ESRD Network of New York
Incorporating the Patient's Voice

May 23, 2017
IPRO ESRD Program Mission Statement

The mission of the IPRO End-Stage Renal Disease (ESRD) Network Program is to promote healthcare for all ESRD patients that is safe, effective, efficient, patient-centered, timely, and equitable.
About IPRO

• Over 30 years in business as a trusted partner to state and federal agencies working to measure and improve healthcare for all

• Headquartered in Lake Success, New York, with clients in more than 33 states, in addition to national contracts

• Currently supporting over 100 government healthcare programs

• Serving as the ESRD Network of New York for more than 10 years

• Now holding four Network contracts
  • Working with stakeholders in 13 states to promote safe, effective, patient centered care to more than 117,000 individuals with ESRD
  • IPRO ESRD satellite offices: Connecticut, North Carolina, and Ohio
Agenda

- Meet the Staff
- Network Demographics
- Patient Engagement
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Network 2 Service Area
Patient Demographics

<table>
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<tr>
<th>Year</th>
<th>Prevalence</th>
<th>Incidence</th>
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<td>2011</td>
<td>25884</td>
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<td>7721</td>
</tr>
<tr>
<td>2016</td>
<td>29532</td>
<td>7683</td>
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Ways We Engage Patients?

- Patient Advisory Committee
- Patient Speakers Bureau
- Subject Matter Experts
- Peer Mentoring Program
Patient Advisory Committee (PAC)

The PAC is a group of active dialysis patients, transplant recipients, care partners, and family members who are committed to improving the quality of life for ESRD patients across New York State.

PAC Representatives:

- Selected by their facility social workers to promote communication among patients and staff
- Inform patients about the ESRD Network
- Serve as a link between patients and the ESRD Network
- Focus on engaging their peers and sharing educational materials
- Involved in the development of our quality improvement activities
- Report to the ESRD Board
- Represented on the IPRO Board of Directors
Patient Advisory Committee

The Network is continuously working to expand PAC membership

- Increased from 645 to more than 700 patients in 2016
- Represents 206 facilities or 75% of the facilities in the Network’s service area
- Eleven regions in NYS - each with a patient appointed PAC Chairperson
- PAC members actively recruit new members through community outreach
Patient Subject Matter Experts (SMEs)

The Network’s Patient Subject Matter Experts provide the patient perspective for all Network initiatives.

Highlights of 2016 activities:

• Served as Network representatives on national initiatives with the Forum of ESRD Networks
• Worked with ESRD National Coordinating Center (NCC) and Kidney Community Emergency Response (KCER) program
• Participated in Network presentations on infection and transplantation
• Attended and presented at the 2016 CMS Annual Quality Conference.
2016 PAC/SME Activities

Local Community Events- Lobby Day Sessions

• The Nephrology Foundation of Brooklyn
• South Brooklyn Dialysis—Brooklyn, NY
• South Nassau Outpatient Dialysis—Oceanside, NY
• “Meet and Greet Social Workers”—Bronx, NY
• Lunch Learn and Live—Restoration Center, Brooklyn
• American Kidney Fund kickoff walk event—Plainview, Long Island
• New York State Chronic Kidney Disease Champions- Cultural Arts Event/SUNY Downstate, Brooklyn
Network and Patient Activities

• **PAC Speaks**: A patient written newsletter

• PAC Members are part of the HAI Learning and Action Network (LAN), Transplant Advisory Committee, Vascular Access Webinars

• PAC Monthly Calls: Monthly feedback for project development and interventions

• Patient Annual Meeting: Face-to-face meeting to discuss strategies for strengthening and expanding the PAC

• Peer Mentor Training Program
Peer Mentorship Training Program

- Structured patient-centered training curriculum
- Peer mentor approach on kidney care health outcomes
- Supportive intervention in quality improvement activities (QIAs)
- Available in multiple formats, online and hard-copy, including both audio and visual components
- Patient developed role-playing scenarios to support patients practice mentoring
- Supplemental resource toolkits developed with patients, for patients.
Program Curriculum

Module #1: Talking Effectively With Another Patient
Module #2: Mentoring to Support Choices
Module #3A: Discussing Transplant as an Option
Module #3B: Helping Peers Plan for a Vascular Access
Program Goals

The Training Program will help patients to:

- Understand peer mentoring
- Become strong leaders
- Develop effective communication skills
- Share resources with other patients on kidney care choices
- Understand the importance of keeping patient information confidential.
Training Program Completion

• Take course either on paper by reviewing the reference guides, presentation slides, or listening to audio/video recordings
• Complete 4 modules and competency quizzes
• Receive a course completion certificate and badge that identifies them as Network-trained Peer Mentors
Summary

Our patient representatives are at the heart of everything we do to accomplish the mission of the IPRO ESRD Network Program.
Thank you.
Enjoy the Meeting!

Susan Caponi, MBA, RN, BSN, CPHQ
CEO, IPRO ESRD Program