



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



Jerome Bailey
Associate Director, PFE

Kim Buettner
Associate Director, PFE



Gequincia Polk
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



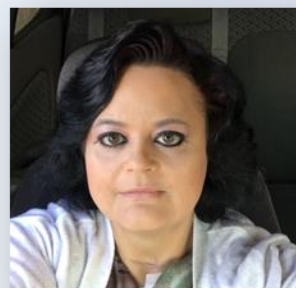
Barry Gardner
Home Dialysis AG



Brenda Dyson
Home Dialysis AG



Brenda Williams
BSI AG



Candida Griffin
Home Dialysis AG



Daniel Perez
Patient-Selected Topic AG



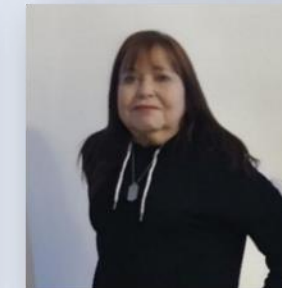
Doris Lew
Patient-Selected Topic AG



Eva Tak
Home Dialysis AG



John Bayton
Home Dialysis AG



Julie Crandall
Transplant AG

NPFE-LAN SME Members, Part 2



Lonnie Green
Patient-Selected Topic AG



Loren Woolery
Transplant AG



Maria Casa
BSI AG



Maria Robinson
BSI AG



Michael Butler
Home Dialysis AG



Neltje Gedney
Home Dialysis AG



Olga Hernandez-Perez
BSI AG



Renita Peck
Home Dialysis AG



Rowena Novy
Transplant AG



Sergio DeHaro
BSI AG



Sardeliah Pearson
BSI AG



Subrina Fields
Transplant AG

NPFE-LAN SME Members, Part 3



Tim Nelson
Transplant AG



Yalonda Moore
Home Dialysis AG



Andrew Moncada
Transplant AG



Brenda Taylor
Home Dialysis AG



Candise Washington
Pt Selected Topic AG



Nelson Nunez
Home Dialysis AG



Patrick Gee
Transplant AG



Tina Gee
Pt-Selected Topic AG



Yvonne Steele
Home Dialysis AG



Willie Washington
BSI AG

NPFE-LAN SME Members, Part 4



Renee Minor
Transplant AG



Cynthia Tellez
BSI AG



Norma Cooper
Pt Selected Topic AG



Jose Santiago
Pt-Selected Topic AG

An Introduction to the NPFE-LAN

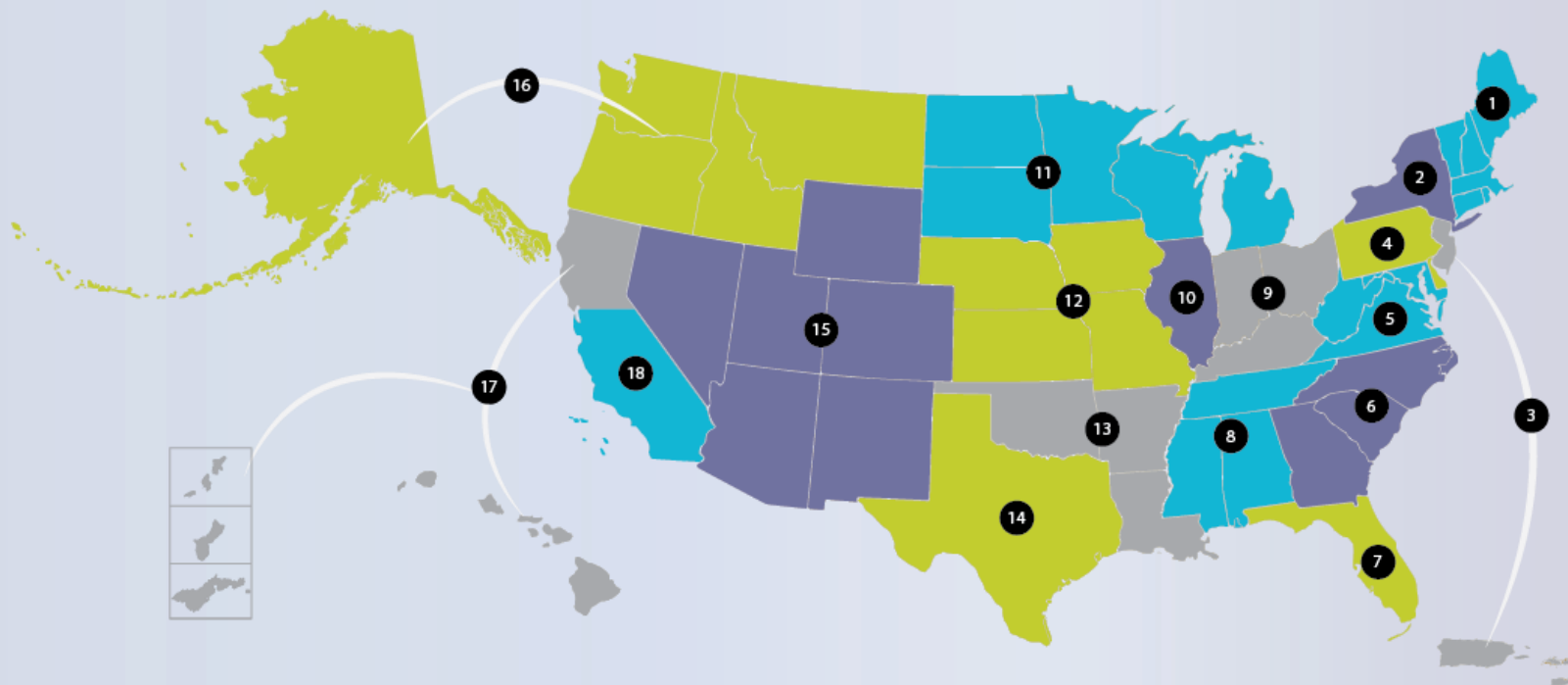
- What is it?
 - 90+ ESRD patients and caregivers
 - All modalities—in-center hemodialysis, home therapies (home hemodialysis and peritoneal dialysis), and kidney transplant recipients
- What is the goal?
 - Capture patient and caregiver perspective
 - Foster an “all teach, all learn” environment
 -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

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.”

<https://www.esrdncc.org/en/resources/patients/treatment-choices/lets-talk-home-dialysis/>



 **Let's Talk: Home Dialysis Discussion Notes**

Write down your thoughts. Take it to your next kidney appointment or dialysis treatment. Share your answers with your healthcare team. Ask to talk about your home dialysis treatment options.

 Quality of Life	Notes:
 Flexibility	Notes:
 Family	Notes:
 Travel	
 Diet	

This material was prepared by the ESRD NCC National Coordinating Center. © 2015


Let's Talk: Home Dialysis

Questions to Spark Conversation

A Tool for Patients and Family Members




Let's Talk:
Health and Quality of Life



What do you already know about home dialysis?

7

Let's Talk: Flexibility



Are you willing to do your own dialysis?
If no, why not?

10

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



Renita Peck, SME

Questions

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

- **Jerome Bailey**, *Associate Director, PFE*
 - Call: 813.865.3542
 - Email: JBailey@ncc.esrd.net
- **Kim Buettner**, *Associate Director, PFE*
 - Call: 813.865.3608
 - Email: KBuettner@ncc.esrd.net