



Promoting Kidney Transplantation With Patient-Centered Resources: The Role of the National Patient and Family Engagement (NPFE) Learning and Action Network (LAN)

January 21, 2020

What We Will Do on Today's Call

- Discuss the definition of a LAN
- Explain how Affinity Groups support the LAN
- Share the vision and goals for the LAN and Affinity Groups
- Review Kidney Transplant Affinity Group developed resource
- Hear from a Kidney Transplant Affinity Group patient subject matter expert (SME)

NPFE-LAN Team



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CMS—NPFE-LAN SME

CMS = The Centers for Medicare & Medicaid Services

NPFE-LAN SME Members, Part 1



Albert Diaz-Cruz
Transplant AG



Arthur Thomas
BSI AG



Aula Sumbry
Transplant AG



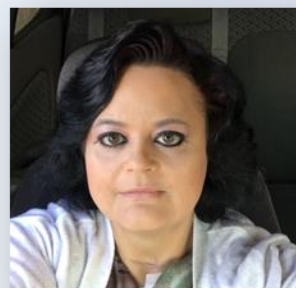
Barry Gardner
Home Dialysis AG



Brenda Dyson
Home Dialysis AG



Brenda Williams
BSI AG



Candida Griffin
Home Dialysis AG



Daniel Perez
Patient Selected Topic AG



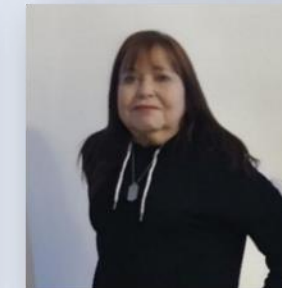
Doris Lew
Patient-Selected Topic AG



Eva Tak
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NPFE-LAN SME Members, Part 2



Lonnie Green
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Renita Peck
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NPFE-LAN SME Members, Part 3



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Tina Gee
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NPFE-LAN SME Members, Part 4



Renee Minor
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Cynthia Tellez
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Norma Cooper
Pt Selected Topic AG



Jose Santiago
Pt-Selected Topic AG

An Introduction to the NPFE-LAN

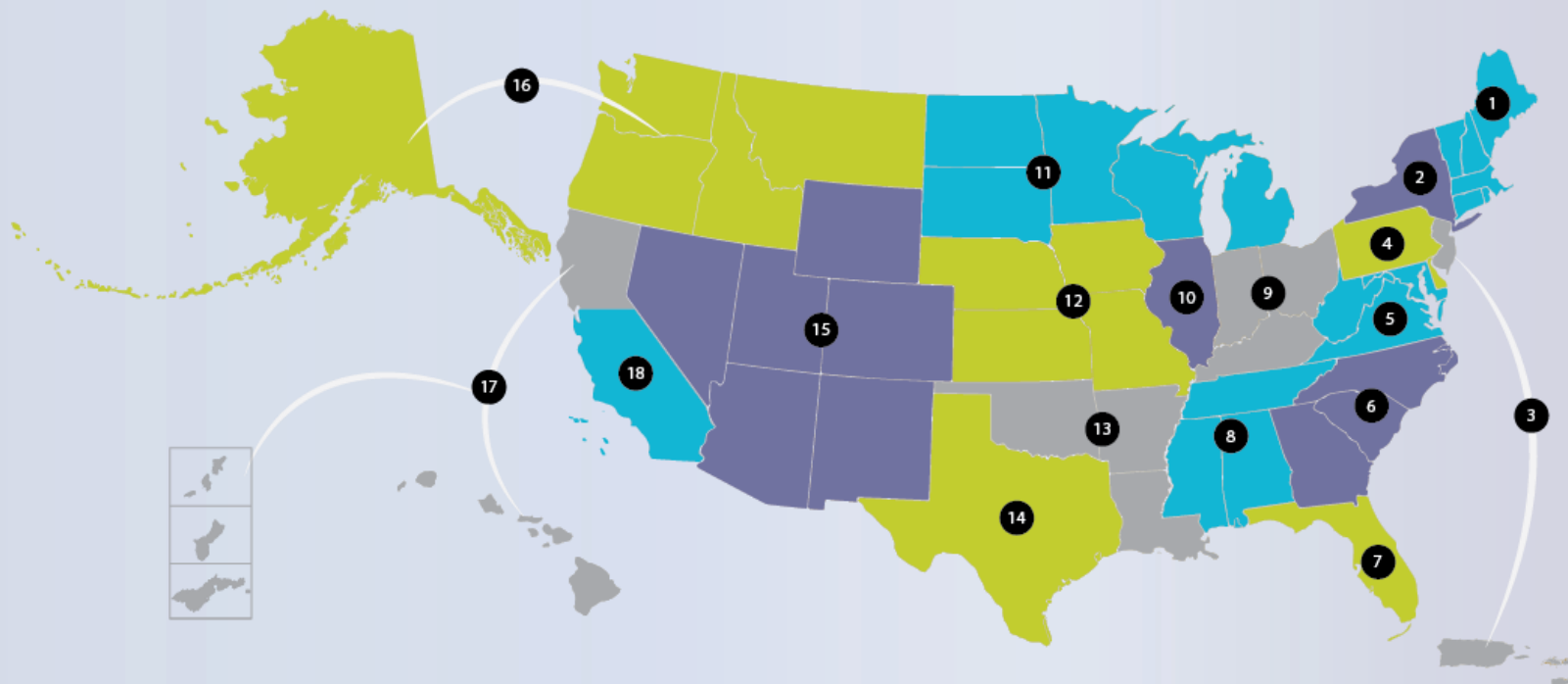
- What is it?
 - 90+ ESRD patients and caregivers
 - All modalities represented—in-center hemodialysis, home therapies (home hemodialysis and peritoneal dialysis), and kidney transplant recipients
- What is the goal?
 - Capture patient and caregiver perspective
 - Foster an “all teach, all learn” environment
 - 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

Topic	Goal
Bloodstream Infection (BSI)	Reduce BSIs
Home Dialysis	Increase patients receiving dialysis at home
Kidney Transplant	Increase patients receiving a transplant
Patient-Selected Topic	Help patients and caregivers improve their emotional well-being

Every QIA is better when it includes patients and family members!

Polling Question #1

Kidney Transplant Affinity Group Told Us...



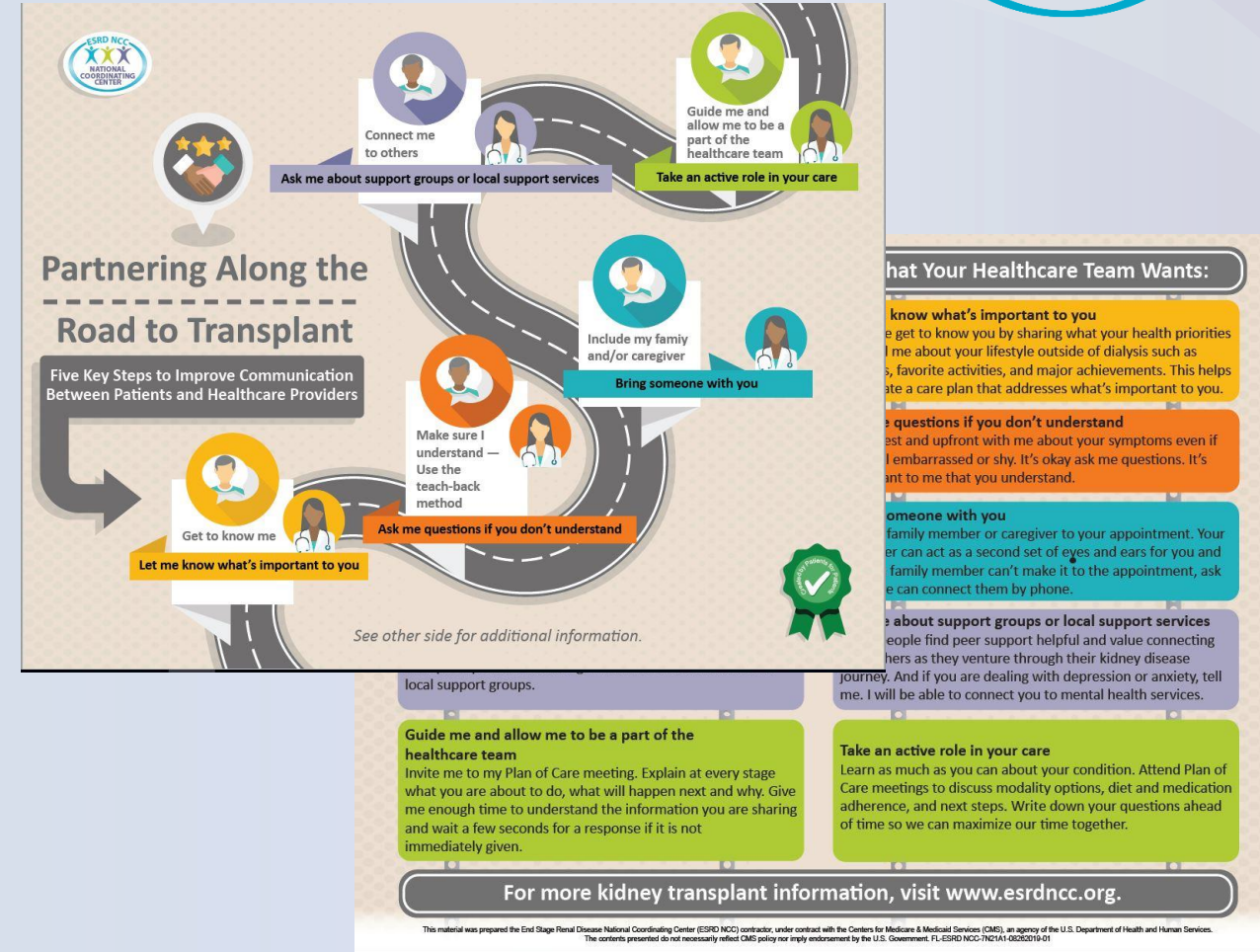
- Develop resource to help improve communication between the patient and his or her healthcare team
- Create statements to inspire discussion between patients and healthcare professionals about kidney transplant options
- Educate their healthcare team about their healthcare goals as well as their personal goals
- Partner with their healthcare team to get on the transplant waitlist

Partnering Along the Road to Transplant



A communication guide for patients and healthcare providers

- Five key concepts:
 - Get to know me
 - Make sure I understand
 - Include my family
 - Connect me to others
 - Guide me to treatment options
- English:
 - <https://www.esrdncc.org/en/resources/patients/treatment-choices/lets-talk-home-dialysis/>
- Spanish:
 - <https://www.esrdncc.org/en/resources/patients/treatment-choices/lets-talk-home-dialysis/>



Polling Question #2

Patient Engagement in Kidney Transplant

- Timmy Nelson, patient SME
 - Visited five dialysis facilities
 - Shared resources with 86 patients and caregivers
 - 41 people expressed interest in learning more about the kidney transplant process



Timmy Nelson, SME

Question

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

Important Contact Information

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