

**Patient SME Speakers Bureau**

# **Transplant is a Treatment Option Not a Cure**

**October 26, 2016**



Improving Healthcare for the Common Good

End-Stage Renal Disease Network of New York

# Agenda

---

- Network Transplant Project
- Peer Mentor Program Launch
- The Transplant Wait List: Pete Savage
- New Approaches to Transplant: Ken Teasley
- Coping with Complications: Nelson Nuñez
- Available Network Resources

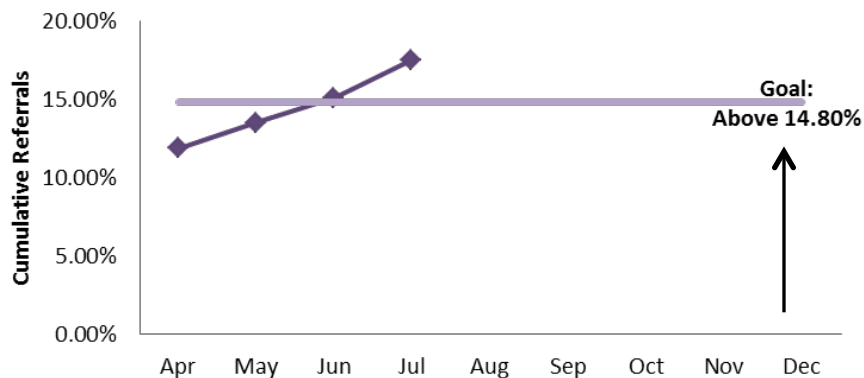


# **ESRD Network Transplant Project**

# Network Transplant Project

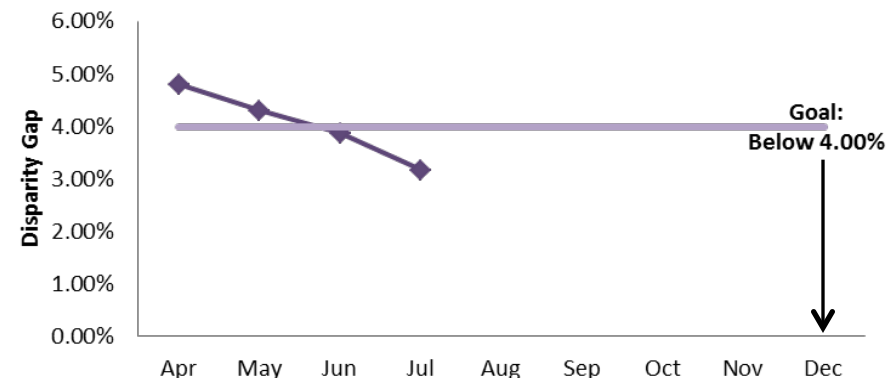
AIM 2 PHFPP: Transplant Referrals & Disparity Gap  
5% Increase in Transplant Referrals & 1% Decrease in Disparity

**Network 2 - Increase in Transplant Referrals**



Baseline	Target Value
9.80%	14.80%

**Network 2 - Decrease in AIM 2 PHFPP Identified Disparity (Race)**



Baseline	Target Value
5.00%	4.00%



# Project Interventions

- Educational Toolkit
- Education Stations
- Advisory Committee
- Peer Mentors


## New York State Transplant Center Referral Guide

A kidney transplant is a possible treatment option for people on dialysis. However, not everyone who wants a transplant can be considered eligible to receive one. Only transplant center professionals can determine if a patient is a good candidate for a transplant.

Each transplant center uses its own set of standards for deciding if a patient is a good candidate for a kidney transplant.

In some cases, a patient is turned down by one center, but found to be a good candidate for another transplant.

On the following page, you will find a list to help guide you and your family members to the transplant center that could most likely meet their needs.



**To file a grievance, please contact us:**  
**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](mailto:info@nw2.esrd.net) • Web: [www.esrd.ipro.org](http://www.esrd.ipro.org)

Developed by IPRO ESRD Network of New York while under contract with Centers for Medicare & Medicaid Services, Contract HHSM-500-2016-00020C

5/20/16

## New York State Renal Transplant Centers

### ALBANY MEDICAL CENTER

47 New Scotland Avenue MC-61-GE, Albany, NY 12208 • Phone: (518) 262-5614 • Fax: (518) 262-5571  
[www.amc.edu/Patient/Services/Surgery/transplant\\_surgery](http://www.amc.edu/Patient/Services/Surgery/transplant_surgery)

### DOWNSTATE MED CENTER - SUNY

450 Clarkson Ave., Transplant Unit, Brooklyn, NY 11203 • Phone: (718) 270-3168 • Fax: (718) 270-3762  
[www.downstate.edu/transplant/kidney\\_transplant.html](http://www.downstate.edu/transplant/kidney_transplant.html)

### ERIE COUNTY MEDICAL CENTER

462 Grider Street, Renal Transplant Unit - 10th Floor, Room 1032, Buffalo, NY 14215 • (716) 898-5001  
[www.ecmc.edu/medicalservices/kidney/transplant.asp](http://www.ecmc.edu/medicalservices/kidney/transplant.asp)

### MONTEFIORE HOSPITAL & MEDICAL CENTER

111 East 210th Street, Renal Transplant Unit - Rosenthal 2, Bronx, NY 10467 • (718) 920-6757  
[www.montefiore.org/surgery-services-professional-training-programs-transplant-kidney](http://www.montefiore.org/surgery-services-professional-training-programs-transplant-kidney)

### MT. SINAI MEDICAL CENTER

Transplant Center, 5 East 98th Street, 12th Floor, New York, NY 10029 • (212) 659-8086  
[www.mountsinai.org/patient-care/service-areas/organ-transplants/programs-and-services/kidney-pancreas](http://www.mountsinai.org/patient-care/service-areas/organ-transplants/programs-and-services/kidney-pancreas)

### NY-PRESBYTERIAN HOSPITAL/COLUMBIA

622 West 168th Street, Transplant Ctr., 12th Floor, New York, NY 10032  
 (212) 305-6469 • New Patient Referral (877) NY1-KIDNEY  
<http://columbiasurgery.org/pat/kidneypancreas/tscare.html>

### NY PRESBYTERIAN HOSPITAL/WEILL CORNELL

525 East 68th Street, Box 98, Kidney Transplant Program, New York, NY 10065 • (212) 746-3099  
<http://cornellsurgery.org/transplant>

### NEW YORK UNIVERSITY HOSPITAL

403 East 34th Street, 3rd Floor, New York, NY 10016 • (212) 263-8371  
<http://surgery.med.nyu.edu/transplant/kidney/patients>

### NORTH SHORE UNIVERSITY HOSPITAL MANHASSET

1554 Northern Blvd., Transplant Center, Manhasset, NY 11030 • (516) 472-5800  
[www.northwell.edu/find-care/locations/transplant-center](http://www.northwell.edu/find-care/locations/transplant-center)

### STRONG MEMORIAL HOSPITAL UNIVERSITY OF ROCHESTER

601 Elmwood Avenue, Transplant Unit, Box 675, Rochester, NY 14642 • (585) 275-7753  
[www.urmc.rochester.edu/surgery/transplant/procedures/kidney-transplant.aspx](http://www.urmc.rochester.edu/surgery/transplant/procedures/kidney-transplant.aspx)

### SUNY HEALTH SCIENCE CENTER AT SYRACUSE UNIVERSITY HOSPITAL

750 East Adams Street, Syracuse, NY 13210 • (315) 464-5413  
[www.upstate.edu/surgery/healthcare/transplant](http://www.upstate.edu/surgery/healthcare/transplant)

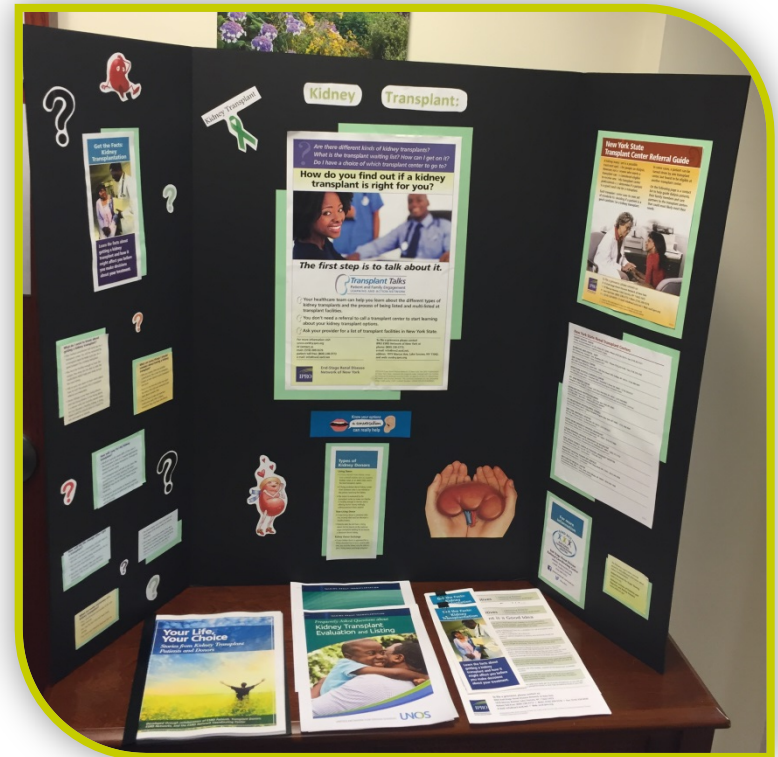
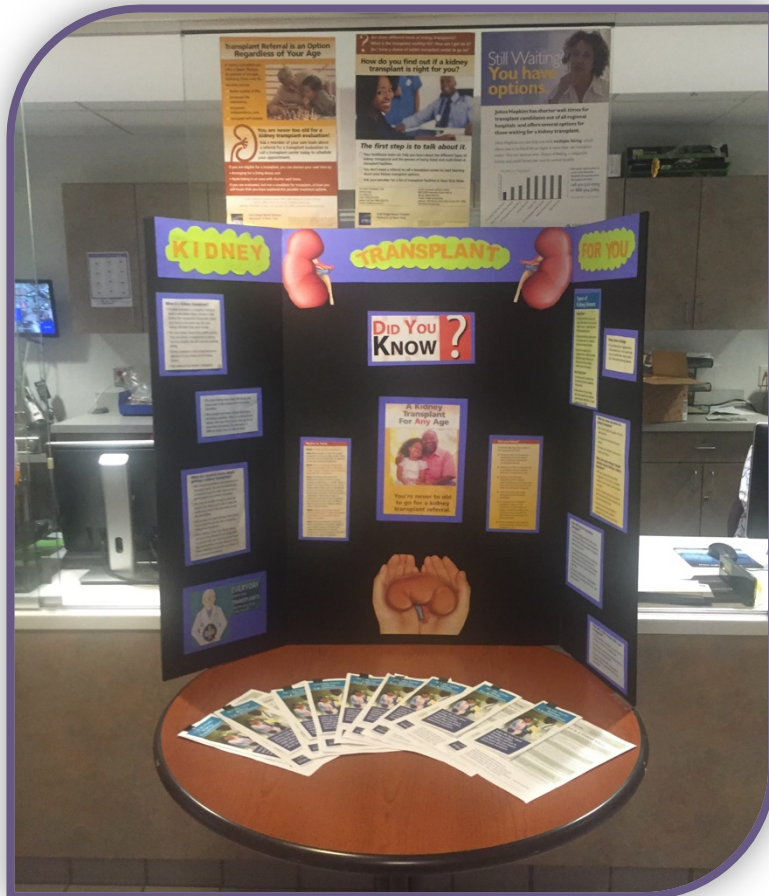
### UNIVERSITY HOSPITAL TRANSPLANT SERVICES

Hospital Road, Hcst-19-Rm 040, Transplant Unit, Stony Brook, NY 11794 • (631) 444-2209  
[www.stonybrookmedicalcenter.org/transplant](http://www.stonybrookmedicalcenter.org/transplant)

### WESTCHESTER MEDICAL CENTER

95 Grasslands Road, BHS- A Wing- Lower Level, Valhalla, NY 10595 • (914) 493-1998  
[www.westchestermedicalcenter.com/kidney-transplant](http://www.westchestermedicalcenter.com/kidney-transplant)

# Education Station Example



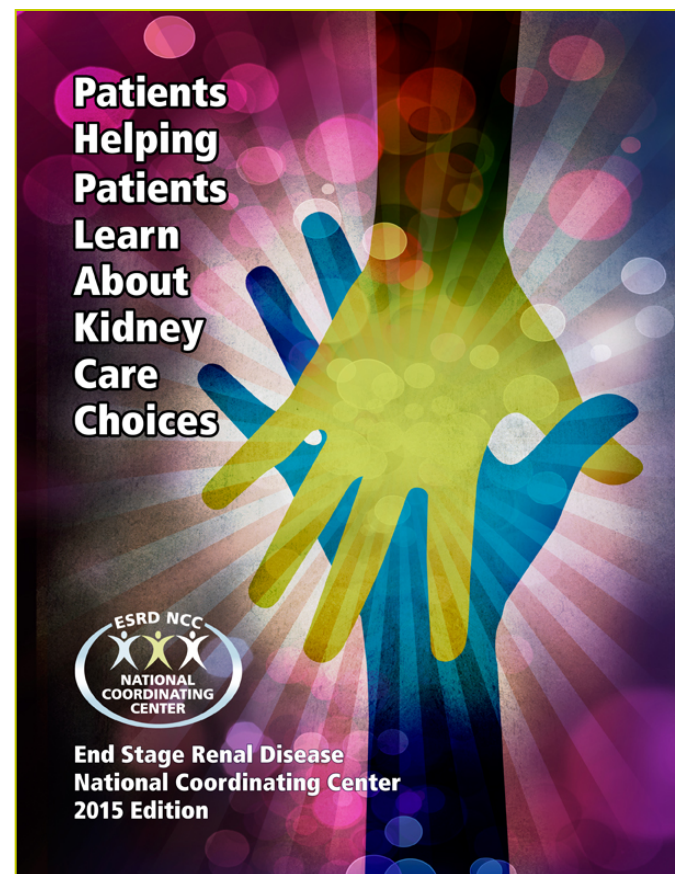


# **Benefits of Peer Mentor**



# Use of Peer Mentors

- Use of national peer mentor training course to develop patients as “Transplant Navigator” patient educators
- Regional PAC Chairs support participating facilities with peer mentor program development
- Facilities with interested peer mentor candidates will partner with Network to support program graduation





# The Role of a Peer Mentor

- Peer mentors can have several roles, including:
  - Providing information,
  - Listening to concerns,
  - Sharing experiences,
  - Promoting positive behavior,
  - Offering encouragement, and
  - Relieving anxiety.



# PEER MENTORS ARE AVAILABLE





# **Patient Perspective Stories**

# List for a Transplant...(again and again)

## Pete Savage

- A brief history
- The Dialysis Center
- Investigating the transplant option
- The Transplant
- Wait listed again
- All of them and no where to go
- “At least I have my wife”



# New Approaches to Transplant

## Ken Teasley

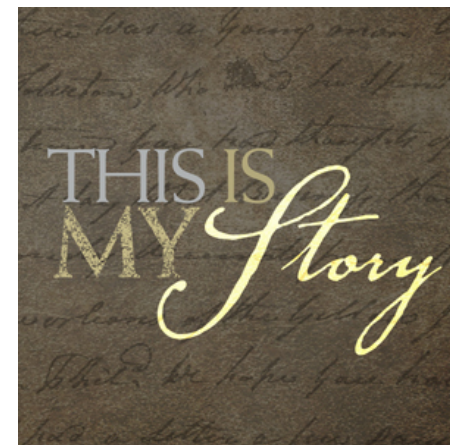
- Getting diagnosed
- Lifestyle adjustments
- Dietary Changes
- Learning about HIV Transplant
- Finding a transplant center
- Participating in research project
- Surgery and Post Surgery Care
- Recovery Process
- Getting back to where you were



# Coping with Complications

## Nelson Nuñez

- Brief history timeline
- Post-transplant experience
- Experiencing Cytomeglovirus
- Medical issues with BK Virus
- Coping with Complications
- Emotional/Physical Impact
- Accepting transplant rejection
- Would I do it all over again?



# Open Forum – Questions/Comments?







# Closing Remarks

# Available Resources

- IPRO website <http://esrd.ipro.org/>
- Transplant Project page  
<http://esrd.ipro.org/qia/2016transplant/>
- Peer Mentor Training Program  
<http://esrd.ipro.org/initiatives/patient-engagement/patient-advisory-committee-pac/peer/>
- Follow and like us on Facebook  
<https://www.facebook.com/IPROESRDProgram/>
- Send input and comments to  
[qualityimprovement@nw2.esrd.net](mailto:qualityimprovement@nw2.esrd.net)



## For more information

---

### **IPRO ESRD Network of New York Patient SME Speakers Bureau**

[Info@nw2.esrd.net](mailto:Info@nw2.esrd.net)

**(516) 209-5578**



**Improving Healthcare  
for the Common Good**

**CORPORATE HEADQUARTERS**  
1979 Marcus Avenue  
Lake Success, NY 11042-1002  
[www.ipro.org](http://www.ipro.org)