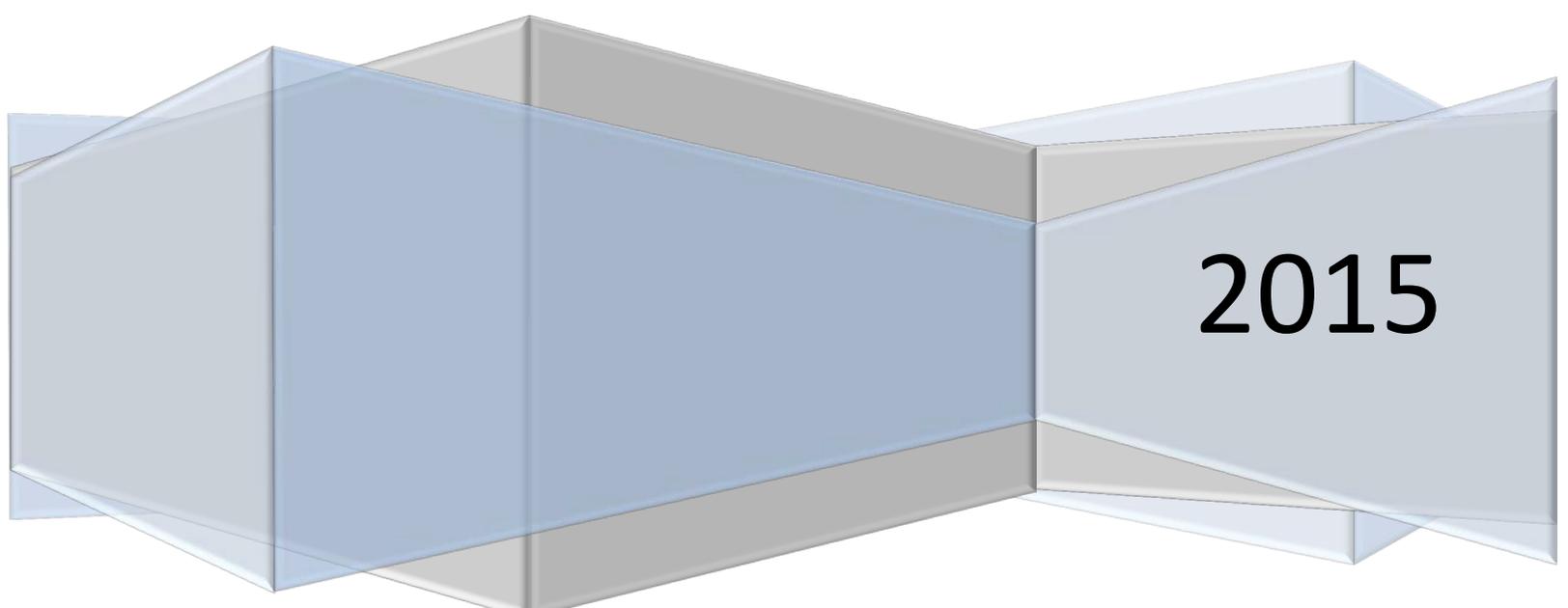


**End Stage Renal Disease Network of Texas, Inc.**

# **Facility Patient Representative Handbook**



**2015**

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\* See the **Commonly Used Terms** section at the back of this handbook for more information.

## Facility Patient Representative Handbook

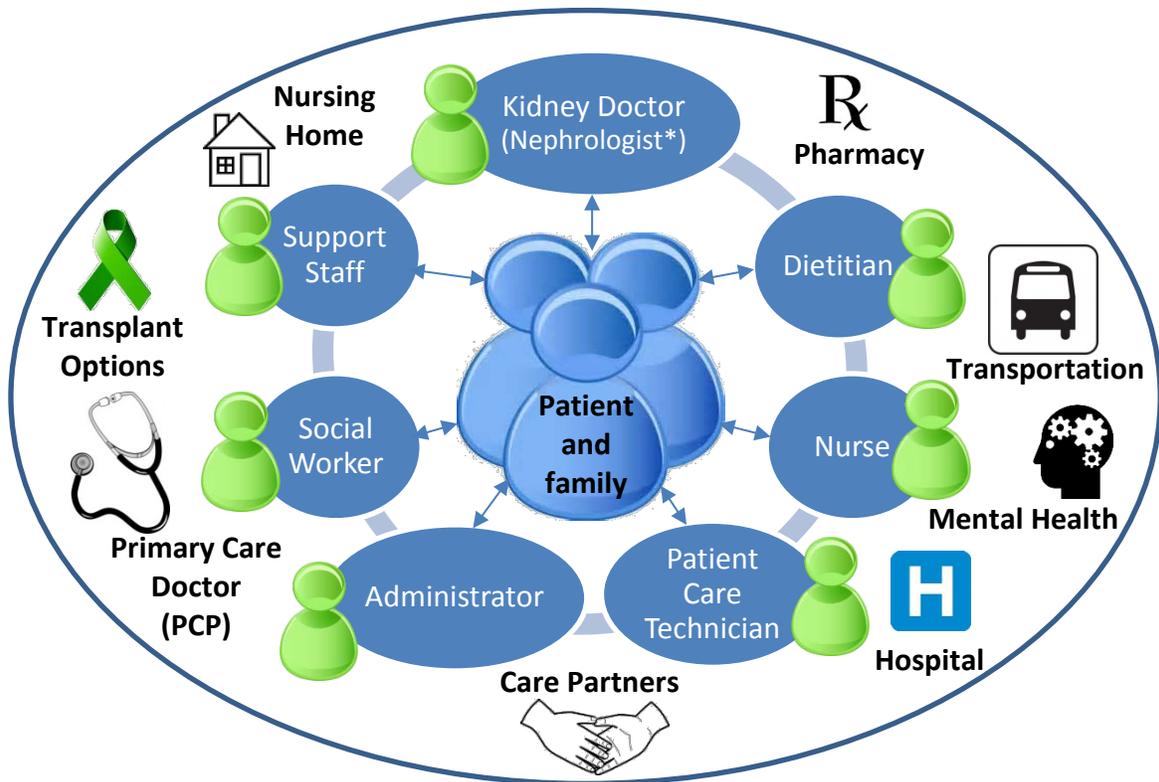
Thank you for agreeing to serve as a Facility Patient Representative (FPR) for your local dialysis center. The most important person on the healthcare team is YOU, the patient! That's why FPRs are so important.

FPRs do many different things in dialysis centers, but your most important responsibility is to help the staff at your center understand what is important to patients and how they feel about their dialysis care. This will help your dialysis center improve and help you become more involved and plan your care.

This handbook is intended to:

- Tell you about the *End Stage Renal Disease\** (ESRD) program and the ESRD Networks
- Give you and your center some guidelines to help you be the best FPR you can be
- Explain how patients get involved in improving dialysis care

**When YOU are at the center of your care,  
you and your family are surrounded by healthcare professionals and services!**



**Figure 1.** Patients and families are surrounded by dialysis center staff and community resources.

\* See the **Commonly Used Terms** section at the back of this handbook for more information.

## What is a Facility Patient Representative (FPR)?

FPRs are the link between the other patients and the center's managers and staff. To improve *patient- and family-centered care*\* in the state of Texas, every dialysis center is asked to pick at least one patient to serve as a Facility Patient Representative (FPR).

### What do FPRs do?

Every person has skills and experiences that can help improve care at their dialysis centers. The things that you are good at doing might be different than the things another FPR is good at doing. Take time to share your talents and ideas with staff and learn more about the center. Together, YOU can decide how YOU can make a difference!

Here are some of the ways that FPRs might help at their centers:

- Identify themselves as FPRs and welcome new patients
- Help staff give out information
- Mentor or coach other patients by helping them understand handouts.
- Go to the first 10 or 15 minutes of the monthly quality meeting (*Quality Assessment and Performance Improvement*\*) and/or *governing body*\* meetings to help staff understand patient concerns
- Help with lobby day education
- Work with staff to start and run patient and family groups like Patient Advisory Councils or support groups
- Start a newsletter for your center
- Write articles or poems for the Network newsletter
- Plan patient and staff events like picnics, holiday parties, and art shows
- Decorate the center for holidays and events
- Participate in community health fairs
- Share information about organ donation
- Help patients understand how to work with staff to fix problems
- Make a patient bulletin board and/or activity calendar
- Organize team events like a Kidney Walk
- And many more!

\* See the **Commonly Used Terms** section at the back of this handbook for more information.

## How can FPRs help patients that have concerns?

When another patient has a concern, you might be able to help. Here are some steps that you should follow to help improve care at your facility:

- Encourage the patient to talk to staff about the concern. It is always best if the patient can explain the problem to staff in his or her own words.
- If the patient is not comfortable talking to staff, ask the patient for permission to share his or her concern with staff. You should never share ANY information with staff or other patients without permission.
- Take a positive approach to all concerns; be cheerful and approach staff at the right time with questions or concerns. Your thoughtfulness will be appreciated!
- Most dialysis companies have a Guest Services department at the corporate level that may be able to help with patient concerns. If the patient is not satisfied with the answer from the center's staff, you can ask the administrator for the corporate contact information.
- If the problem can't be fixed at your dialysis center or at the corporate level, the patient may need to file a grievance. You can share ESRD Network 14's toll-free phone number, 1-877-886-4435, with patients that would like to discuss concerns or questions about the quality of their care. You should not file a grievance for another patient.
- You can help patients understand that they have the right to file a grievance. They can't be retaliated against for filing a grievance with the facility or the Network; federal regulations covering dialysis and transplant centers protect patient rights.

## What should FPRs NOT do?

There are some things that FPRs should avoid doing. You should not:

- Try to train or manage staff members
- Ask staff or patients about confidential patient information
- Post or share information that has not been approved by the clinic manager
- Share the concerns of another patient without the patient's permission

\* See the **Commonly Used Terms** section at the back of this handbook for more information.

## HIPAA and Medical Information

### What does *Patient Confidentiality* mean?

Information about your health is private. This means that health information should only be shared with staff that needs the information to give medical care.

The Health Insurance Portability and Accountability Act of 1996 (HIPAA\*) is a law that protects the privacy of individually identifiable health information. FPRs do not have the right to see the medical information of other patients.

However, patients do have the right to share their OWN personal information. Some patients may choose to tell FPRs about their health. If this happens to you, you must keep the other patients' health information confidential. It is very important for patients to feel that they can trust FPRs to protect their privacy.

**You should not share any information that you learn about another patient with anyone unless the patient tells you it is okay and puts it in writing.** For example, you should get permission to use a patient's name and birthday in a newsletter or calendar. The patient should write down the information that is okay to share and sign it.

There is one exception to this rule. If a patient plans to harm himself/herself and/or someone else, you have a responsibility to tell your staff. Safety first!

### Can I share MY medical information with other patients?

As an ESRD patient, you have a lot to teach other patients about kidney disease. You can share your own experiences, but you should not give medical information or advice. Medicines or a diet that work for you may be dangerous or even deadly to another patient with different medical conditions. Remember, YOU are the expert on being a patient and medical professionals are the experts on health care.

You can help other patients by sending them to the right staff member:

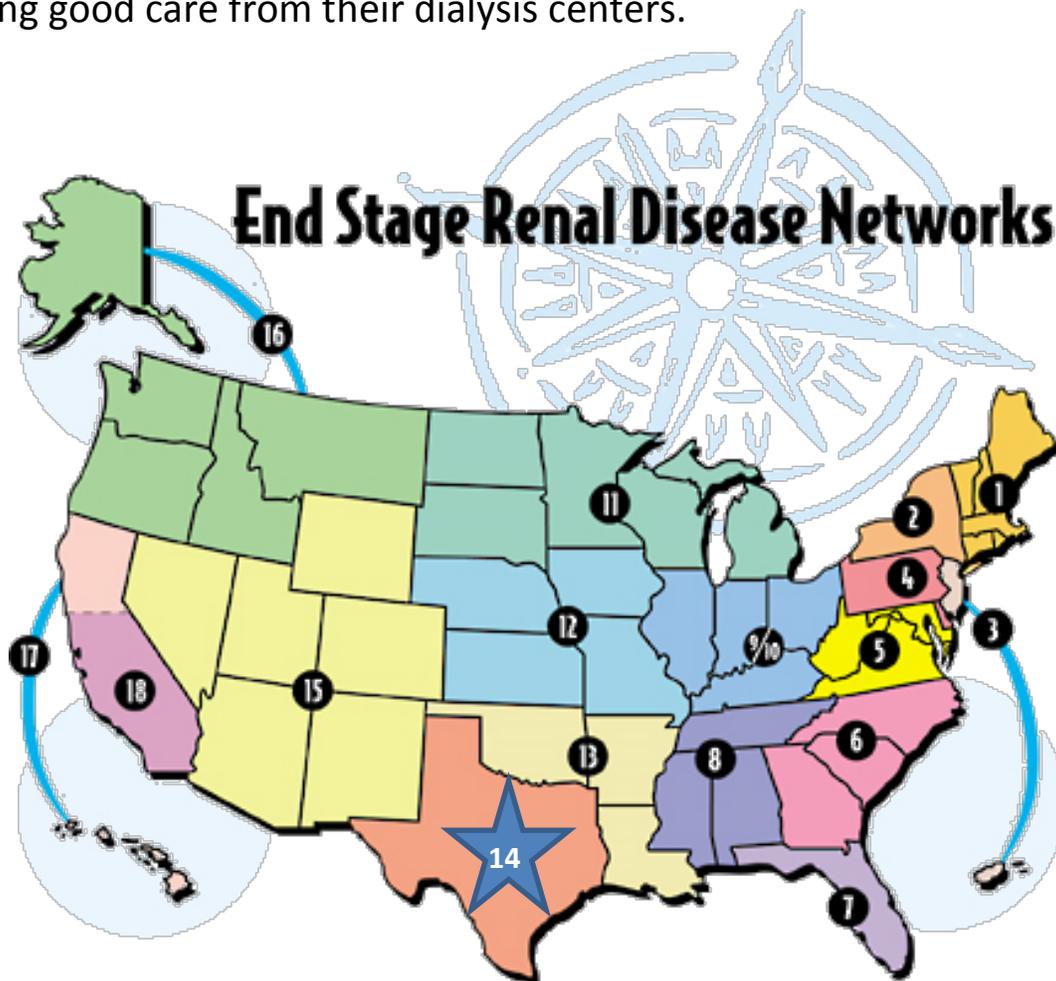
- For medical questions, always refer to the patient's doctor or nurse.
- For questions about diet, always refer to the dietitian.
- For questions about stress, quality of life, and coping concerns, always refer to the social worker.
- For questions about insurance, always refer to the insurance counselor.
- NEVER repeat personal or confidential information that you learn as a FPR.

\* See the **Commonly Used Terms** section at the back of this handbook for more information.

## The Federal ESRD Program and ESRD Networks

Before Congress passed section 1881 of the Social Security Act in 1972, the *Centers for Medicare & Medicare Services (CMS)*\* did not cover dialysis treatments. Patients had to pay for their own treatment. That changed in 1972, when Congress set up the ESRD Program to pay for dialysis and transplant services through CMS.

Now the program is run by the Centers for Medicare & Medicaid Services (CMS). Under CMS, there are 18 ESRD Networks that oversee the quality of care for dialysis patients. The ESRD Network of Texas, Inc. (ESRD Network 14) is a non-profit organization contracted by CMS to make sure that people that need dialysis in the state of Texas are getting good care from their dialysis centers.



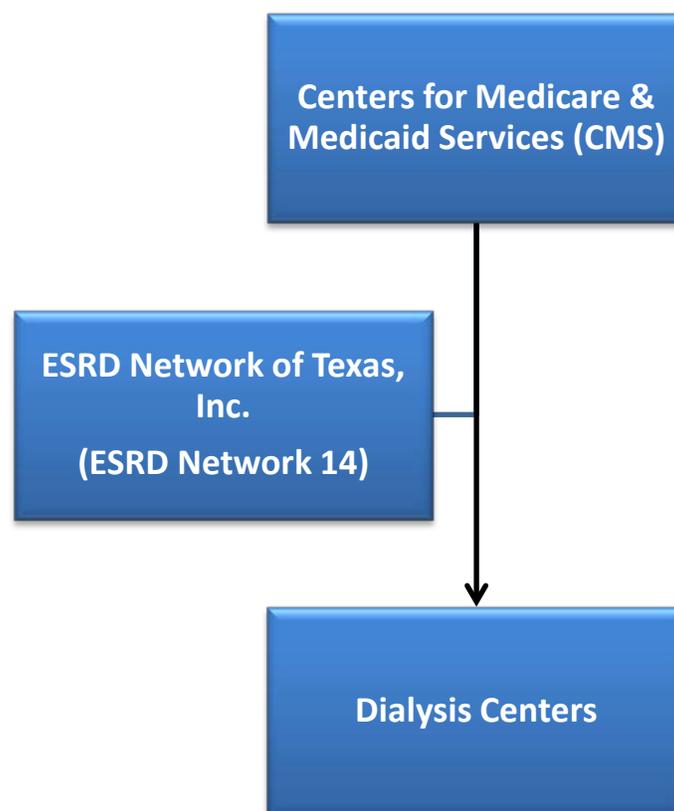
**Figure 2.** There are 18 ESRD Networks in the U.S.

\* See the **Commonly Used Terms** section at the back of this handbook for more information.

## What does ESRD Network 14 do?

ESRD Network 14 works with dialysis centers to improve the quality of patient care. In 2014, there were almost 57,000 dialysis and kidney transplant patients in Texas. Some of the ways that ESRD Network 14 improves care are by:

- Helping patients and families understand how to better manage kidney disease by making patient education materials available
- Helping centers keep good records in the patient database (*CROWNWeb\**)
- Helping patients and staff improve the quality of care at the center
  - This includes patient complaints and concerns (*grievances\**) about dialysis care that patients ask ESRD Network 14 to help them fix.
- Working with dialysis centers to improve the quality of care for kidney patients



**Figure 3.** CMS sets the standard for dialysis care and pays dialysis companies for dialysis treatment if the patient has Medicare. CMS contracts the ESRD Network of Texas, Inc. to make sure that the quality of care in dialysis centers is good.

\* See the **Commonly Used Terms** section at the back of this handbook for more information.

## How else can patients get involved?

Being an FPR is only one way you can get involved. Dialysis and transplant patients and their family members can also volunteer for Network committees. Some of the committees include the Patient Advisory Committee (PAC) and Learning and Action Networks (LANs). These committees help ESRD Network 14 understand what is important to patients and their families to improve care for all patients in the state of Texas.

### What is the Patient Advisory Committee?

The Patient Advisory Committee (PAC) is made up of patients and family members that go to dialysis or have a functioning kidney transplant. PAC members help ESRD Network 14 understand patient concerns, problems, and educational needs.

The Network may not participate in lobbying activities. PAC members may participate as individuals in these activities or through the American Association of Kidney Patients (AAKP), Dialysis Patient Citizens (DPC), Renal Support Network, or other organizations.

The PAC meets in person (usually in Dallas) and by conference calls during the year. The PAC members are representative of the state's geographic and demographic diversity. It includes persons and family members with all treatment types (*modalities\**), like in-center, peritoneal, and home hemodialysis, or a transplant.

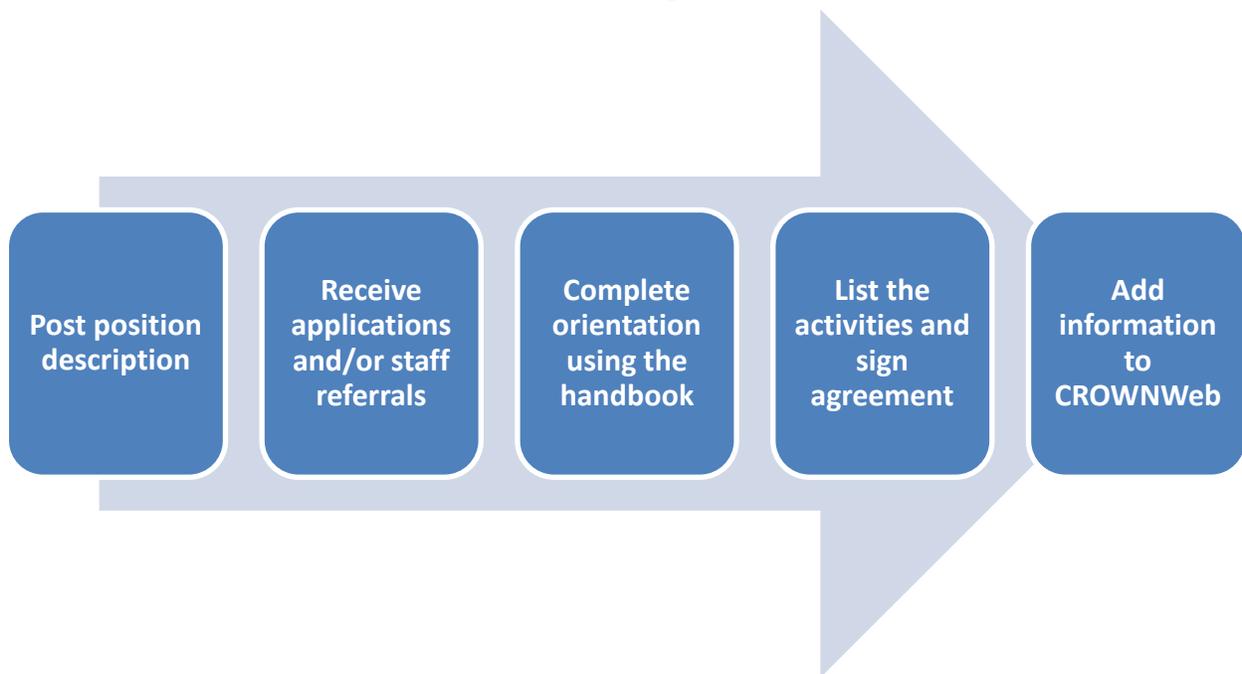
### What is a Patient Engagement Learning and Action Network?

In 2013, CMS asked all ESRD Networks to bring kidney patients, family members, and dialysis staff together to improve ESRD care. These groups are known as Patient Engagement Learning and Action Networks (PE LANs).

Each of the 18 Networks has a PE LAN. LANs provide individuals and organizations with a chance to work together to make big improvements in health care. LANs consider all of the members to be Subject Matter Experts (SMEs) that can share knowledge and improve care. In a LAN, many experts on different subjects share their ideas. This helps everyone learn something new and find better ways to solve problems.

\* See the **Commonly Used Terms** section at the back of this handbook for more information.

## FPR Recruiting Process



## Orientation Checklist

- Facility Patient Representative Handbook
- The Federal ESRD Program and ESRD Networks
- What is a Facility Patient Representative (FPR)?
- HIPAA and Medical Information
- How else can patients get involved?
- Commonly Used Terms
- Additional Resources
- Contact Information
- Facility Patient Representative (FPR) Agreement
- Add Patient Representative (FPR) to CROWNWeb

\* See the **Commonly Used Terms** section at the back of this handbook for more information.

## Commonly Used Terms

### Acronyms

- AMA – Against medical advice
- BMI – Body mass index
- CfC – Conditions for Coverage. These are the rules centers must follow to be paid by CMS for dialysis treatments.
- CIA – Comprehensive interdisciplinary assessment
- CIPA – Comprehensive interdisciplinary patient assessment
- CKD – Chronic kidney disease
- CMS – Centers for Medicare & Medicaid Services
- EDW – Estimated dry weight
- ESRD – End Stage Renal Disease
- FDOD – First date of dialysis
- FPR – Facility Patient Representative
- HHD – Home Hemodialysis
- HIPAA - Health Insurance Portability and Accountability Act of 1996
- ICH – In-center hemodialysis
- IDT – Interdisciplinary Team
- IDWG – Interdialytic weight gain
- KDQOL – Kidney disease quality of life
- MWF/TTS – Monday, Wednesday, and Friday dialysis schedules; Tuesday, Thursday, and Saturday dialysis schedules
- PAC – Patient Advisory Committee
- PD – Peritoneal dialysis
- PE LAN – Patient Engagement Learning and Action Network
- POC – Plan of Care
- QAPI – Quality Assessment and performance Improvement
- SSA – Social Security Administration
- SME – Subject Matter Expert
- TKHC – Texas Kidney Health Care

\* See the **Commonly Used Terms** section at the back of this handbook for more information.

## Commonly Used Terms

### Definitions

- **Advocate:** A person who looks out for another person's best interests.
- **Centers for Medicare & Medicaid Services (CMS):** An agency of the federal government that sets rules for dialysis centers and pays for treatment for patients that get Medicare benefits.
- **Confidentiality:** Protecting private information like patient medical records.
- **CROWNWeb:** CROWNWeb is Medicare's patient database. This is where medical information is reported by your center and stored by CMS. CROWNWeb includes information like your lab values. It does not include personal information or notes that your Care Team makes about your treatment plan.
- **Governing Body:** Each center's governing body includes the manager, kidney doctor (nephrologist), and area manager.
- **Grievances:** Patient concerns and/or complaints that are reported to ESRD Network 14 for help to fix the problem.
- **Mentor:** A teacher, guide, and/or sources of information.
- **Modalities:** Different kinds of dialysis treatments like in-center hemodialysis, peritoneal dialysis, home hemodialysis, and transplant.
- **Patient- and Family-Centered Care (PFCC):** Patient- and family-centered care means that healthcare decisions are made WITH patients and not FOR them. It means that patients and their loved ones are an important part of the healthcare team and that staff respect patients' wishes about their care.
- **Peer:** A group of people who are going through the same experiences in life.
- **Transplant:** When an organ like a kidney is removed from one person (a donor) and placed in another person (the recipient).

\* See the **Commonly Used Terms** section at the back of this handbook for more information.

## Commonly Used Terms

### Clinic Staff

- CCHT: Certified Clinical Hemodialysis Technician
- SW/MSW/LMSW/LCSW: Social Worker/Master's degree in Social Work/Licensed Master Social Worker/Licensed Clinical Social Worker. These are different types of social work education, experience, and licensing.
- PCT: Patient Care Technician
- RD: Registered Dietitian
- RN: Registered Nurse
- IDT: Interdisciplinary Team
- FA: Facility Administrator
- AA: Administrative Assistant
- MD: Medical Director
- ROD: Regional Operations Director
- AQM: Area Quality Manager
- RQM: Regional Quality Manager
- IC: The Insurance Counselor can help you with insurance questions.
- Bio Med: The bio med staff repair machines like water treatment and TVs
- Secretary: The secretary can help with new admissions and arrange travel

## Additional Resources

For additional information, you may want to visit the following websites:

- American Association of Kidney Patients (AAKP)—[www.aakp.org](http://www.aakp.org)
- American Kidney Fund (AKF)—[www.akfinc.org](http://www.akfinc.org)
- Dialysis Patient Citizens (DPC)—<http://dialysispatients.org/>
- ESRD Network of Texas, Inc.—[www.esrdnetwork.org](http://www.esrdnetwork.org)
- Forum of ESRD Networks—[www.esrdnetworks.org](http://www.esrdnetworks.org)
- National Kidney Foundation (NKF)—[www.kidney.org](http://www.kidney.org)
- National Kidney Foundation Transplant Resources—  
<https://www.kidney.org/atoz/content/kidneytransnewlease>
- Patient education website—[www.ikidney.org](http://www.ikidney.org)
- Texas Department of Aging and Disability Services (DADS) —  
<http://www.dads.state.tx.us/>
- Texas Department of Assistive and Rehabilitative Services (DARS) —  
<http://www.dars.state.tx.us/>
- Texas Department of State Health Services (DSHS) —  
<http://www.dshs.state.tx.us/default.shtm>
- United Network for Organ Sharing (UNOS)—<http://www.unos.org>

\* See the **Commonly Used Terms** section at the back of this handbook for more information.

## Facility Patient Representative (FPR) Role Description

The Facility Patient Representative (FPR) program is designed for people who are on dialysis or have a kidney transplant or family members and have been selected to represent their fellow patients at a dialysis center. FPRs volunteer to work with staff to foster a positive environment in their dialysis center. FPRs serve as experts on what it is like to be a patient. This helps centers improve patient care. Every dialysis center should have an FPR!

### FPRs should be:

- Receiving hemodialysis, peritoneal dialysis, or have a kidney transplant OR be the family member of someone receiving dialysis
- Willing to serve for one or more years
- Able to participate in their dialysis center's Quality Assessment and Performance Improvement (QAPI) and/or governing body meetings
- Willing to respond to ESRD Network 14 requests for information and feedback

### FPR responsibilities may include:

- Telling fellow patients about ESRD Network 14
- Handing out ESRD Network 14 communications and educational materials
- Participating in their dialysis facility's Quality Assessment and Performance Improvement (QAPI) and/or governing body meetings
- Giving updates to fellow patients about the dialysis center (at the staff's request)
- Sharing useful ideas and experiences with patients and staff
- Sharing patient concerns with the clinic manager or other staff
- Serving as a role model to other patients by following their own treatment plan
- Telling patients who to speak to when concerns or complaints are voiced
- Giving encouragement and support to new patients
- Supporting other dialysis center and ESRD Network 14 activities as needed

If you are a dialysis patient or transplant recipient interested in becoming a Facility Patient Representative, talk to your dialysis or transplant center social worker about getting involved or learn more on our website at [www.esrdnetwork.org](http://www.esrdnetwork.org).

\* See the **Commonly Used Terms** section at the back of this handbook for more information.

## Facility Patient Representative (FPR) Application

### Applicant Information – to be completed by the patient

---

Name Email

---

Address City, State, and Zip Code

---

Home Phone Cell Phone

Modality:  Home Hemodialysis  In-center Hemodialysis  Peritoneal Dialysis  Transplant

If you are a dialysis patient or family member, are you or the patient on a transplant list?  Yes  No

Dialysis Schedule:  M/W/F Time: \_\_\_\_\_  T/T/S Time: \_\_\_\_\_

Do you have computer access?  Yes  No

### Please read the following statements and check if you agree (all must be checked to be considered):

- I have read the FPR role description and agree to fulfill the responsibilities to the best of my ability.
- I authorize ESRD Network 14 and \_\_\_\_\_ (dialysis center) to utilize my name and email address for specific Facility Patient Representative (FPR) communications.
- I further authorize \_\_\_\_\_ (dialysis center) to use my name where necessary in FPR meeting minutes and other business documentation.

### Facility Information – to be completed by a staff member

---

Name of Dialysis Center CCN (six-digit Medicare provider number)

---

Staff Member's Name Email

---

Staff Member's Phone Number

**Please complete this form and submit it to your facility social worker. Thank you!**

## Facility Patient Representative (FPR) Staff Referral

### FPR Candidate Information

---

Name \_\_\_\_\_ Email \_\_\_\_\_

---

Address \_\_\_\_\_ City, State, and Zip Code \_\_\_\_\_

---

Home Phone \_\_\_\_\_ Cell Phone \_\_\_\_\_

Modality:  Home Hemodialysis  In-center Hemodialysis  Peritoneal Dialysis  Transplant

If the candidate is a patient or a patient's family member, is the patient on a transplant list?  Yes  No

Dialysis Schedule:  M/W/F Time: \_\_\_\_\_  T/T/S Time: \_\_\_\_\_

FDOD: \_\_\_\_\_ Transplant Date: \_\_\_\_\_

Does the candidate have computer access?  Yes  No

Are there any treatment adherence concerns with this candidate?  Yes  No  Unsure

If yes, explain: \_\_\_\_\_

---

Comments: \_\_\_\_\_

---

### Facility Information

---

Name of Dialysis Center \_\_\_\_\_ CCN (six-digit Medicare provider number) \_\_\_\_\_

---

Staff Member Referring Candidate \_\_\_\_\_ Email \_\_\_\_\_

**Please complete this form and submit it to your facility social worker. Thank you!**

\* See the **Commonly Used Terms** section at the back of this handbook for more information.

## Facility Patient Representative (FPR) Agreement

This agreement is between the patient, \_\_\_\_\_  
and the facility, \_\_\_\_\_, CCN \_\_\_\_\_.

By signing this agreement, the patient shows that s/he understands that:

- The agreement is between the FPR and the facility
- The FPR is willing to help at the facility during personal time (not during treatment)
- The facility will share the FPR's name with other patients so that they can talk with the FPR about his/her and tell them that the patient is a FPR
- The patient has the right to resign if s/he is no longer able to serve as an FPR
- The agreement can be ended by the patient or the facility at any time without retaliation,
- The FPR understands that patient information is confidential and will respect the privacy of other patients
- The best way to reach the patient is (phone number) \_\_\_\_\_ and/or email \_\_\_\_\_

The FPR and staff agree that the FPR will help by (check all that apply):

- Welcome new patients
- Help staff give out information
- Mentor or coach other patients by helping them understand handouts.
- Go to the first 10 or 15 minutes of the monthly quality meeting (*Quality Assessment and Performance Improvement\**) and/or *governing body\** meetings to help staff understand patient concerns
- Help with lobby day education
- Work with staff to start and run patient and family groups like Patient Advisory Councils or support groups
- Start a newsletter for your center
- Write articles or poems for the Network newsletter
- Plan patient and staff events like picnics, holiday parties, and art shows
- Decorate the center for holidays and events
- Participate in community health fairs
- Share information about organ donation
- Help patients understand how to work with staff to fix problems
- Make a patient bulletin board and/or activity calendar
- Organize team events like a Kidney Walk
- \_\_\_\_\_
- \_\_\_\_\_

Patient Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Staff Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Staff Name (print) and Title: \_\_\_\_\_

\* See the **Commonly Used Terms** section at the back of this handbook for more information.

## Contact Information

We, ESRD Network 14, and your dialysis facility look forward to working with you as a Facility Patient Representative. If you have questions or would like to discuss any concerns or recommendations from your facility, please call the Network's toll-free number: 1-877-886-4435.

**Community Outreach:** The Network's liaison to Facility Patient Representatives, the Patient Advisory Committee, and the Patient Engagement Learning and Action Network is Rachelle DuBose Caruthers, LMSW, Outreach Coordinator, rcaruthers@nw14.esrd.net.

**Patient Services:** The Network's Patient Services Director is Charlonda Thrower, LMSW, cthrower@nw14.esrd.net.

ESRD Network of Texas, Inc.  
4040 McEwen Rd, Suite 350  
Dallas, Texas 75244  
Phone: 1-877-886-4435  
Fax: 972-503-3219  
www.esrdnetwork.org

For grievances, contact:  
Charlonda Thrower, LMSW  
Patient Services Director  
cthrower@nw14.esrd.net  
Phone: 1-877-886-4435  
Fax: 972-503-3219

## Acknowledgement

The ESRD Network of Texas, Inc. would like to thank each of the 350 dialysis professionals, patients, and care partners that participated in the 2015 Patient Engagement Learning and Action Network (PE LAN). Your contributions to the project made this toolkit possible!

\* See the **Commonly Used Terms** section at the back of this handbook for more information.