herbs, onion and peppers. Your renal dietitian most surely has some cookbooks that you can browse through or borrow. Renal cookbooks have familiar recipes that have

been altered a bit to reduce the sodium, potassium, phosphorus and fluid content. For example, many family recipes that have been handed down use very high-sodium ingredients such as broth or canned soup for a base. Asian recipes may contain soy sauce which is high in sodium. Check with your renal dietitian if you have any doubts or need ideas for substitutions.



It is almost always better to start with fresh ingredients with minimal processing to avoid phosphorus additives. This is your chance to taste-test and find some new family favorites!

[*Editor's Note: For a listing of renal cookbooks visit <http://www.kidneypatientnews.org/diet/cookbooks.php>.*]

This brings us to a popular comfort food – soup. Of course there are claims that the common cold can be “cured” with chicken noodle soup. But for a dialysis patient, soup contains large amounts of sodium and fluid with little protein and calories. Think about those SMALL pieces of meat actually floating around in that bowl! Even homemade soups usually are based on high sodium broths.

Did you know that some of the lower-sodium soups actually use potassium additives which are also not recommended on a renal diet. Be sure to check your recipe with your renal dietitian before using AND have a good protein source along with your soup.

If you cannot eat enough protein and calories, your dietitian may recommend that you use protein supplements in the form of

powder, liquid, bars or drinks. These supplements may be essential until you regain your appetite and are able to eat a better quality diet. Powders and liquids can be added to some of your favorite comfort foods to “beef them up.” For example, hot cereal can absorb some protein powder, along with some extra calories in the form of margarine. In all cases, you should check with your registered dietitian about the supplements that will work for you and where to find them in your local area. Supplements can also be ordered for home delivery.

It is very important that you keep eating well after starting dialysis, that you keep up your strength and that you enjoy your meals! Express any concerns that you may have to members of your renal team – they can contact your dietitian for you and relay your questions. The renal dietitian at your treatment center is there to help you to reach all of your nutrition goals AND have a great time doing it. Take good care of yourself!

Immunosuppressive... - Continued from page 5
transplant team. Most of the symptoms can be reduced or resolved by treating with additional medications, lowering the dose of the immunosuppressant, or switching to a different immunosuppressant.

In summary, immunosuppressive medications are a group of drugs used to prevent rejection in organ transplantation. It is important to take them as prescribed to ensure their effectiveness. Follow your transplant team’s recommendations to minimize the side effects of these medications, and enjoy many good years with your new kidney.

[*Editor's Note: Part of a series of articles on kidney transplatation issues.*]

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It's Flu Season Again!

Take time to get vaccinated.

- Kidney patients are at high risk for catching the flu and are advised to get the **Seasonal Flu Vaccine**. The seasonal flu vaccine protects against the three most common flu viruses.
- Also available this Fall is the H1N1 (Swine) Flu Vaccine. Only the H1N1 vaccine protects against the H1N1 flu. Talk to your doctor about H1N1.

Take everyday preventive actions.

- Wash your hands often with soap and water. Alcohol-based hand cleaners are also effective.
- Avoid touching your eyes, nose or mouth. Germs spread this way.
- Avoid close contact with sick people.

DON'T LET THE BUG
CATCH YOU!



If you do get the flu:

- Cover your nose and mouth with a tissue when you cough or sneeze to keep from spreading flu viruses to others. Throw the tissue away after you use it and wash your hands afterwards.
- Instead of covering your mouth with your bare hands, sneeze or cough into the crook of your elbow to keep from spreading germs.
- Continue to wash your hands often with soap and water, especially after you cough or sneeze.
- Avoid unnecessary contact to keep from infecting others and spreading the virus. Call your dialysis unit to let them know you have the flu and to discuss your dialysis treatment and care while you are sick.

Stay informed:

- Visit Kidney Patient News online at <http://www.kidneypatientnews.org> for the latest information on H1N1 and seasonal flu.
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