



Kidney Community Emergency Response Program
National Patient and Family Engagement
Patient/Caregiver Subject Matter Expert

2019 Guidebook



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“Believe in yourself. You are braver than you think, more talented than you know, and capable of more than you imagine.”

—Roy T. Bennett

Welcome Subject Matter Expert (SME),

Thank you for agreeing to volunteer as a member of the National KCER Patient and Family Engagement Learning and Action Network (N-KPFE-LAN).

The role of a SME is an important one. This guidebook will explain more about what your role as a patient or caregiver SME will be, including:

- How you can help.
- What is expected of you.
- Who KCER is.
- What KCER, with your help, strives to achieve.

After you have had a chance to read this guidebook, please let us know if you have any questions. Your time and effort are greatly appreciated. We welcome every opportunity to connect with you and look forward to your input and partnership.

Sincerely,

The KCER Team

What is KCER?

KCER serves as the leading authority on emergency preparedness and response for the end stage renal disease (ESRD) community. The KCER Program provides organization and guidance to seamlessly bridge the needs of emergency management stakeholders and the ESRD community nationwide. The goals of the KCER Program are to:

- Raise public awareness of:
 - The critical needs of people with kidney failure.
 - The need to plan ahead to ensure that life-saving dialysis services are obtainable in the event of an emergency and/or disaster.
- Promote and distribute tools and resources to:
 - Individuals with kidney failure.
 - Dialysis facilities.
 - Federal, state, and emergency workers.
 - ESRD Networks
- Test and refine the existing national response strategy to assist federal, state, and local efforts in the event of an emergency and/or disaster.

“One emergency resource I wish I had when starting dialysis was the emergency preparedness tools that KCER has created. Such resources would have taught me how to prepare for a disaster.”

-2018 N-KPFE-LAN SME

What is a LAN?

A LAN brings people together to solve a shared problem on a large scale. The N-KPFE-LAN is a group of patients, caregivers, healthcare professionals, other interested groups of people who work together to improve emergency preparedness for ESRD patients. LANs value the knowledge that members bring to the group. LANs use the information and ideas shared by members, like you, to make improvements quickly through many small changes. These small, quick improvements can add up to make a big difference in the lives of ESRD patients.

Your Role

You were nominated to be a SME by your ESRD Network. Your Network staff believes you have a lot to contribute about the patient/caregiver experience. Your input will add greatly to the ESRD community emergency preparedness improvement efforts and to meeting national goals set by the Centers for Medicare & Medicaid Services (CMS). We agree.

Your role may include:

- Helping with the creation and development of educational resources for patients and caregivers.
- Reviewing KCER materials to make sure they are meeting the needs of patients and are “patient-centered.”
- Joining bi-monthly conference calls.
- Providing the patient/caregiver perspective on KCER activities.
- Spreading the work of KCER and increasing overall awareness.

SME Participation Guidelines

As a volunteer for the N-KPFE-LAN there are requirements for your participation:

- Sign and return the N-KPFE-LAN agreement, if you have not already done so.
 - The agreement form includes a waiver that permits us to share your voice through pictures, writing, and video/photographic formats.
- If you have any changes in your contact information (phone number, email, or mailing address), please let a KCER staff member know as soon as possible.
 - This ensures we can stay in touch with you.
- Actively participate during the bi-monthly conference calls and Webex® meetings.

- Your perspective makes a difference, so we ask that you attend the calls regularly.
- If you are unable to attend a call, please let a KCER staff member know as soon as possible. A staff member will provide you a summary of the call to allow you to give input if you choose to do so.

Recommendations for Participation in LAN Meetings

You were nominated to be a SME because you are an expert in understanding the patient or caregiver perspective and want to make meaningful change. The information below will assist you in in this role.

- Before the meetings/calls, whenever possible:
 - Prepare to join the meeting in a quiet location and keep your phone on mute unless you are speaking.
 - Background noises are easily heard during phone conferences.
 - Please read the materials sent to you prior to the meeting.
 - Your meeting information will arrive at least three days before the meeting.
 - Plan for what you will share during the meeting.
 - Because all SMEs will have an opportunity to share their ideas, it is helpful to plan for what you will share.
- Sharing during the meetings:
 - N-KPFE-LAN meetings are unique because they give SMEs the opportunity to share their experiences.
 - Collectively those experiences are shared with CMS.
 - There may be times when you decide to share your personal experiences.
 - Remember, only share what you are comfortable with others knowing about you and your situation.
 - If you share about something that did not go well, it's helpful to offer suggestions on what would have made it better for you.
 - Think about the words you use to tell your story.
- After the meetings:
 - Please complete the post-meeting evaluation.
 - Your feedback is essential.
 - You are encouraged to talk with fellow patients, friends, community members, and healthcare professionals regarding your work with KCER.
 - The feedback you receive from others could assist with the development of KCER resources.

- When the KCER resources are finalized, you will be invited to share the resources with fellow patients, friends, community members, and healthcare professionals.

Sharing Your Input Outside of the Meetings

Your role as a SME goes beyond the monthly meetings and providing input during the calls. Below are a few suggestions to help make sure your perspectives are spread beyond the KCER meeting discussions.

- Meeting Pre-Work:
 - You may be asked to share your thoughts as part of meeting prework.
 - Pre-work questions are valuable and the information you provide is included in meeting minutes.
- Document Review:
 - You may be asked to review documents and provide feedback through emails or electronic communications.
 - Sharing your perspective on these documents can make an impact.
 - If you are able, take part in any email or electronic forums conducted by the N-KPFE-LAN.
 - If you miss a meeting, review the meeting minutes and share your thoughts about what was discussed with the KCER staff.

“I wasn’t sure at the beginning of the year where all this was going. But real progress got made and positive improvements achieved. Satisfied. I would do it again.” -2018 N-KPFE-LAN SME

Health Insurance Portability and Accountability Act of 1996 (HIPAA) and the Privacy of Medical Information

You are receiving information about HIPAA because, as a SME, you might hear health information about other patients. It is important to know how that information should be protected and why.

What is HIPAA?

HIPAA is the legislative act that protects the healthcare privacy of all Americans. Basically, HIPAA ensures that all information about your health is private and should be kept private.

Sharing Your Medical Information with Other Patients

You may choose to share your health information with others, but that is up to you. If someone shares their health information with you, you must keep it confidential.

Don't Give Medical Advice

As ESRD patients, you have a lot to teach each other; and you are free to share your own experiences. But be careful! ***Never act as an authority regarding medical information. Never give medical advice.*** Medicines or a diet that works for you may be dangerous or even deadly to another patient. Even a tiny difference in a person's medical condition can make a difference. Remember, you are the expert on being a patient or caregiver. Medical professionals are the experts on healthcare. The best medical help you can give to another patient is to send them to the right staff member.

Acronym Guide

There are many acronyms or abbreviations used in healthcare discussions. Below is a list of common abbreviations that may be used during meetings.

A	
AAKP	American Association of Kidney Patients
AKF	American Kidney Fund
AVF	Arteriovenous Fistula
AVG	Arteriovenous Graft
B	
BMI	Body Mass Index
BP	Blood Pressure
BSI	Bloodstream Infection
C	
CAPD	Continuous Ambulatory Peritoneal Dialysis
CCPD	Continuous Cycling Peritoneal Dialysis
CDC	Centers for Disease Control and Prevention
CKD	Chronic Kidney Disease
CM	Clinic Manager
CMS	Centers for Medicare & Medicaid Services
E	
EMR	Electronic Medical Record
ESRD	End Stage Renal Disease
ESRD NCC	End Stage Renal Disease National Coordinating Center
F	
FA	Facility Administrator
H	
HAI	Healthcare-Associated Infection
HD	Hemodialysis
HHD	Home Hemodialysis
HIPPA	Health Information Portability and Accountability Act of 1996
HSAG	Health Services Advisory Group, Inc.
I	
ICHD	In-Center Hemodialysis

ICH CAHPS	In-Center Hemodialysis Consumer Assessment of Healthcare Providers and Systems
K	
KDOQI	Kidney Disease Outcomes Quality Initiative
KDQOL	Kidney Disease Quality of Life Survey
L	
LAN	Learning and Action Network
LDO	Large Dialysis Organization
N	
NCC	National Coordinating Center
NKF	National Kidney Foundation
NPFE LAN	National Patient and Family Engagement Learning and Action Network
P	
PA	Physician Assistant
PCP	Primary Care Physician, Primary Care Provider, Primary Care Practitioner
PD	Peritoneal Dialysis
PFE	Patient and Family Engagement
Q	
QAPI	Quality Assessment and Performance Improvement
QI	Quality Improvement
QIA	Quality Improvement Activity
R	
RCA	Root Cause Analysis
S	
SME	Subject Matter Expert
U	
UNOS	United Network of Organ Sharing

Here's What KCER SMEs are saying about sharing the patient created resources:



Emergency Preparedness Checklist and Tips

An emergency can happen at a moment's notice.
Act now and prepare before disaster strikes!

This checklist will help you get started.

You're not prepared if you cannot check these items on your plan:

- My dialysis facility has the current street address and phone number(s) needed to contact me and/or household member(s) or care partner(s).
- I have discussed my emergency plan and my dialysis facility with my household members.
Dialysis facility name: _____
Dialysis facility address: _____
Dialysis facility telephone number: _____
- I have a back-up plan to get care if my dialysis facility is closed.
Alternative dialysis facility: _____
Alternative dialysis facility address: _____
Alternative dialysis facility telephone number: _____
- I have a copy of my current treatment prescription record.
- I check the items in my emergency kit every six months to ensure they have not expired and are working properly.
- I review and update my emergency list at least every six months.
Use this list to help you build your emergency kit:
 - Prescription medications and list of medications
 - Insurance and/or Medicare card
 - Current copy of monthly lab report
 - First aid kit
 - Bottled water
 - Non-perishable food
 - Cash
 - Spare glasses
 - Manual can opener
 - Warm blanket
 - Battery-powered radio
 - Flashlight with extra batteries
 - Cell phone with charger
 - Books, games, puzzles
 - Contact list of healthcare members
 - Picture ID
 - Car tank full of gas/alternative transportation

Patient Assistance Hotlines

ARA: 888-550-6967 CA/VA: 800-463-8321 DC: 800-424-1930 FL: 800-424-1930 GA: 800-424-1930 HI: 800-424-1930 IL: 800-424-1930 IN: 800-424-1930 IA: 800-424-1930 KS: 800-424-1930 KY: 800-424-1930 LA: 800-424-1930 MA: 800-424-1930 MD: 800-424-1930 MI: 800-424-1930 MN: 800-424-1930 MO: 800-424-1930 MS: 800-424-1930 MT: 800-424-1930 NC: 800-424-1930 ND: 800-424-1930 NE: 800-424-1930 NH: 800-424-1930 NJ: 800-424-1930 NV: 800-424-1930 NY: 800-424-1930 OH: 800-424-1930 OK: 800-424-1930 OR: 800-424-1930 PA: 800-424-1930 RI: 800-424-1930 SC: 800-424-1930 SD: 800-424-1930 TN: 800-424-1930 TX: 800-424-1930 UT: 800-424-1930 VT: 800-424-1930 WA: 800-424-1930 WI: 800-424-1930 WY: 800-424-1930

ESRD Network:

Emergency Disconnect Procedure for In-Center Hemodialysis Patients

If you are on a dialysis machine during an emergency:

- Stay calm.
- Wait for instructions from a dialysis staff member.
- If a staff member is NOT available to help you and you need to disconnect yourself from a dialysis machine, follow these steps:

1



Close each clamp on your access needles before the red and blue connection points.

2



Close the two clamps on the thick tubing coming from the hemodialysis machine.



Unscrew the lines between the two sets of closed clamps at the red and blue connection points.

These instructions are for emergency situations only.

WARNING: If you have a catheter that is used for treatment, DO NOT disconnect yourself! A healthcare team member will further assist you.



I AM ON DIALYSIS.

VITAL INFORMATION

NAME: _____
 Network: _____ Toll-Free #: _____
 Kidney Community Emergency Response (KCER) Program
www.kcercoalition.com

Medication	Dose	Frequency

Pharmacy Phone: _____
 Special Needs: _____
 Diagnosis: _____
 Allergies: _____

PERSONAL INFORMATION

Address: _____
 Home Phone: _____
 Cell Phone: _____
 Emergency Contact: _____
 Relationship: _____
 Emergency Contact Phone: _____
 Nephrologist: _____
 Nephrologist Phone: _____

DIALYSIS PRESCRIPTION

Hours: _____ Times per week
 Dialyzer: _____
 Dialysate: _____
 Medicare #: _____
 Medicaid #: _____
 Other Insurance ID: _____

FACILITY

Name: _____
 Phone: _____

"We have a lobby day coming up in about emergency preparedness, and I will share these resources during that time."

2018 KCER SME

"I provided copies of the materials to the dialysis clinic manager."

2018 KCER SME

"I shared the checklist with several patients. Each of them realized that they were not as prepared as they thought they were. The checklist is something that will be useful to everyone, particularly the information regarding prescriptions and packing an emergency kit."

2018 KCER SME

"I've been in contact with my former dialysis clinic, and I plan to share these resources with the social worker at the clinic."

2018 KCER SME

"I host a support group at my former transplant center and I will be sharing the resources with the group members."

2018 KCER SME

Below is a listing of kidney-related websites that provide information for patients and families.

American Association of Kidney Patients (AAKP)	www.aakp.org
American Kidney Fund (AKF)	www.kidneyfund.org
Dialysis Patient Citizens (DPC)	www.dialysispatients.org
ESRD NCC	www.esrdncc.org
ESRD NCC NPFE LAN	www.esrdncc.org/npfe-lan
Forum of ESRD Networks	www.esrdnetworks.org
Kidney Community Emergency Response Program (KCER)	www.kcercoalition.com
National Kidney Foundation (NKF)	www.kidney.org
ESRD NCC QIA LAN	https://www.esrdncc.org/en/qia/
United Network for Organ Sharing (UNOS)	www.unos.org

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