



KIDNEYS R US

FROM THE
QIRN3 PATIENT ADVISORY
COMMITTEE

March 2010

MY TRANSPLANT EXPERIENCE

By Swami Swaminathan

I began my current transplant journey when I was put on the waiting list in April 2009 at New York Presbyterian Hospital. I tried very hard to not become anxious about the transplant and to go on living my life as I had been for the past several years on dialysis. I avoided telling people about my listing because many would ask me every two weeks whether or not I had made any progress regarding the transplant. I was told by New York Presbyterian when I qualified for the waiting list that the waiting time was one to three years.

I had pursued transplant in the past at five different hospitals in New York, Pennsylvania, New Jersey and Maryland. I choose to concentrate my efforts towards qualifying at New York Presbyterian for the following reasons:

1. I felt comfortable with the doctors and medical staff whenever I went in for tests.
2. I attended a support group and found that the patients who transplanted there had very satisfactory outcomes.
3. I considered the travel time from my home to the hospital. I knew I would need to visit the hospital frequently after transplant for follow-up visits. This hospital was easily accessible with all highway driving taking about one and a half hours travel time. Traveling to the other transplant hospitals could take longer due to distance and road conditions.

Much to my surprise, I received a call from New York Presbyterian on October 1, 2009 stating they had a kidney waiting for me. I couldn't believe it

was possible in such a short amount of time. I began to believe my life was about to change.

I was hospitalized for just six days in New York City and left the hospital with a thermometer and a blood pressure measuring unit. I was instructed to get a scale to keep track of my weight and received discharge instructions that require me to take my vital signs twice a day. I was prescribed medications to prevent the transplant from rejecting. There is the chance of a few bumps on the road to recovery after transplant but don't be discouraged. The transplant team is accessible to help with any problems or questions you may have after transplant.

The transplant medications result in a lowered immune system. I have had to make some adjustments to my life to ensure that I am not exposed to illness. I follow this protocol without exception. You may want to consider the following advice:

1. Don't receive visitors at the hospital or at home immediately after discharge. Any cold or flu from a visitor could be easily picked up by a transplant patient.
2. Avoid crowded places such as stores or restaurants.
3. Get plenty of rest. Don't fight sleeping during the day. Your body needs plenty of rest to recuperate.
4. Contact your transplant emergency number if you have any signs of onset of illness, i.e. cold, flu, fever, cough, etc.

I have always believed in the need to stay active in life. I was always exercising while on dialysis and

I plan to continue this practice as a transplant patient. I have always maintained a strong desire to be self-reliant and I feel I was able to do this on dialysis by remaining as strong as possible. This also has benefited me with my transplant.

My journey has been an amazing experience. I am so grateful for this second chance at life. I strongly believe it is important to join a support group and

share your experience with others. And don't forget, reach out to the family who donated their loved one's kidney with a thank you note. They decided to give the gift of life which has the power to change your life forever. I will never forget my great fortune at receiving my transplant and my donor and his family for their selfless act which has changed my life for the better.

NOCTURNAL DIALYSIS

Have you ever wondered if there was an option to the conventional hemodialysis that takes three to four hours, three times per week at a dialysis center? Home hemodialysis is an option for some people. Peritoneal dialysis is also available for appropriate patients. Another option that is now becoming available in New Jersey is nocturnal hemodialysis in a center. This form of hemodialysis was first initiated in Canada in the 1990s. The success of that program is now being replicated in other countries.

Nocturnal hemodialysis is a form of hemodialysis that is done either at home or in-center when the patient is sleeping at night. Most home patients dialyze three or four nights per week, anywhere from six to 12 hours, on average for eight hours. The home patient, in consultation with his nephrologist, may choose to dialyze more frequently. The in-center nocturnal hemodialysis patient will typically continue to dialyze three times per week for a longer period of time than is usually done during the day. This will allow the patient to attain better lab values and ultimately feel better. The night time treatments can help preserve a patient's normal schedule of work, school or family activities.

Some of the advantages of nocturnal hemodialysis include: feeling better, more alert and more energetic; have more time for daytime activities; save money due to fewer hospital visits and fewer medications such as phosphate binders; more liberal diet; decrease preva-

lence of sleep apnea; lower blood pressure; improve cardiac function and may help improve sexual performance.

Some of the concerns regarding dialyzing when you are sleeping include the noise of the machine and the possibility of needles disconnecting. The machine noise has not been shown to be a problem for patients currently on nocturnal dialysis. They are able to block it out and sleep soundly. The needles need to be properly taped and anchored to ensure they will not be dislodged. In-center patients will have nurses and PCTs available to monitor and assist while they are sleeping.

Patients who choose home nocturnal hemodialysis will need to arrange for training with a partner during business hours at a home training center. If you think you may be interested in nocturnal hemodialysis speak to your nephrologist. New Jersey currently has several centers offering this option and more are in the planning stages.

For more information please visit the websites used for this article: www.aakp.org and www.wikipedia.org

JOIN THE PAC TODAY!

The Patient Advisory Committee (PAC) consists of patients from dialysis facilities in our ESRD Network # 3. The committee supports the mission of the Renal Network to improve the quality of care provided to ESRD patients and to represent and support the ESRD patient population. The committee develops the patient newsletter and promotes educational materials for ESRD patients. The PAC members have a genuine concern for the quality of care issues and encourages patients to be involved in their healthcare, share skills and experience, and attend meetings. Call toll free 1-888-877-8400 and join the PAC!

How to Contact QIRN3
Cranbury Gates Office Park
109 South Main Street, Suite 21
Cranbury, NJ 08512
Phone: 888-877-8400 (toll-free)
Fax: 609-490-0835
Email: qirn3@nw3.esrd.net

We're on the
Web!
www.qirn3.org