Patient Facility Representative (PFR) Alliance Meeting

August 3, 2023
Patient and Family Engagement Facilitators

Stephanie Cole, BA, PSM, QP
Community Outreach Specialist

Agata Roszkowski, LMSW
Social Worker
Patient Services Speaker

Caroline Sanner, MSN, RN-BC, CPHQ
Transplant
Quality Improvement Assistant
Director
Quality Improvement Speaker
Today’s Agenda
Topics for Review/Discussion

Meeting Reminders

PFR Check-In

Quality Improvement Topic

Patient Services Topic

Closing Remarks
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, efficient, patient-centered, timely, and equitable.
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)
Network Check-In

Polling Question

Have you heard about Kidney Transplant Compare?

• Yes
• No
• Unsure
Network Check-In

Polling Question

Have you ever utilized the grievance processes at the Networks?

• Yes
• No
• Unsure
Transplant

Caroline Sanner
Transplant Project Lead
Quality Improvement Assistant Director
Agenda

• Transplant Goals
• Interventions
  • Kidney Transplant Compare
  • Kidney Donor Profile Index
• Action Items
Transplant Goals

• Increase the number of patients added to the waitlist
• increase the number of patients who receive a kidney transplant
Interventions

Introducing... Kidney Transplant Compare

transplantcompare.org

Putting patients and family members in the driver’s seat of their transplant journey

Choose the Best Transplant Center For YOU.

1. Learn the basics of kidney transplant and find FREE patient resources. Consider your life plan and decide if kidney transplant is the best treatment option for you.

2. Search, filter, and save transplant centers that you are interested in based on their location, patient selection criteria, support services, and results.

3. Compare the transplant centers you are interested in to choose the best option for you!

Use the camera on your mobile phone or tablet to scan this image code to learn more about kidney transplant compare or visit transplantcompare.org
Demonstration
Action Items

What are action items in the PFR Alliance Call?

At the Network we have guidelines and goals we must meet, set by CMS. As a Patient Facility Representative, you have signed up to work with the Network to support these goals. This may mean that we ask you to help share resources or create a bulletin board on a modality topic or practice that you would not choose for yourself. We ask that you complete your assigned action items as requested in support of the ESRD Networks quality improvement and patient services initiatives. Doing so will increase the support and improve outcomes for other patients who would benefit from this information.

Each month there will be a requested action item to complete based on the topic. We will follow up and ask for the results of the work at the next meeting.
Action Items

By next month:

1. Work with your facility staff to PRINT and POST the patient flyer for Kidney Transplant Compare
2. Gather feedback from a patient on their use of the application - be ready to share!

At next months call, we will be surveying you on the results of these action items!
Kidney Transplant Compare

Important Links

• Kidney Transplant Compare Desktop Application: https://transplantcompare.org/home
• 3-Part Demo Series: https://www.youtube.com/watch?v=fIPSoKTPfAk&list=PLj5TtqQaycuRvOKCQ7kM-1J5nlGlPaLQt
• IPRO ESRD Website for Kidney Transplant Compare: https://esrd.ipro.org/kidney-transplant-compare/
Questions?
Kidney Donor Profile Index (KDPI)

The Network wants to ask the PFR Alliance a few questions about their understanding of KDPI and what that means for kidney transplant.

Please answer the following polling questions to the best of your ability.

Your answers are anonymous and will be the starting point for a new patient education about these types of kidneys.
Kidney Donor Profile Index

Polling Question 1

In your own words, what is the Kidney Donor Profile Index (KDPI)?
Kidney Donor Profile Index

Learn about polling question 1

What is Kidney Donor Profile Index (KDPI)?

Kidney Donor Profile Index is a number used to evaluate the quality of a kidney from a deceased donor.

The KDPI can measure how long a kidney from a deceased donor may function after transplant.

The KDPI ranges from 0 (higher quality) to 100 (lower quality).

Even a low quality kidney can last up to 5 years, usually longer.
Kidney Donor Profile Index

Polling Question 2

What are some conditions that can cause a kidney to have a higher KDPI score?

(Remember, high KDPI means lower quality)
Kidney Donor Profile Index

Learn about polling question 2

What conditions cause a kidney to have a high KDPI?

Many patients and providers term a high KDPI kidney a “hepatitis kidney”

Did you know?
KDPI scores are based on MANY factors, a few are:
1. the deceased donors age, height, and weight
2. race/ethnicity
3. the cause of death
4. whether the donor has high blood pressure or diabetes
5. whether the donor had hepatitis C or was exposed to it
6. the overall kidney function of the donor
Questions?

Learn more about Kidney Donor Profile Index:


2. Patient Education Video: [https://youtu.be/viFqw83IxiQ](https://youtu.be/viFqw83IxiQ)
Patient Experience of Care (PExoC)

Agata Roszkowski, LMSW
Social Worker
References to General Patient Experience of Care (PEoC)

In the Network SOW, CMS discusses Grievances and patient-Appropriate Access to Care as:

- Patient centered care advocates and educators
- Create a collaborative relationship between patients and providers through patient and family engagement
General PEOC
Patient’s Rights:

“Be informed of the facility's internal grievance process;(15) Be informed of external grievance mechanisms and processes, including how to contact the ESRD Network and the State Survey Agency;(16) Be informed of his or her right to file internal grievances or external grievances or both without reprisal or denial of services; and (17) Be informed that he or she may file internal or external grievances, personally, anonymously or through a representative of the patient's choosing.”
General PEOC

Grievance:

A written or verbal communication from an ESRD patient, and/or an individual representing an ESRD patient, and/or another party, alleging that an ESRD services received from a Medicare-certified provider did not meet grievant expectations with respect to safety, civility, patient rights, and/or clinical standards of care.
Grievance received by another party representing patient following is to be obtained to protect patient’s rights:

- Appointment of Representative is to be signed.
- Power of Attorney
- Health Care Proxy
Improving PEOC by Resolving Grievances and Access to Care Issues

• Issues may arise at dialysis facilities that cannot be resolved without mediation.
• The Network has the responsibility to assist patients and dialysis facilities to resolve concerns in a manner that is satisfactory to all parties, as possible.
• A grievance is defined as a formal or informal written or verbal complaint that is made to any member of the dialysis or transplant center staff, by a patient, or the patient’s representative, regarding the patient's care or treatment.
• If the grievant does not feel comfortable filing a grievance with the facility, a grievance may be filed directly to the Network.
General Resources
Network Staff CAN

- Advocate for Patient’s rights
- Provide educational resources
- Investigate concerns about issues related to quality of care
- Help patients understand their rights
General Resources
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, view videotape of incidents (HIPPA violation)
- Add a patient to transplant list
- Recommend a lawyer
- Get staff member fired or docked their pay
- Force a facility to change its admissions policy
- Verify Medicare coverage or give out Medicare cards
- Interfere with facility surveys
- Hide a patient’s involuntary discharge
Grievance Resources

The treatment you receive should meet your need for safety, your rights as a patient, clinical standards of care, and be provided by staff who treat you fairly and respectfully. If you feel your treatment does not meet these standards...

Speak Up. Here's how...

First...
Ask a staff member for a copy of your facility’s grievance policy to find out how you can file a grievance.

However...
If you are still unsatisfied or do not feel comfortable filing a grievance with your facility...

Contact
IPRO End-Stage Renal Disease Network Program
Corporate Office: 5179 Marietta Avenue, Lake Success, NY 11042-3572 Patient Services (516) 231-9767 • Toll-Free Patient Line: (800) 238-2373 E-mail: endnetworkprogram@ipro.us

Division of Long Term Care, Indiana State Dept. of Health
Toll-Free: 1-800-822-3100 (1-800-822-3100) Local: (317) 233-7462 (Long Term Care) Fax: (317) 233-7464 E-mail: complaints@ldt.in.gov • Website: www.in.gov/dlt/3562.htm

IPRO End-Stage Renal Disease Network Program
http://esrd.ipro.org

IPRO End-Stage Renal Disease Network Program
http://esrd.ipro.org

Grievance Process Questions & Answers
A Guide for Dialysis Facilities

What is a grievance?
A written or oral communication from an ESRD patient, entails an individual representing an ESRD patient, and/or another party, alleging that an ESRD service provider did not meet the provider’s expectations with respect to safety, quality, patient rights, or other clinical elements of care.

Who should be responsible for receiving and documenting a grievance?
Everyone. Any staff person who receives a grievance is responsible for documenting the grievance in the grievance log and reporting the occurrence to the Facility Administrator. Clinic Managers for follow-up. Reviewers, family members and care supporters should be able to report any problems and or concerns to anyone at the unit without complication. As care provider, if it is our obligation to clarify an environment that fosters open communication and patient engagement with a willingness to take every opportunity available to improve care.

Who is responsible for investigating an allegation of a grievance?
The health care facility administrator is responsible for the investigation and resolution of all grievances. If the grievance involves the health care facility, and administrator, the grievances shall be investigated by that individual’s direct supervisor, with the administrator, or his designee if necessary, determining the investigator. The investigator may help the grievant understand and resolve questions and get help in understanding and resolving questions about their treatment. The investigator shall follow up with the grievant who files a complaint.

http://esrd.ipro.org

All patients, family members, and care partners have the right to file a grievance internally or externally, without fear of retaliation.

End-Stage Renal Disease Network Program
http://esrd.ipro.org
Next Steps

Aisha Edmondson,
Patient Family Engagement
Next Steps

- **Follow** us on social media!
- **Join** the PFR Alliance Facebook Group [https://www.facebook.com/groups/ipropfralliance](https://www.facebook.com/groups/ipropfralliance)
- **Create** your IPRO Learn Account [https://esrd.iprolearn.org/login/index.php/](https://esrd.iprolearn.org/login/index.php/)
- **Participate** in a call with Network staff and CMS to share your experience as a PFR, address issues impacting your facility and peers, and offer recommendations on how to improve patient care - volunteers needed each month!
- **Become** a Peer Mentor:
  - Understand the steps [https://esrd.ipro.org/patients-family/pfe/peer-mentoring/](https://esrd.ipro.org/patients-family/pfe/peer-mentoring/)
  - Register online: [https://redcap.ipro.org/surveys/?s=CJMXNFDNR](https://redcap.ipro.org/surveys/?s=CJMXNFDNR)
  - Have questions?
- **Contact** Aisha Edmondson at (216)755-3056 or Stephanie Cole (919) 928-6042
Next PRF Meeting - Mark Your Calendar!
Thursday, September 7th 2023 at 5:30pm ET

• Upcoming Topics:
  Depression
  Emergency Preparedness

• Things to Think About: Do you know who to call or reach out to in a disaster?

Do you know what to expect during your first therapy appointment?
National Immunization Awareness Month is observed in August annually across the USA.

### COVID-19 Vaccine
- Coronavirus disease (COVID-19) is an infectious disease caused by the SARS-CoV-2 virus.
- COVID-19 vaccines help your body develop protection from the virus that causes COVID-19.
- Although vaccinated people sometimes get infected with the virus that causes COVID-19, it helps prevent severe COVID-19 illness. The vaccine is the best way to protect yourself and others from COVID-19.
- COVID-19 vaccines are safe and effective with a strong safety profile. It has been shown to be effective against new variants of the virus.
- It is important to get vaccinated as soon as possible to protect yourself and others.

### How Vaccines Prevent Diseases
Vaccines reduce the risk of infection by working with the body’s natural defenses to help it safely develop immunity to disease. When germs, such as bacteria or viruses, invade the body, they can attack and multiply. This invasion is called an infection, and the infection leads to what is called illness. The immune system then has to fight the infection. Once it fights off the infection, the body is left with a supply of cells that help recognize and fight that disease in the future.

Vaccines help develop immunity by including an infection, but this "simulation" of infection does not cause illness. It does, however, cause the immune system to develop the same response as it would to a real infection, so the body can recognize and fight the vaccine-preventable disease in the future.

For more information about these vaccines, speak with your healthcare team and visit these CDC website pages:
- [www.cdc.gov](http://www.cdc.gov)

To file a grievance, please contact us:
IIPRD End-Stage Renal Disease Network Program
Corporate Office: 1799 Marietta Avenue, Lake Success, NY 11042-3172
- Patient Services: (516) 223-9767 • Toll-Free: (800) 230-3773
- Email: [info@kidneytransplant.org](mailto:info@kidneytransplant.org) • Web: [www.cdc.gov](http://www.cdc.gov)

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<th>Vaccines recommended for dialysis patients:</th>
<th>Annual Flu Vaccine</th>
<th>Pneumonia Vaccine</th>
<th>Hepatitis Vaccine</th>
<th>COVID-19 Vaccine</th>
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- Flu is a contagious and serious respiratory disease.
- As a dialysis patient, if you get the flu, you are more likely than others to develop serious problems.
- Each year there are different types of flu vaccines available. Some are better suited for kidney patients. Ask your healthcare team about which flu vaccine is best for you.
- Receiving an annual flu vaccine will help protect you from getting the flu.
- According to the Centers for Disease Control and Prevention (CDC), influenza season usually starts in October and can last until late May. The best time to receive a flu vaccine is October or November.

- Pneumonia is an infection of the lungs, usually affects millions of people worldwide each year.
- Pneumonia is caused by bacteria and can lead to serious infections.
- Pneumonia infections can often be prevented and can usually be treated.
- The pneumonia vaccine protects your body from many types of harmful bacteria.
- You should receive a pneumonia vaccine every five years.
- You can receive this vaccine any time of year.

- Hepatitis is caused by the liver and affects millions of people worldwide each year.
- Hepatitis is the main cause of liver cancer.
- Hepatitis B vaccine is given in a series of three to four injections or doses over a six-month period.

- COVID-19 Vaccine
- Coronavirus disease (COVID-19) is an infectious disease caused by the SARS-CoV-2 virus.
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- It is important to get vaccinated as soon as possible to protect yourself and others.
Social Media
Follow Us!

- [Link to IPRO ESRD Network Program’s Facebook Page]
- [Link to IPRO ESRD Patient Facility Representative (PFR) Alliance Group]
- [Link to IPRO ESRD Network Program’s Twitter Page]
- [Link to IPRO ESRD Network Program’s Linkedin Page]
- [Link to IPRO ESRD Network Program’s Instagram]
Questions?
Comments?
Thank you for your ongoing commitment to the ESRD community!

For more information, contact:

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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 #