Patient Facility Representative (PFR) Alliance Meeting

June 6th, 2024
Patient and Family Engagement Facilitators

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Patient and Family Engagement
Lead
Patient and Family Engagement Facilitators

Brooke Andrews, MSW
Patient Services Speaker
Today’s Agenda
Topics for Review/Discussion

- Meeting Reminders
- PFR Check-In
- Patient Spotlight Recap
- 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, 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)
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.
Welcome Our New PFRs!

- Julius Minsky
- Michelle Maess
- Joseph Iovino
- Devone Miller
- Matrice Huff
- Keith Jackson
- Tema Hill
- Julie Lindsey
- Cary Kelly
- Kenneth Cook
- Sue Sheldon
- Awilda Ortiz
- Alice Sweet
Patient Spotlight Recap!
Continue to give....

We have patient’s who are advocates for life!

- We have PFR’s who advocate for HOME/PD
- We have PFR’s who advocate for Transplant
- We have PFR’s who advocate for IN CENTER
- We have PFR’s who advocate for CHANGE!!

We hope that you able to continue to be PRESENT, be PATIENT and be HEARD!

We thank you for sharing your stories and we hope you continue to do so.
Meeting Updates!!

We are on the MOVE....

We will be transitioning from WebEx to Teams in the upcoming months.

There will not be a monthly PFR meeting in JULY due to the holiday but look forward to seeing you AUGUST!
How about a NEW TIME!?
Let’s talk about it....

If we were to change the time for our Monthly PFR Meetings, what time works best for you?

The first Thursday of each month at 9am-10am?

The first Thursday of each month at 4pm-5pm?

Or OTHER? Suggestions?
New Resource!!!
My Fast Food Plate

What should I be looking for?
Main Meal
Try to look for options that are grilled or baked, like a grilled chicken sandwich or a salad with lean protein. Try to avoid fried items because they tend to be highly processed and could contain more phosphorus.

Sides
If available, try to order sides like steamed vegetables, plain baked potatoes, or a salad. If you order onion rings, ask for no added salt. Avoid items that have cheese, bacon, or creamy sauces. These items may be high in sodium and phosphorus.

Drinks*
Water is your best choice for a drink. If you would like something different, try to find drinks that are low in phosphorus or phosphorus free.
* Always remember to watch your fluid intake. One of the biggest challenges with being on dialysis is fluid overload.

Remember, customization is key! Don’t hesitate to make changes to your order. You can ask for sauces and dressings on the side, ask for no added salt, or remove any items that do not fit into your diet. Most fast food restaurants are willing to accommodate their customers.

Eating healthy at fast food restaurants while on dialysis is not only possible but could be a positive experience with the right tools. This guide will help you learn how to identify kidney-friendly food options, understand recommended portion sizes, and make informed decisions that align with your dietary restrictions.

Understanding how to read a fast food menu can be a little tricky while following a renal-friendly diet. Here’s a guide for when you are grabbing something fast on the go:

Watch out for sodium levels: Avoid foods with salt as the first ingredient.

Be aware of phosphorus and potassium: When reading nutritional information, phosphorus can disguise itself under different names. Look for ingredients that start with P-HOS like phosphoric acid or sodium tripolyphosphate.

Foods Low in Phosphorus:
- Fresh fruits and vegetables
- Lightly colored sodas
- Homemade iced tea
- Almond milk

Foods Low in Potassium:
- Applesauce
- Cabbage
- Cooked rice
- Cranberry or grape juice

Identify smart protein selections: Some examples of smart protein selections are:
- Chicken without the skin
- Lean cuts of meat
- Fish

For more information or to file a grievance, please contact us:  
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This material was Developed 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 ESRO/IPRO-GA-NW-22040127-2014/7/26/2021 V2
New Resource!!!

My Fast Food Plate…

Main meal:
- Plain hamburger
- Grilled chicken sandwich
- Salad with grilled chicken
- Soft taco, no beans or tomatoes
- Slice of thin crust cheese pizza
- Fish sandwich, no tartar or cheese
- Tuna salad sandwich

Fast Food Hack!
Order a kid’s meal for smaller portions

Main meal: plain hamburger
Side: apple slices
Drink: lemon lime soda

Drinks (small):
- Water
- Apple juice
- Lemon Lime Soda
- Coffee

Sides:
- Salad
- Small onion rings, no salt
- Small French fries, no salt
- Applesauce

Disclaimer: It is vital for registered dietitians to help guide patients to better options.

USDA uses the recipe provided by the restaurant to calculate the nutrients; unfortunately, this does not contain preservatives or additives added to the food, meaning that the phosphorus content provided could be less than half of the actual phosphorus consumed for each item.
Network Check-In
Polling Question

Do you think this will be a easy transition, or would you like more assistance?

• Yes
• No
• Unsure
Preparing For Hurricane Season & The Heat

Brooke Andrews, MSW
Patient Services Speaker
Network Check-In
Polling Question

Do you have the ESRD Emergency Hub Mobile App?

• Yes
• No
• Unsure
The ESRD Emergency Hub Mobile App

Application Features

- Emergency notifications
- Emergency and healthcare support organization's contact information
- My Vital Dialysis Information, prescriptions, and checklist
- Go bag supply checklist
- 3-Day emergency diet plan and shopping list
- Evacuation information page
- Medical needs shelter information page
- Severe weather information page

Scan QR Code for Quick Access

Apple Store

Google Play
Beat The Heat

Make sure you have access to a cool place to rest. Drink non-alcoholic fluids regularly, though follow your doctor’s guidelines — drinking large amounts of plain water in a short amount of time can be dangerous because of the risk of electrolyte imbalance in some people. Please talk with your Dietician about summer friendly snacks and fluid intake!
Tips & Tricks

Next Steps

Aisha Edmondson
Patient and Family Engagement
Next PRF Meeting - Mark Your Calendar!
Thursday, August 1st 2024 at 5:30pm ET

- Upcoming Topics:

- Things to Think About: Patient Activation!
Community Awareness Campaigns
June 1st, Kicks Off Men’s Health Month!!!

Father’s Day is quickly approaching and now is the perfect time to encourage the men in your life to take care of themselves. The month of June is National Men’s Health Month we encourage men to stay healthy by eating right, exercising and seeking regular medical checkups to prevent disease and injury so they may live healthy lives.

Men’s health is not just a ‘man’s issue’, it’s a family issue. Men’s health can impact everyone around them: wives, mothers, daughters, and sisters, etc.

So the question is, what can men do to be healthier?

The answer? Simple: Take action!
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
Questions?
Comments?
Thank you for your ongoing commitment to the ESRD community!

For more information, contact:

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