

National Patient and Family Engagement- Learning and Action Network (NPFE-LAN) Peer Connection Call

July 20, 2023



Before We Get Started

Please be respectful and remember:

- All lines are muted.
- The lines will be unmuted for questions.
- This call is being recorded and will be made public.
- Do not disclose any personally identifiable information.
- Do not ask for medical advice.
- Each person's situation and experience is unique.
- Before making changes to your health practices, speak with a member of your healthcare team.



Disclaimer

The views and opinions expressed during this call are those of the panelists and do not necessarily reflect the official policy or position of the End Stage Renal Disease (ESRD) National Coordinating Center (NCC) or the Centers for Medicare & Medicaid Services (CMS). Any content provided by the panelists is of their opinions and is not intended to substitute for professional medical advice, diagnosis, or treatment. Always seek the advice of your physician or other qualified health provider with any questions you may have regarding a medical condition.



Today's Moderators

Emma Okamoto



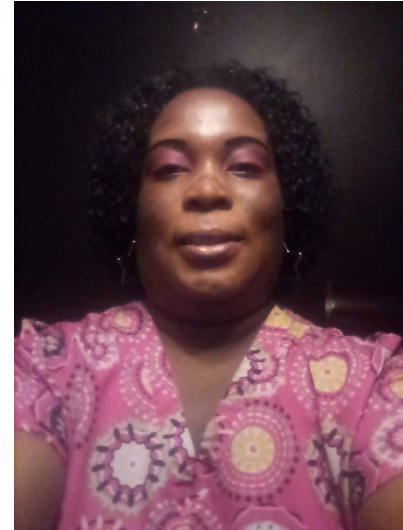
Stephanie Hull



Care Partners– Subject Matter Experts



Katie McAllister
Kidney Care Partner

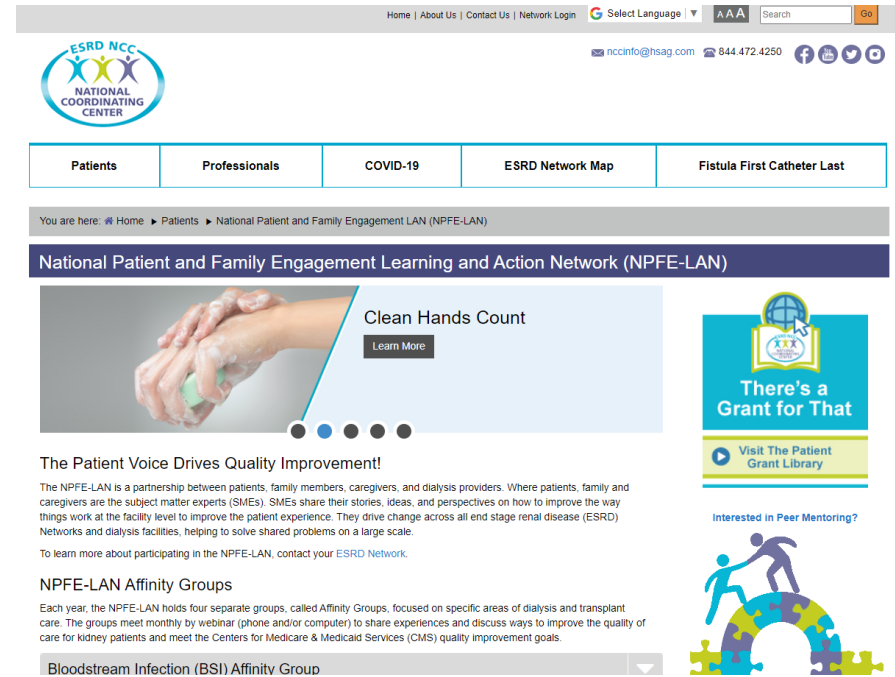


Verneeky Jackson
Kidney Care Partner

Patient and Care Partner Resources

For tools and resources to help you in your kidney disease journey, visit : esrdncc.org/en/patients/national-patient-and-family-engagement-lan-npfe-lan/

- Caregiver/Care Partner
- Depression
- Home Dialysis
- Kidney Transplant



The screenshot shows the website for the ESRD NCC National Coordinating Center. The header includes navigation links (Home, About Us, Contact Us, Network Login), a language selector, and a search bar. The main navigation menu has tabs for Patients, Professionals, COVID-19, ESRD Network Map, and Fistula First Catheter Last. The breadcrumb trail indicates the current location: Home > Patients > National Patient and Family Engagement LAN (NPFE-LAN). The main content area features a banner for 'Clean Hands Count' with a 'Learn More' button, a section titled 'The Patient Voice Drives Quality Improvement!' with a 'Learn More' button, and a 'There's a Grant for That' section with a 'Visit The Patient Grant Library' button. A 'Bloodstream Infection (BSI) Affinity Group' dropdown menu is visible at the bottom.



Home Dialysis Caregiver



<https://www.youtube.com/watch?v=HVk07YIOAtc>

Tips for Kidney Caregivers

From kidney patients who appreciate their support and the caregivers who understand the experience. Read through the tips and check the boxes you want to accomplish.

Tip 1—Talk About It

The person diagnosed with kidney disease may not act like the person you knew prior to starting treatment. Get to know them as they adjust to treatments. If you have a hard time talking with your loved one, ask to speak with the social worker or another member of the care team.

To keep the lines of communication open:

- Be honest with your feelings and talk about concerns together.
- Do something together, such as taking a walk while you talk.
- Listen openly, stay positive, but don't feel you have to have all the answers.



Tip 2—Be Prepared

Kidney disease comes with many changes and different treatment options.

To learn about kidney disease:

- Visit www.esrdncc.org for resources.
- Create a list of your loved one's medications and
- Talk to a healthcare professional about kidney re

Tip 3—Set a Schedule

A daily plan keeps things on track and lets you see it can also highlight if there is a need to ask others

To start your schedule:

- Write down and prioritize your daily and weekly to
- Ask for help when you need it.
- Plan for breaks.



Tip 4—Take Time for You

It's okay, and necessary, to take time for yourself. A Care Team When you feel recharged, you're better able to help

To use a moment for you:

- Take 30 minutes and go to your favorite place.
 - Try a relaxation method, such as yoga or meditat
 - Find local and online support groups or talk to a f
- (Contact your End Stage Renal Disease Network f



¹Bova-Collis R, MSW, LCSW. A Caregiver's Wish List: Tips on How D [online] Nov. 2011. Available at: <http://askp.org/a-caregivers-wish>. Accessed on June 6, 2015.

Important Medical Information

Name Phone/email Additional Info

Medication Reaction

Medication Allergies

Name Phone/email Additional Info

Other Important Numbers

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Understanding How Dialysis Makes Me Feel, and How You Can Help

Dialysis is a medical treatment that does some of the things that healthy kidneys usually perform. The treatment can be performed at a dialysis center, or it can be performed at home. During the treatment, the patient is connected to a dialysis machine. The machine removes blood from the body, cleans it, and returns the clean blood back to the body. This process can take 3 to 5 hours. And it's done at least 3 times a week.

The treatment can leave the patient very tired. The patient may need to rest or may need help doing things that he/she normally would not have trouble doing. If you are a caregiver, family member, or friend to someone who receives dialysis treatment, here are some ways you can support the dialysis patient.

How I Feel After Dialysis Treatment	How You Can Help
I feel tired after treatment.	Let me sleep. It may be for an hour. It may be for 3 hours. My body needs time to recover.
I have an upset stomach, or I want to vomit.	Allow me to lay down. Offer me crackers or sip of Ginger Ale.
My skin itches.	Remind me to keep my skin moisturized. I may also need help finding foods with less phosphorus.
I'm hungry.	Help me make food to eat.
I don't feel like eating.	Make sure I eat something. Offer me a small snack instead of a big meal.
My mouth is dry.	Offer me a hard candy, frozen grapes, a lemon to suck on, or mouth wash to soothe my mouth. Don't give me water.
I feel dizzy or have blurred vision.	Let me sit down for 15–30 minutes.
My muscles are cramping.	Help me talk to my dialysis team about my treatment plan.
I feel overwhelmed.	Suggest listening to music, writing down my feelings, taking a hot bath, or going for a walk.
My blood pressure dropped.	Help me talk to my dialysis team about my treatment plan.
My body shakes.	Let me lay down when I get home and cover up with a blanket.
I feel moody.	Give me some time to be by myself. Don't keep asking if something is wrong.



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Thank You

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