

ESRD NETWORK 13

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KIDNEY CONCERNS

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ESRD DOESN'T SLOW DOWN THIS VOLUNTEER

We would like to share this letter with you that was recently submitted to Kidney Concerns.

Dear Editor,

I am quite proud of my wife, Joel, who has been on kidney dialysis since March 2000. Despite a lifetime of battling health problems such as diabetes since 1947, triple bypass heart surgery in 1984, partial foot amputation in 1992 and 1995, heart attack in 2000 and unfortunately numerous hospital stays over the last few years, she still manages to devote herself to a "vocation" she enjoys immensely, mainly, volunteering at Touro Infirmary where she was born in 1937.

Earlier this year she was named "Volunteer of the Year" at Touro and was honored at a lunch gathering. Touro Auxiliary President Barbara Maslansky offered these words to honor Joel H. "It is my great privilege to introduce the Volunteer of the Year. Although all of our volunteers are very dedicated, occasionally there is one who rises above the rest, as in the case of our honoree, Joel H. Her connection with the "Touro family" goes back to 1884 when the first baby born at the "new Touro" was named Touro Glucksman, Joel's uncle.

"Joel began her volunteer career as a teenager in 1952, working in the Diabetic Unit. This was the beginning of her dedication to serve. Using empathy gained from her own health problems, she was able to give guidance and support to patients and their families facing similar treatments. Later, her own heart surgery gave her first hand knowledge in how to counsel patients in cardiac rehabilitation. She shared her knowledge and strength, always with good humor and a twinkle in her eye.

"In amassing 4000 hours of volunteer time, Joel has worked in the Mammography Unit, Medical Records and the volunteer office. She has been a dedicated Auxiliary board member since 1986, now chairing the Membership Committee. There is a story about Joel which has become a legend around Touro. A couple of years ago Joel was hospitalized and before anyone had time to greet her properly, she called the Volunteer office to see if there was anything she could do while she recovered. Instead of calling on her with a bunch of flowers, we called on her with a bunch of envelopes.

Joel continues to be an example for all of us to live by. Besides her Touro family, this giving and dedicated woman is blessed with her own loving family-husband, Jay, son, David, daughter, Susan and twin granddaughters. The Touro Auxiliary is proud to bestow the Volunteer of the Year to Joel H. Congratulations Joel! "

Sincerely,
Jay H.

Glad You Asked That

You are the Most Important Part of your Health Care Team
By: Penney Pilkington, Chair, PAC and Hemodialysis Patient

Have you ever thought about your responsibilities in making your dialysis treatment a success? Your quality of life is directly affected by how closely you follow your doctor's treatment plan. You should actively participate in the development of your treatment plan and address your needs and concerns in the process. Some areas that patients impact are following fluid and dietary restrictions, care of dialysis access site, and duration of dialysis. **This article focuses on duration of dialysis or the length of time spent on dialysis.**

The doctor decides how long a patient must dialyze to remain healthy, remove the required toxins and to get adequate lab results. The doctor then writes a prescription for dialysis that the staff at your facility follow and monitor. **The goal of the prescription is to allow the patient to reach at least the minimum results in the least amount of time possible and still control symptoms.**

The patient's role in the dialysis process is as important as that of the doctor who decides the plan of care or the staff that carry out the dialysis procedure. Your first responsibility is to show up on time for dialysis. Dialysis cannot begin unless you are there. Missed treatments have a direct relationship with the increase in probability of death of the patient and an increase in hospitalizations. Studies show that even two missed treatments in a year can increase a patient's risk of death by 2.3%. Two missed treatments per month increase the likelihood of death to jump to 28%. That means a patient has almost a third more chance of dying. Is this something you really want to volunteer for?

Cutting dialysis treatment time also increases the risk of death and hospitalization. Even five minutes missed can make a big difference in treatment when viewed over time. A patient that arrives five minutes late for each dialysis treatment would miss 12 hours of treatment time per year. The same is true for the patient who ends their treatment early. Time is a major factor in how well you feel and the desired outcomes of your treatment.

The amount of time a patient dialyzes, **duration**, is one of the major factors of how well a patient is dialyzed, **adequacy**. We must remember that dialysis of approximately 12 hours per week attempts to replace our native kidneys that worked 24 hours per day filtering waste products and fluids from our bodies. We can see that even when we dialyze the full time, only a small portion of the blood is cleaned when compared to normal kidney function.

Patients often look to how they feel rather than lab values to rate how well dialysis is going. Remember, adequacy of dialysis and problems caused by the lack of adequacy do not often show up until time has passed and negative effects have had time to accumulate. Then it is a harder road back to wellness. Doctors and staff do all they can to make our lives more comfortable, but it is you, the patient, that ultimately decides how useful dialysis is by following your prescription to control your health. ♦

Visit www.network13.org

At Network 13, we have been working on updating our web site. This new and improved site will feature many topics that were not featured on the old site. We hope that this new site will benefit you in learning more about ESRD and assist you in improving your way of life. Some of the new pages that are being added to our web site will include new and old Kidney Concerns, our Clearinghouse Library material list, monthly updated facility listings, and Quality Improvement projects that we have completed. These specific pages on our site will offer you a chance to see what we do as well as assist you in learning more about ESRD. We are also offering a page that will link to other web sites that we feel will be beneficial to you. This new site will be up and running very soon. If you have any suggestions of things that you would like to see on our new web site, please contact us at webmaster@nw13.esrd.net. ♦

Immunosuppressants in Transplantation

The Critical Role of Immunosuppressive Therapy

By: Marcia Bos, BscPhm of the Synapse Group

The miracle of organ transplantation represents a second chance for many people who, for various reasons, have had one or more of their organs fail. This miracle has been made a reality by the evolution of surgical techniques and immunosuppressive therapy. Things have come a long way since the early days of transplantation. Today, immunosuppressive therapy is the most important factor to ensure the health and survival of the transplanted organ.

Immunosuppressant drugs are necessary to control the immune system, which normally responds to protect the body against foreign invaders such as viruses and bacteria. The immune system also identifies a transplanted organ as something foreign and therefore will attack it as long as it is present. This process, known as rejection, kills the organ unless it is prevented.

The Need for Variety

The immune system can be compared to a strong army with many different types of soldiers, each with a different fighting function. Because of this complexity, a number of different approaches are required to fight back against the effects of the immune response. This is why immunosuppressive therapy must rely on a combination of medications to prevent rejection of an organ.

Primary immunosuppressants are the most powerful medications for suppressing the immune response and they form the backbone of the immunosuppressive therapy that every transplant patient must take. Presently, two accepted primary immunosuppressants are available, cyclosporine and tacrolimus.

In addition to primary immunosuppressants, one or more of the following combination immunosuppressants are often used: corticosteroids, azathioprine, mycophenolate mofetil or sirolimus. Each of these drugs acts in slightly different ways to suppress different parts of the immune system. Because of this, they help enhance the effects of primary immunosuppressants.

The Value of Understanding Immunosuppressive Medication

Along with their benefits, each immunosuppressant may also have unwanted side effects. This makes therapy a balance between controlling the immune system and minimizing the side effects. Different drug combinations and dosages may be prescribed to protect the new organ while reducing unwanted side effects.

Because everyone is unique, some patients will not tolerate certain medications as well as others. It is important that patients talk to their transplant team about the benefits and side effects. Patients should feel good about their immunosuppressive therapy because it is critical that they do not stop taking any of their medications. Patients experiencing problems or bothersome side effects, such as excessive hair growth or growth of their gums, should talk to someone on their transplant team. They should be able to provide the information they need about any alternatives which may be more suitable. ♦

The American Association of Kidney Patients 2001 National Convention

The 2001 National Convention of The American Association of Kidney Patient will be held August 30-September 2, 2001 in Memphis TN. The convention will be held at the famous Peabody Hotel (did someone see that duck get on the elevator?). Rooms are available at the Peabody for \$105 per night. You can call 1-800-732-2639 for reservations. The cost of the convention is \$95 for patients and family and \$125 for professionals. For more information visit the AAKP website at www.aakp.org or call the National Office at 1-800-749-2257.

Talking About End of Life Plans Beneficial

Have you had this discussion with your physician? A new study by the Indiana University School of Medicine reports that elderly or chronically ill patients who had such conversations with their primary care doctor were happy they did. In general, doctors think patients should bring up the topic for discussion and patients think it is something the doctor should bring up, so these conversations are not happening. The study surveyed 696 patients who were at least 75 years old or 50 years old with a chronic condition and 87 doctors. The study found 98% of the patients had not had these conversations with their doctors in which they discuss end of life details like the types of life saving measures they wanted to have in the event they were dying and could not communicate their wishes. 110 patients did have these discussions with their doctors and it was determined that 51% of those patients rated their later office visits as excellent compared with only 34% of patients who did not have these discussions. The study reveals the importance for the discussion of end of life issues between patient and doctor. If the doctor does not bring up the subject, it is important that the patient does. Your needs are addressed and your stress is reduced in knowing that your doctor will take the actions you request. ♦

Free Transplant Information

Learn more about transplantation from the voice of experience. Being prepared for what lies ahead may be a key factor in the success of your transplant. You can begin to educate yourself by ordering your free copy of the Transplant Information Kit produced by Fujisasa Healthcare. The kit contains a video hosted by journalist Faith Daniels titled "Voices of Experience" which highlights the success stories of transplant recipients like you. Their personal experiences will help answer some of your questions and concerns about living with a transplant. You will also find a Transplant Journal filled with helpful information to use before and after your transplant. To receive your free copy of the Transplant Information Kit call 1-877-482-7627. ♦

Cooking for David: A Culinary Dialysis Cookbook is a modern up-to-date dialysis cookbook. It is filled with helpful information on food composition, food trade-offs, cooking tips, favorite recipe modifications, portions and menus, as well as 160 tested culinary recipes. The cookbook was developed by a Sara Coleman, dialysis dietitian and Dorothy Gordon, dialysis nurse, whose husband was a hemodialysis patient. For more information about the cookbook or to get additional renal nutrition information go to website www.culinarykidneycooks.com. ♦

Life Options Website Receives Award from HealingWell.com

Madison, Wisconsin - The Life Options Rehabilitation Program website, <http://www.lifeoptions.org>, has been selected as a recipient of the Editor's Choice Award from HealingWell.com. Life Options recently redesigned its website to be more colorful and user-friendly, making it easier to find resources to help people live long and live well with kidney disease. The site features patient stories, tips and ideas, an extensive series of kidney links, and will soon host patient and professional bulletin boards on rehabilitation. ♦



KIDNEY KONCERNS NEEDS YOU!

Kidney Koncerns is published quarterly by the Patient Advisory Committee of ESRD Network 13. The next edition is scheduled for FALL/OCTOBER. To make this newsletter a success, we need your assistance. If you are interested in contributing to this newsletter, please send any articles, materials and/or ideas to:

Kidney Koncerns

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