



# PAC Speaks

A NEWSLETTER FOR PATIENT ADVISORY COMMITTEE REPRESENTATIVES

#### **About Me:**

Kenneth Teasley SME, Peer Mentor, PAC Chair Bronx, NY, Network Medical Review Board, NCC NPFE LAN/Affinity Groups

My name is Kenneth Teasley, I live in the Bronx but am originally from Salisbury, North Carolina. My journey with kidney failure started 23 years ago when I was diagnosed with CKD. Of those 23 years, I have been on dialysis for 5 years, and I was transplanted in 2016. I have been a volunteer Network PAC Chair and member of the ESRD National Coordinating Center for 3 years and previously, I was employed as a harm reductionist where I specialized in addiction treatment.



## Transplants are for Everyone!

As told by Kenneth Teasley

I was originally supposed to get an evaluation for transplantation in 2002, but I did not think I wanted a transplant so I did not go. It was not until years later, after I met my partner and started dialysis; I decided I wanted to pursue transplantation. I was lucky to have had an easy time getting on the transplant list. Two months post- transplant, I became diabetic and had to be hospitalized.

Thankfully, I had learned about a correct diet and some healthcare tools to prepare myself for kidney failure years ago, which reduced my diabetes to pre-diabetes, and helped me to continue to work towards my goal to stop taking insulin entirely. Overall, my transplant experience has been a positive one.

There are many statistics that show that a disconnect between the number of minority patients who have kidney disease those who have received kidney transplants. I feel that this disparity is due in part to a lack of early intervention and education in the minority community.

Minorities are less likely to have insurance, and as a result discover their conditions in later stages. I have always considered myself lucky because I found out about my kidney failure early on. This gave me time to learn how to make the necessary changes in diet and lifestyle to prevent progression of my kidney disease. It also gave me time to learn about the treatment options I would need once I progressed to ESRD. While early intervention is a great way to prevent racial disparities in renal disease treatment, there are also many things we can do now, as ESRD patients, to bridge the gap between groups.



As patient advocates, we can start investing in the education and instruction of new dialysis patients. Since many minority patients are finding out later that they have kidney failure and renal disease, they have a greater learning curve when it comes to the lifestyle and treatment changes they will have to make. It is not enough just to tell people they have to eat and live differently; we must provide them with constant support and advice as they learn how they navigate this new transition and what their options really are. Being a Network Subject Matter Expert (SME), a Network Patient Advisory Council (PAC) Member and Peer Mentor are excellent opportunities for patients to share their experience and advice with the people who are starting their ESRD journey.

### Tips when learning about transplants:

- Make sure your family members are being tested regularly for kidney disease, especially if you have a known family history of kidney disease.
- Educate yourself! At first all the information may seem overwhelming, don't get discouraged! Educating yourself is important in your journey!
- Share your story! There is no telling how your experience may help someone who is starting his or her own journey with kidney failure.
- Ask your doctor any questions you can think of and give yourself time to truly learn about your condition.

The IPRO End-Stage Renal Disease Network Program, ESRD contractor for Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont (NW1), New York (NW2); Georgia, North Carolina, South Carolina (NW6) and Ohio, Indiana and Kentucky (NW9) developed this material under contract with the Centers for Medicare & Medicaid Services (CMS), an agency of the U.S. Department of Health and Human Services. The contents presented do not necessarily reflect CMS policy. CMS Contract Numbers: NW1: HHSM-500-2016-00019C; NW2: HHSM-500-2016-00020C; NW6: HHSM-500-2016-00006C

## To file a grievance, please contact your local ESRD Network:

## IPRO End-Stage Renal Disease Network of New England

1952 Whitney Avenue 2nd Floor

Hamden, CT 06517

Patient Toll-Free: (866) 286-3773

Main: (203) 387-9332 Fax: (203) 389-9902 E-mail: info@nw1.esrd.net Web: network1.esrd.ipro.org

### IPRO End-Stage Renal Disease Network of New York

1979 Marcus Avenue Lake Success, NY 11042-1072 Patient Toll-Free: (800) 238-3773

Main: (516) 209-5578 Fax: (516) 326-8929 E-mail: info@nw2.esrd.net

Web: network2.esrd.ipro.org

## IPRO End-Stage Renal Disease Network of the South Atlantic

909 Aviation Parkway

Suite 300

Morrisville, NC 27560

Patient Toll-Free: (800) 524-7139

Main: (919) 463-4500 Fax: (919) 388-9637

E-mail: info@nw6.esrd.net Web: network6.esrd.ipro.org

#### IPRO End-Stage Renal Disease Network of the Ohio River Valley

3201 Enterprise Parkway Suite 210

Beachwood, OH 44122

Patient Toll-free: (844) 819-3010

Main: (216) 593-0001 Fax: (216) 593-0101

E-mail: info@nw9.esrd.net Web: network9.esrd.ipro.org