Promoting Home Dialysis With Patient-Created Resources: The Role of the National Patient and Family Engagement (NPFE) Learning and Action Network (LAN)

January 14, 2020
What We Will Do on Today’s Call

- Discuss what a LAN is
- Explain how Affinity Groups support the LAN
- Share the vision and goals for the LAN and Affinity Groups
- Review Home Dialysis Affinity Group developed resources
- Hear from a Home Dialysis Affinity Group patient subject matter expert (SME)
NPFE-LAN Team

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AG = Affinity Group
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An Introduction to the NPFE-LAN

• What is it?
  ▪ 90+ ESRD patients and caregivers
  ▪ All modalities—in-center hemodialysis, home therapies (home hemodialysis and peritoneal dialysis), and kidney transplant recipients

• What is the goal?
  ▪ Capture patient and caregiver perspective
  ▪ Foster an “all teach, all learn” environment
  ▪ Share knowledge and experiences
  ▪ Identify and spread promising approaches and best practices to improve care and quality of life
The Work of the NPFE-LAN

- Identify quality improvement activity (QIA) resources
- Adapt resources for patient and caregiver use
- Share resources with ESRD Networks and community partners
- Request Networks to share the resources with their facilities
- Ask SMEs to share resources at their facilities
- Discover partnerships with kidney community stakeholders
- Spread the resources through collaboration, social media, and website postings
NPFE-LAN Alignment to ESRD Networks

• There are 18 ESRD Networks
• All Networks work on QIAs
• All QIAs need ideas from patients and family members
• Patients and caregivers have ideas that can help
What Is an Affinity Group?

Within the LAN there are smaller groups called Affinity Groups (AGs). These groups:

- Work collaboratively to promote communication, choice, and respect. They build on the group’s individual and collective strengths.
- Encourage patient/caregiver SMEs to share their valuable perspectives and ideas to improve the quality of care for all ESRD patients.
- Promote an “all teach and all learn” environment to develop resources and materials that are ultimately put into action and shared beyond the LAN itself.
## Four AG Topics and Goals

<table>
<thead>
<tr>
<th>Topic</th>
<th>Goal</th>
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<tbody>
<tr>
<td>Bloodstream Infection (BSI)</td>
<td>Reduce BSIs</td>
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<tr>
<td>Home Dialysis</td>
<td>Increase patients receiving dialysis at home</td>
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<tr>
<td>Kidney Transplant</td>
<td>Increase patients receiving a transplant</td>
</tr>
<tr>
<td>Patient-Selected Topic</td>
<td>Help patients and caregivers improve their emotional well-being</td>
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*Every QIA is better when it includes patients and family members!*
Polling Question #1
Home Dialysis Affinity Group Told Us …

• Shared the importance of learning what matters to patients
• Identified engaging patients with staff in the discussion about home-treatment modality as an obstacle
• Reported many patients will answer “no” when asked if interested in home dialysis because of lack of education
Polling Question #2
Let’s Talk: Home Dialysis

Conversation Cards

• Developed the Let’s Talk: Home Dialysis conversation cards with questions to start the conversations about dialyzing at home

• Created Discussion Notes for recording answers to the questions
  ▪ Patients are encouraged to share their answers with healthcare team members.

• SME-tested with in-center dialysis patients and newly diagnosed patients
  ▪ “I used the cards to help a young adult recently diagnosed with kidney failure. The cards have helped her understand her treatment choices and how they will impact her life. This individual is now interested in home dialysis as a treatment option.”

Patient Engagement: Using the Resources

• Renita Peck, patient SME, ESRD Network 9
  ▪ Invited to share the conversation cards as part of in-service for dialysis technicians
  ▪ Received favorable input about the purpose of the cards
Questions

Do any of the dialysis facility staff members or ESRD Network staff members have questions, comments, or thoughts about the SME-created resources?
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