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A NEWSLETTER FOR PATIENT ADVISORY COMMITTEE REPRESENTATIVES

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August – 2013



Surviving CKD: From Diagnosis, to Dialysis, to Transplant

By Nelson Nuñez, PAC Chair, Manhattan/Staten Island

The Diagnosis and The Wait

In 1999, I was a junior in college, and was devastated to hear that I was in stage four of CKD. Looking back on those days, I was always tired and slept for 10-12 hours a day, but I could never find the restful sleep I needed. When I was told that my kidneys were failing, my life was turned upside down. I had to quit school in Springfield, Missouri and return to New York City to move back in with my parents.

It was a lonely time, I thought I had returned home to die, because I was rejected for Medicaid back in Missouri and had no means to pay for a doctor. As the realization of my truth came to light, a depression set in, and I spent most days sleeping or in bed, making the occasional bathroom trip with great difficulty. To my surprise, after two months I was still alive and was not getting any better or worse. I found a program where they charged for medical care based on income and finally went to see a doctor. With medical care and dozens of pills each day, I was downgraded from stage four CKD to stage two in six months.

Seven years after that first diagnosis, in September 2006, I started hemodialysis. The following February, I finished all of my initial medical evaluations and was placed on the transplant list to wait my turn. I started with in-center hemodialysis eventually switching to in-center self-care dialysis, then to home short daily hemodialysis, and finally to nocturnal home hemodialysis. I had adapted to ESRD, dialysis was

Nelson Nuñez, PAC Chair, Manhattan/Staten Island

I was diagnosed with CKD in 1999 and after six long years ESRD, I started dialysis in 2006. Through my journey with family being on dialysis and in assisting my parents with their healthcare, I learned the importance of patients being engaged in their own care. My dialysis center observed this and asked me to become a Patient Advisory Committee Representative in 2007. After four years of bridging the gap between patient and center, I decide to apply for PAC Chairperson for Manhattan/Staten Island and was accepted. Today I encourage all patients to partake in their healthcare treatment as much or as little as they can, it all helps in the end.

This material was prepared by IPRO End Stage Renal Disease Network of New York, the ESRD Organization for New York State, under contract with the Centers for Medicare & Medicaid Services (CMS), and agency of the U.S. Department of Health and Human Services. The contents presented do not necessarily reflect CMS policy. CMS Contract Number: HHSM-500-2013-NW002C

just keeping me alive. Once I began nocturnal home hemodialysis, I really started living life and having more freedom, but still waiting on the list for a kidney. Getting on the transplant list was difficult as I was 100 lbs. above their desired weight for me to have the surgery. I was allowed to stay on the list in order to accrue time, but I would not be transplanted until I lost the weight. It took a lot of effort as I had to change the way I used to eat, but two years later, I was able to get down to my goal weight. Like so many others, I had to wait for someone to die in order to get a resemblance of my life back, one life for another, anticipating the freedom of a transplant, I was excited about the possibility of “The Gift of Life”, and in March 2012, I got the call.

The Transplant

The much anticipated call came at 1:27 am on March 1st. I had received two calls in the months before, but was only one of the backups in case someone refused the kidney. At first I thought this was another backup call, but then the coordinator asked me “when can you get here?” It was like a slap on the face. I stuttered “wait, is this THE OFFICIAL CALL?” She told me “Yes, and we need an ETA now”. When the call came, I was on the NxStage machine doing nocturnal dialysis at home. I told her that I would be there by 2:00 am. In the short time that I was disconnecting from my dialysis machine I was overcome with emotions, I had waited five long years for this moment and it had finally arrived!

At the hospital there were some pre-surgery medical tests, to make sure that I was healthy enough for surgery, and all was well. The surgery started around 6:00 am and I was told that it was uneventful, several hours later I awoke in the recovery area with a new kidney. My kidney was considered a “sleepy kidney” so it took a while to start functioning. I had to have dialysis once while I was in the hospital and was released from the hospital after seven days. I’ve had some complications since my transplant, and I will write another *PAC Speaks* Article to follow up on my journey. Fight on Dialysis Warriors!

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If your facility would like a PAC Chairperson to be a guest speaker, please contact the Network at least one month before the meeting to allow for scheduling: (516) 209-5578 or info@nw2.esrd.net.