

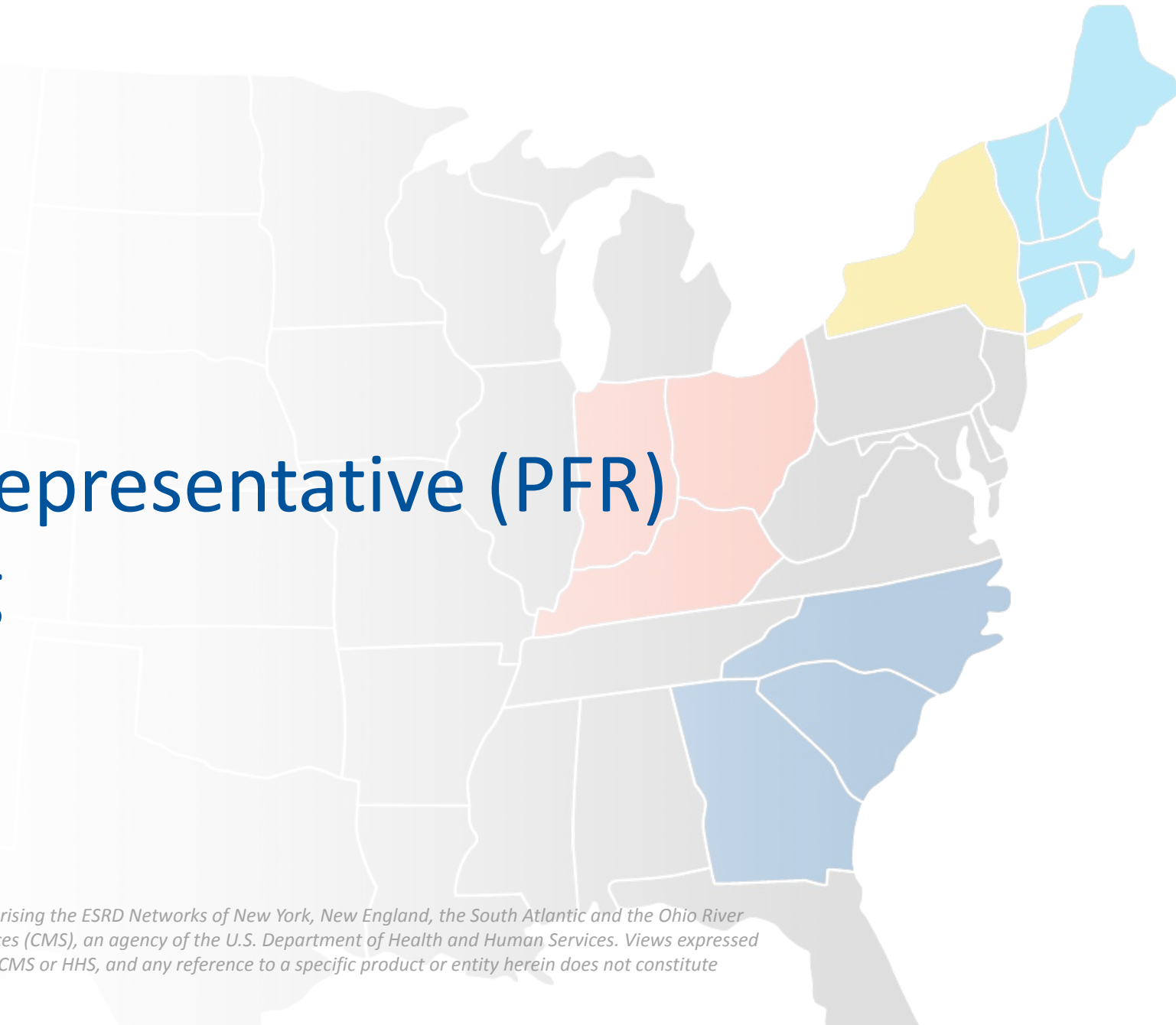


End-Stage Renal Disease
Network Program

Patient Facility Representative (PFR) Alliance Meeting

September 5th, 2024

This material was prepared by the IPRO ESRD Network Program, comprising the ESRD Networks of New York, New England, the South Atlantic and the Ohio River Valley, under contract with the Centers for Medicare & Medicaid Services (CMS), an agency of the U.S. Department of Health and Human Services. Views expressed in this material do not necessarily reflect the official views or policy of CMS or HHS, and any reference to a specific product or entity herein does not constitute endorsement of that product or entity by CMS or HHS. Publication #



Patient and Family Engagement Facilitators



Aisha Edmondson
Patient and Family Engagement
Lead

Patient and Family Engagement Facilitators



Katie Chorba, MSN, RN
Quality Improvement Speaker



Julia Dettmann, BSW
Patient Services Speaker

Today's Agenda

Topics for Review/Discussion



Meeting
Reminders

Patient
Services
Topic

PFR Check-In

Closing
Remarks

Quality
Improvement
Topic



Meeting Reminders



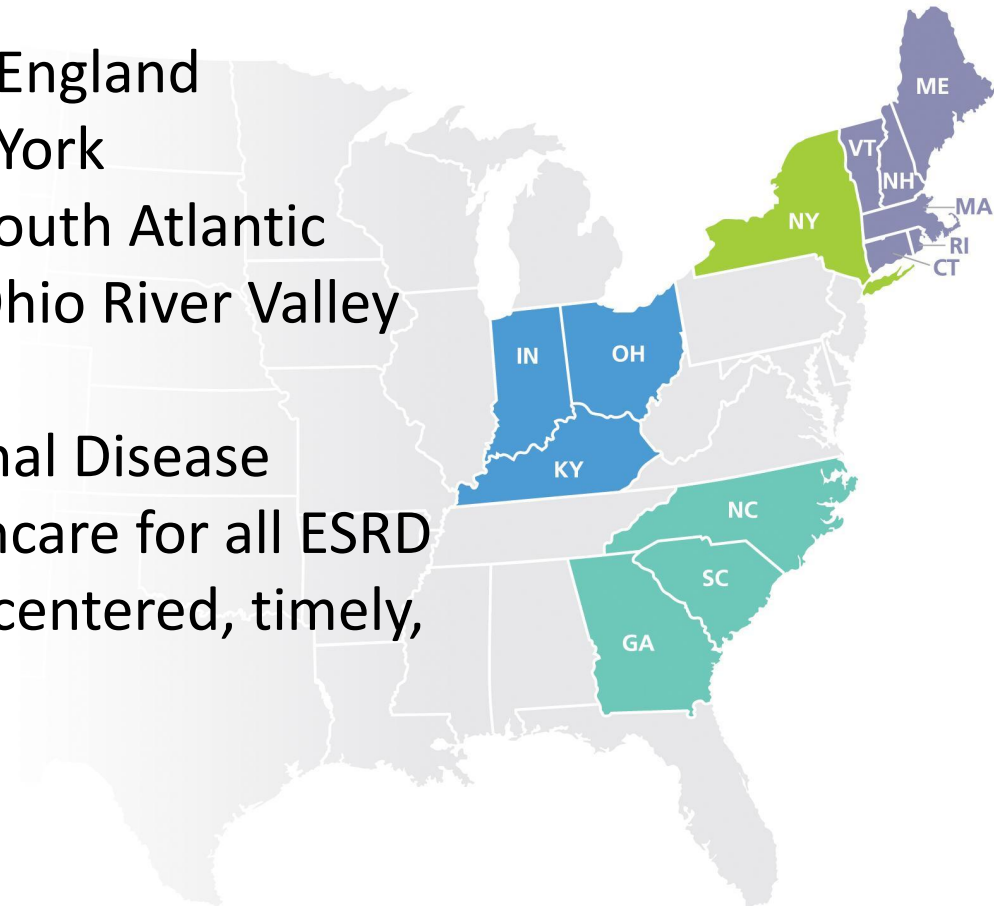
- All phone lines are muted upon entry to eliminate background noise/distractions
- We will be monitoring Chat throughout the meeting for questions or comments
- All slides will be shared within a week of completion of the meeting



IPRO ESRD Network Program



- The IPRO End-Stage Renal Disease Network Program includes four ESRD Networks:
 - Network 1: ESRD Network of New England
 - Network 2: ESRD Network of New York
 - Network 6: ESRD Network of the South Atlantic
 - Network 9: ESRD Network of the Ohio River Valley
- The mission of the IPRO End-Stage Renal Disease Network Program is to promote healthcare for all ESRD patients that is safe, efficient, patient-centered, timely, and equitable.



The Network's Role

What the Network's staff CAN and CANNOT do



Network staff CAN...

- Advocate for patients' rights, depending on the situation.
- Provide information and educational resources.
- Investigate concerns about issues related to quality of care.
- Help patients understand their rights and help them navigate the ESRD care delivery system.

Network staff CANNOT...

- Force a facility to accept a patient.
- Close a dialysis facility.
- Go onsite to investigate a facility's clinical procedures, witness interactions between staff and patients, or view a videotape of incidents (HIPAA violation).
- Add a patient to the transplant list.
- Recommend a lawyer and assist with a lawsuit.
- Get staff members fired or arrange for staff to have their pay docked.
- Force a facility to change its admissions policy regarding catheters.
- Verify Medicare coverage or give out Medicare cards.
- Interfere with facility surveys.
- Hide a patient's involuntary discharge (IVD) history.

The IPRO ESRD Network Program can help resolve many concerns you may have about the care you receive as a dialysis patient.

The mission of the IPRO End Stage Renal Disease (ESRD) Network Program is to promote health care for all ESRD patients that is safe, effective, efficient, patient-centered, timely, and equitable.

| Network staff CAN... | |
|---|--|
| Advocate for patients' rights, depending on the situation. | ~ Example: "My unit is too cold" With your permission, a Network staff member can contact your facility to find out if the temperature can be controlled. |
| Provide information and educational resources. | ~ Example: "I need a fourth shift, and my facility does not offer one" The Network can provide you with a list of facilities in your area that offer a fourth shift (Dialysis Facility Compare tool available on www.medicare.gov) |
| Investigate concerns about issues related to quality of care. | ~ Example: "I am upset about the care I am receiving at my facility" The Network can conduct a review of your medical record to evaluate the quality of care you are receiving. |
| Help patients understand their rights and help them navigate the ESRD care delivery system. | ~ Example: "I don't agree with a policy at my facility" The Network can advocate on your behalf and could help you work with facility staff to find a compromise that would work for you and the facility. |

However, some concerns may be beyond the Network's scope. Network staff CANNOT...

| | |
|---|--|
| ✘ Force a facility to accept a patient. | ✘ Get staff members fired or arrange for staff to have their pay docked. |
| ✘ Close a dialysis facility. | ✘ Force a facility to change its admissions policy regarding catheters. |
| ✘ Go onsite to investigate a facility's clinical procedures, witness interactions between staff and patients, or view a videotape of incidents (HIPAA violation). | ✘ Verify Medicare coverage or give out Medicare cards. |
| ✘ Add a patient to the transplant list. | ✘ Interfere with facility surveys. |
| ✘ Recommend a lawyer and assist with a lawsuit. | ✘ Hide a patient's involuntary discharge (IVD) history. |

The Network collaborates with the State Department of Health to advocate for individuals and help resolve concerns about care received at dialysis facilities.

IPRO Better healthcare, realized.

To file a grievance, please contact us:
IPRO End-Stage Renal Disease Network Program Corporate Office:
 1979 Marcus Avenue, Lake Success, NY 11042-1072
 Patient Services: (516) 231-9767 • Toll-Free: (800) 238-3773
 E-mail: esrdnetworkprogram@ipro.us • Web: esrd.ipro.org

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Welcome Our New PFRs!

- Nicole Curry
- Scott Nicoellis
- Birdie Johnson
- Daniel Lennard
- Michelle Tierney
- Stacy Williams
- Desmond Tennison



Network Check-In

Polling Question



Which Network are you from?

- Network 1 (Connecticut, Massachusetts, Maine, New Hampshire, Rhode Island, Vermont)
- Network 2 (New York)
- Network 6 (North Carolina, South Carolina, Georgia)
- Network 9 (Indiana, Kentucky, Ohio)



With You in Mind! NEW!! Alliance Stamp of Approval



We have incorporated the Patient Facility Representative Alliance Voice to the patient centered resources and intervention created here at the Network!!



Patient Resources



Katie Chorba, MSN, RN
Assistant Director; Project Lead
Hospitalizations, Quality of Care
Cases

Network Check-In

Polling Question



How often do you feel that the information you receive about your condition is overwhelming or too much to handle?

1. **Always:** The information is consistently overwhelming.
2. **Often:** I frequently find the information overwhelming.
3. **Sometimes:** Occasionally, the information feels overwhelming.
4. **Rarely:** I rarely feel overwhelmed by the information.
5. **Never:** I never feel that the information is overwhelming.



Don't Miss a Minute

Older Version



Don't Miss A Minute

Reducing Hospitalizations

The Facts: On average, a dialysis patient dialyzes three times a week for 4 hours each treatment. This treatment replaces the work that your kidneys performs 24 hours per day, seven days per week. Missing minutes of dialysis decreases the improved health benefits (outcomes) seen with dialysis and increases the likelihood of complications and hospitalizations.

FREQUENTLY ASKED QUESTIONS

Dialysis is so hard. Why is it important that I stay for my full treatment? The dialysis treatment you are receiving replaces only a small amount of the work your kidneys do to remove fluid and waste products. If you don't get enough dialysis, your blood will accumulate those waste products and excess fluid.

What will happen to my body if I miss dialysis?

- Feeling weak, tired, and getting short of breath when moving around.
- Losing your appetite and feeling nauseated
- Swelling of your ankles, stomach or other areas
- Taste of ammonia in your mouth
- Prolonged bleeding times after dialysis

Additionally, patients who shorten or miss three more treatments in a month have:

- Higher risk of hospitalization
- May develop serious life threatening complications
- Could be delayed from getting wait-listed or removed from the transplant wait list
- A greater chance of infection
- Fluid may accumulate around the heart, causing the heart to swell and ultimately

I feel fine and do not have any problems when I miss or cut my treatments, so why do I need to come or stay the whole time for my treatment? The effects on your health from less dialysis may not show up overnight. You may not feel ill until there are lasting health effects on your body. For example, you may not notice the extra fluid building up in your body but it will make your heart pump harder which can cause it to swell and wear out your heart.

I only miss or shorten a few treatments now and then, how can it hurt?

Missing 1 treatment per month = 12 treatments per year = missing an entire month of treatment per year. Shortening each treatment 1 hour = 144 hours of dialysis a year = 36 missed treatments per year.

How can I make dialysis more enjoyable and complete all my required dialysis time? Other patients who are successful coming and staying on treatment suggest that you make a plan to fill your time during dialysis. Suggested activities include:

- Cards or hand held games
- Hobbies (i.e., sketching, crochet, word puzzles, or reading)
- Be a patient facility representative! Join your facility team to improve the health and quality of life of your fellow patients

What if I have an emergency or prior commitment on dialysis days? Talk to your facility staff to reschedule your treatment so you don't miss a minute of your valuable dialysis!



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Developed by the IPRO
ESRD Network Program
while under contract
with Centers for
Medicare & Medicaid
Services, Contract #
75FCMC1900029
09/23/21 Version 1

Don't Miss a Minute

New and Improved



Don't Miss a Minute of Dialysis!



WHY DIALYSIS IS IMPORTANT

- **What is Dialysis?**

Dialysis is a special treatment that helps remove waste from your blood when your kidneys can't do it. You need dialysis to clean your blood to stay healthy.

- **How Often Do I Need Dialysis?**

Most people need dialysis three to six times a week, depending on the type of dialysis they are getting. It's like a special job that your kidneys need help with.

WHY YOU SHOULDN'T MISS DIALYSIS

- **What Happens if I Miss Dialysis?**

Missing even a little bit of dialysis can make you sick. Your blood won't get cleaned properly, which can cause:



SWELLING IN YOUR ANKLES OR STOMACH



RISK OF INFECTIONS



MORE HOSPITAL VISITS



continued on page 2

Don't Miss a Minute of Dialysis! (continued)



Stay for Your Full Treatment

- **Why Do I Need to Stay the Whole Time?**

If you don't stay for the full treatment, waste and extra fluids build up in your body. Even if you feel okay now, this can hurt you later.

- **Missing Any Treatment Time Matters**

- Missing one treatment a month adds up to missing a whole month of treatment each year.
- Shortening each treatment by just one hour means you miss 36 treatments a year.

Tips to Make Dialysis Easier

- **How to Pass the Time**

- Bring a book to read
- Watch your favorite shows or movies
- Listen to music or podcasts
- Talk to other patients or staff



- **Can't make it to your treatment due to an emergency or conflict?**

- Contact your facility so they can help reschedule your appointment.



End-Stage Renal Disease Network Program

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Your Feedback

Which Version do you prefer?



- **Previous Resource:** I found the old resource more helpful.
- **New and Improved Resource:** I found the new resource more helpful.
- **No Preference:** Both resources are equally helpful.
- **Additional Comments:**

Network Check-In

Polling Question



Would patients be interested in additional resources on managing comorbid conditions to reduce hospitalizations?

- Yes
- No
- Not Sure



Emergency Management



Julia Dettmann, BSW
Patient Services and Emergency
Management Specialist

Network Check-In

Polling Question



Are you using the ESRD Emergency Mobil Hub Application?

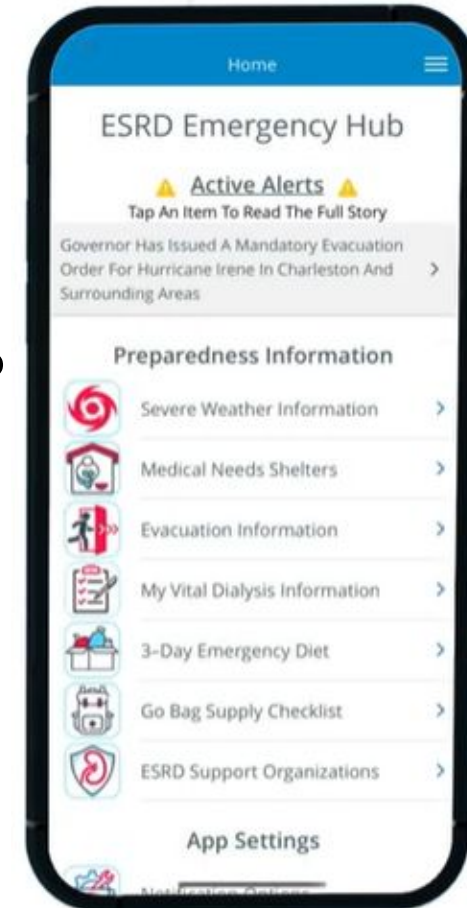
- Yes
- No
- Unsure



ESRD Mobil Hub - Continued

Please utilize the chat!

- App was launched about a year ago.
- Any feedback for updates, changes or amendments are welcome!
- What would be helpful for you to see in the app?
- Would you suggest other patients download the app?



Network Check-In

Polling Question



Has your facility spoken with you about cyber security?

- Yes
- No
- Unsure



Network Check-In

Polling Question



If you answered, YES, what are your key takeaways about cyber security?

Please use the chat to share your experience and learning lessons with cyber security education!



Next Steps



Aisha Edmondson
Patient and Family Engagement

Social Media

Follow Us!



- [IPRO ESRD Network Program's Facebook Page](#)
- [IPRO ESRD Patient Facility Representative \(PFR\) Alliance Group](#)



- [IPRO ESRD Network Program's Twitter Page](#)



- [IPRO ESRD Network Program's LinkedIn Page](#)



- [IPRO ESRD Network Program's Instagram](#)



Community Awareness Campaigns

September is Sepsis Awareness Month!!

Sepsis Awareness Month is celebrated in September to educate people about sepsis and how to prevent it. The month is intended to raise awareness of sepsis, which is the leading cause of death in U.S. hospitals and affects an estimated 49 million people worldwide each year.

For Healthcare Professionals | Doctors of Medicine, Doctors of Osteopathic Medicine, Physician Assistants/Nurse Practitioners, and Nurse Practitioners

Protect your patients from sepsis.

How can I get ahead of sepsis?

- Know sepsis signs and symptoms to identify and treat patients early.
- Act fast if you suspect sepsis.
- Prevent infections by following infection control practices (e.g., hand hygiene, appropriate catheter management) and ensuring patients receive recommended vaccines.
- Educate your patients and their families about:
 - Preventing infections
 - Keeping cuts and wounds clean and covered until healed.
 - Washing chronic wounds.
 - Recognizing early signs and symptoms of worsening infection and sepsis.
 - Seeking immediate care if signs and symptoms are present.

What should I do if I suspect sepsis?

- Know your facility's guidance for diagnosing and managing sepsis.
- Immediately alert the healthcare professional overseeing care of the patient if it is not you.
- Start antibiotics as soon as possible in addition to other therapies appropriate for the patient. If a specific bacterial cause of sepsis is known, therapy should be targeted to optimize treatment, and broad spectrum antibiotics might not be needed.
- Check patient progress frequently. Treatment requires urgent medical care, usually in an intensive care unit in a hospital, and includes careful monitoring of vital signs and other attributes. Early and frequent reassessment of patients with sepsis should be undertaken to determine the appropriate duration and type of therapy.

GET AHEAD OF SEPSIS

For Healthcare Professionals | Doctors of Medicine, Doctors of Osteopathic Medicine, Physician Assistants/Nurse Practitioners, and Nurse Practitioners

Who is at risk for sepsis?

Anyone can develop sepsis, but some people are at higher risk for sepsis:

- 65+** Adults 65 or older
- People with chronic conditions, such as diabetes, lung disease, cancer, and kidney disease
- People who survived sepsis
- People who are pregnant or postpartum
- People with weakened immune systems
- People with recent severe illness, surgery, or hospitalization
- Children younger than one

What causes sepsis?

Infections put your patients at risk for sepsis. Bacterial infections cause most cases of sepsis. The most frequently identified bacterial pathogens among people with sepsis include *Staphylococcus aureus* (staph), *Escherichia coli* (E. coli), and some types of *Streptococcus* (strep). Sepsis can also be a result of other infections, including viral infections, such as COVID-19 or influenza, or fungal infections. Infections that lead to sepsis most often start in the lung, urinary tract, skin, or gastrointestinal tract.

What are the signs and symptoms of sepsis?

A patient with sepsis might have one or more of the following signs or symptoms:

- High heart rate or low blood pressure
- Confusion or disorientation
- Extreme pain or discomfort
- Fever, chills, or feeling very cold
- Shortness of breath
- Clotting or overly thin
- Lung
- Urinary tract
- Skin
- Gastrointestinal tract

We should immediately evaluate and treat patients who might have sepsis.

GET AHEAD OF SEPSIS | KNOW THE SIGNS AND SYMPTOMS OF SEPSIS

LEARN MORE AT uk.gov/sepsis

September is SEPSIS AWARENESS Month

[Sepsis Healthcare Professional Handout](#)



**Questions?
Comments?**



Thank you for your ongoing commitment to the ESRD community!

For more information, contact:

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