



End-Stage Renal Disease  
Network Program

# Patient Facility Representative (PFR) Alliance Meeting

December 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



Liz Lehnes, MSW, LCSW  
Patient Services Speaker



Tiffany Reese-Arrington, CCHT  
Quality Improvement Speaker

# Today's Agenda

Topics for Review/Discussion



Meeting  
Reminders

Patient  
Services  
Topic

PFR Check-In

Closing  
Remarks

Quality  
Improvement  
Topic



# Meeting Reminders



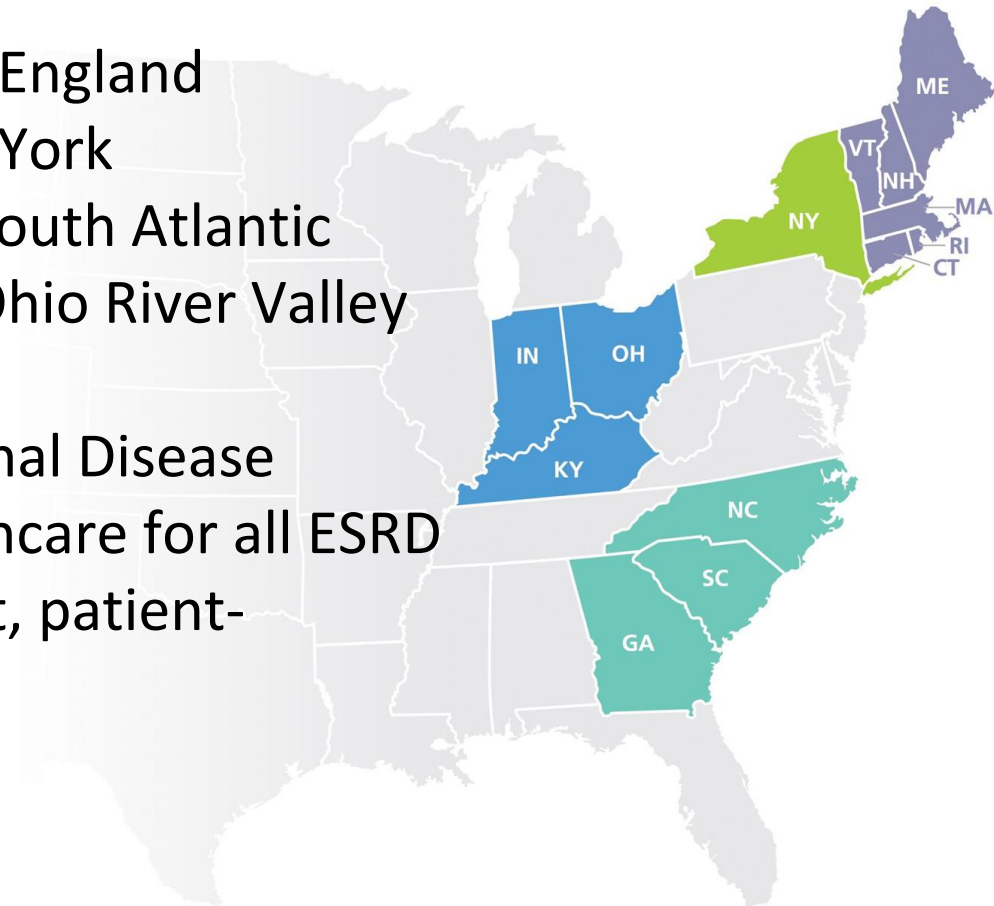
- All phone lines are muted upon entry to eliminate background noise/distractions
- We will be monitoring Chat throughout the meeting for questions or comments
- All slides will be shared within a week of completion of the meeting



# 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, 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)



# Welcome Our New PFRs!

- Diana Ford
- Gayle Henry
- Randall Begin
- Glenford Wade
- Lenor Lamar Leavell
- Dasmond Hinton
- James Steed





# 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.

[We Can Help](#)

### The IPRO ESRD Network Program We Can Help



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.	~ <b>Example: "My unit is too cold"</b> 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.	~ <b>Example: "I need a fourth shift, and my facility does not offer one"</b> The Network can provide you with a list of facilities in your area that offer a fourth shift (Dialysis Facility Compare tool available on <a href="http://www.medicare.gov">www.medicare.gov</a> )
Investigate concerns about issues related to quality of care.	~ <b>Example: "I am upset about the care I am receiving at my facility"</b> 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.	~ <b>Example: "I don't agree with a policy at my facility"</b> 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.



For more information or 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.org](mailto:esrdnetworkprogram@ipro.org) • Web: [esrd.ipro.org](http://esrd.ipro.org)

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# Patient Feedback

## Peer Approval

# My Fast Food Plate



End-Stage Renal Disease Network Program

### 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.

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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 PHOS like phosphoric acid or sodium triphosphate.

#### 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



# Insurance and Coverage



Liz Lehnes, MSW, LCSW  
Patient Services Specialist

# Network Check-In

## Polling Question



Are you feeling comfortable with your understanding of insurance options as a dialysis patient?

- Yes
- No
- Unsure



# What is the difference: Medicare / Medicaid?

Who is eligible for each? How?



## Medicare and Medicaid

Two government programs to help people pay for health care – how they differ.

Medicare	Medicaid
<b>Care for People Who Are Older, Disabled, or Chronically Ill</b>	<b>Care for People With Limited Incomes and Resources</b>
<ul style="list-style-type: none"><li>● Administered by Federal government.</li><li>● Benefits are 100% Federal funds.</li><li>● Eligibility based on age (65 and over), disability, or chronic illness.</li><li>● Coverage is Federally mandated and generally includes hospital, outpatient, nursing home, and prescription drugs.</li><li>● No financial tests to qualify.</li></ul>	<ul style="list-style-type: none"><li>● Administered by States.</li><li>● Benefits are a combination of State and Federal funds.</li><li>● Eligibility based on limited income and resources.</li><li>● Coverage varies by State but generally includes most medical services prescribed by a doctor or dentist.</li><li>● Income and asset tests vary by State.</li></ul>

# Open Enrollment

Medicare Open Enrollment dates are 10/15 to 12/7!



The screenshot shows the Medicare.gov website interface for finding Medicare health and drug plans. At the top, there is a navigation bar with various links. The main heading is "Explore your Medicare coverage options" with a sub-heading "Pick your 2025 plan from Oct. 15 - Dec. 7." Below this is a photo of a man with a mustache, wearing a pink shirt, holding a smartphone. A link "First time joining a Medicare health or drug plan?" is visible. The main content area is titled "Find Medicare health & drug plans" and contains two columns. The left column has a "Use your account" button, a "Save time by logging in" section with bullet points, a "Log In" button, and a link "Don't have an account? [Create one.](#)". The right column has a "Continue without logging in" button, a prompt to "Choose the year you need coverage and enter your ZIP code:", "COVERAGE FOR" options for 2025 (selected) and 2024, a "ZIP CODE" input field, and a "Continue" button. At the bottom left, there is a link "Looking for PACE plans?".

- Great news! The enrollment period is almost up. Mailings should slow down soon.
- If you have not made selections, please play as yourself or guest in the [Medicare Plan Finder tool](#) to test in real time estimates of what your prescription drug cost at your preferred pharmacy, monthly payments, and coverage choices.
- **Make sure when investigating your options, the website ends in .gov.** so that your private information remains private.

# Holiday Healthy Living



**Tiffany Reese-Arrington, CCHT**  
**Project Lead: Healthy Lifestyles**



# Network Check-In

## Polling Question

**Do the holidays cause you stress, anxiety, and/or depression?**

- Yes
- No
- Unsure





# Holiday Healthy Living



- Autumn is what we consider the harvest period. It's the transitional period when we acknowledge growth and expansion and take some time to self-reflect. However, for many of our patients, it's also the start of Seasonal Affective Disorder (SAD), commonly known as “The Holiday Blues.”
- Due to unrealistic expectations from family, loneliness, anxiety or holiday stress, you may feel like they **HAVE** to be holly and jolly when you may or may not have enough strength to get up.
- For some to get through the season, it may require engaging in creative activities. For others, it may include visits to and from family and friends. Either way, the goal is to make sure whatever it is, these events are both healthy to the mind, body, and soul and you look forward to participating.



# Find that Sprinkle of Joy

## Ways to Appreciate the Holiday Festivities

- **Deck the Halls**

- Christmas trees, Holiday lights, Menorahs, Kinaras takes focus off of problems and encourages creativity

- **All I Want for Christmas is.....**

- Send holiday cards, secret santa gift exchange, give without expectations

- **Twelve Days of Christmas**

- cookie exchange, holiday bake-offs/cook-offs, holiday movie night, volunteer to wrap gifts or shelters

- **Joy to the World**

- Caroling, karaoke, holiday get togethers/parties



# Find that Sprinkle of Joy

- **Happy Holidays!**
  - Travel
    - Check and make sure you have enough of your medications
    - Set-up dialysis care
    - Request copy of prescription as back up for emergencies
    - Advise transplant center
    - If days lapse, schedule add't txt

Most importantly  
**GET YOUR VACCINES**



## Stay Safe this Winter – Here's How



As temperatures cool down and we move inside, you are more likely to be exposed to viruses than you were during the summer months. In the fall, it is important that you receive the vaccines you need to protect yourself from illnesses like the flu or COVID-19. Either of these illnesses can lead to long-term, serious issues, like pneumonia, that could eventually result in being admitted to a hospital. There are three vaccines that you should be sure to be up-to-date with now: influenza, COVID and pneumonia vaccines. Below are some of the more frequently asked questions about these vaccines to help you decide what to do.

### Why do I need a influenza (flu) vaccine every year?

The influenza virus changes every year. So to best protect yourself against flu, you need to have a vaccine for the strain of virus that is expected to be the worst that year.

### Why do I need to consider taking the pneumonia vaccine?

The pneumonia vaccine protects you against other viruses that cause you to develop an infection in your lungs. Individuals with kidney disease should seriously consider getting a pneumonia vaccine. Most vaccines are effective for five years, and two-three doses can protect you for a lifetime. Check with your doctor about when you should get your next vaccine and what strength dose you need to stay protected.

### When should I get my influenza and pneumonia vaccines?

These are both recommended in early fall to be prepared for the winter season. If you have had the pneumonia vaccine in the last five years you need to check with your physician about when your next vaccine is due. Keep track of that date, and be sure to take your influenza vaccine every year.

### Why do I need to get a COVID 19 additional dose?

The COVID-19 virus changes frequently. In the beginning of the pandemic, we had a type of COVID known as the Delta strain. Most of us were vaccinated against that strain, but now we are dealing with the COVID e Omicron strain (Ba4/ Ba5). The vaccines offered for the Delta strain do not work against the current Omicron strain, so you'll need to take an additional dose of the new bivalent vaccine to prevent this new strain from making you sick.

*continues on next page*

### When should I get my COVID vaccine now?

The COVID-19 vaccine is available for COVID-19. The COVID-19 vaccine is a 2-dose series. If you had concerns about the Pfizer and Moderna vaccines, you may want to get this new vaccine. It was made through a scientific process that has been very effective in making vaccines like the flu vaccine.

### When should I get all these shots done during the winter?

You can get both the Influenza vaccine and the COVID-19 vaccine. All doses administered at the same time. You can schedule these together, and you can schedule the pneumonia vaccination this time during your next visit!

### If you have a grievance, please contact us:

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# Network Check-In

## Polling Question



**Do you follow your dietary restrictions during the holiday season**

- Yes
- No
- Unsure



# American Kidney Fund

## Food Choices

- **Appetizer**

- Low-Potassium Fruits
  - Grapes
  - Apples
  - Berries
- Snacks
  - Unsalted Popcorn
  - Unsalted Pretzels
  - Angel Eggs
- Spreads
  - Cream Cheese
  - Mango Salsa
  - Low Sodium Cheese

- **Main Course**

- Vegetables
  - Green Salad
  - Peas
  - Green Beans
  - Zucchini
  - Cauliflower
- Meats
  - Turkey
  - Pork
  - Chicken
  - Goose
  - Duck
- Starches
  - Stuffing with no nuts or dried fruit
  - Plain Rice
  - Noodles
- Sides
  - Cranberry Sauce
  - Applesauce
  - Gravy

- **Liquids**

- Water with Lemon
- Sparkling Water
- Iced Tea
- Apple Juice
- Cranberry Juice
- Tea
- Coffee

- **Dessert**

- Fruit Pies
- Sugar Cookies
- Pound, Spice, Angel food cake



# Holiday Recipe



## Honey Herb Glazed Turkey

Live. Learn. Hope.

Dinner, Entrees, Holidays, Low Potassium, High Protein, Low Sodium



### Ingredients

Based on 6-8 servings per recipe.

- 10-12 pounds whole turkey
- 1 onion, cut into wedges
- 2 celery stalks, whole
- 1 lemon, cut into chunks
- 1/3 cup olive oil
- 1/2 cup unsalted butter
- 2 tablespoons fresh sage leaves
- 1/3 cup fresh thyme stripped from stems (about 14 stems)
- 2 fresh bay leaves
- 2 teaspoons celery seed
- 1/4 cup honey
- 2 teaspoons lemon juice

### Nutrition Facts per serving

Calories	412
Carbohydrates	7 g
Protein	49 g
Sodium	119 mg
Potassium	526 mg
Phosphorus	357 mg

**Sodium:** All of our recipes are low in sodium because it is hard on kidneys and raises blood pressure. Most people should limit sodium to 1,500 milligrams per day.

**Potassium:** If you are on hemodialysis, limit potassium too, to 2,000 milligrams per day. If you are on peritoneal dialysis or short daily dialysis, limit potassium to 3,500 milligrams per day.

**Phosphorus:** If you are on dialysis, limit phosphorus to about 1,000 milligrams per day.

**Protein:** If you are not on dialysis but have kidney disease, you might benefit from a diet lower in protein. Check with a kidney doctor or dietitian for guidelines.

### Preparation

1. Heat oven to 350 degrees.
2. Remove neck and giblets from turkey.
3. Fill bird with onion, celery and lemon.
4. Rub skin with olive oil.
5. Put on 2 sheets of aluminum foil.
6. Cover top of bird with separate sheet of foil, which you will remove later.
7. Seal the edges of the foil and put on a rack and roast in the oven.
8. While turkey is cooking, melt butter, chop sage and thyme leaves finely.
9. Add bay leaves, chopped herbs, and honey to butter.
10. Simmer 10 minutes, until butter is lightly browned, then remove the bay leaves.
11. When the turkey reaches 145-155 degrees, raise oven temperature to 500 degrees, remove top foil and baste turkey with honey herb mixture, every 5-10 minutes or so.
12. Using a thermometer, when the turkey reaches 160 degrees remove from oven, tent with foil and let rest 30 minutes before carving.

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Learn more about the Transparency in Coverage Rule. (<https://healthy.kaiserpermanente.org/front-door/machine-readable>) - Terms

## Savory Maple Sausage Stuffing

Dinner, Holidays, Low Phosphorus, Low Potassium, Low Sodium



### Nutrition Facts per serving

Calories	170
Carbohydrates	14 g
Protein	7 g
Sodium	254 mg
Potassium	171 mg
Phosphorus	75 mg

**Sodium:** All of our recipes are low in sodium because it is hard on kidneys and raises blood pressure. Most people should limit sodium to 1,500 milligrams per day.

**Potassium:** If you are on hemodialysis, limit potassium too, to 2,000 milligrams per day. If you are on peritoneal dialysis or short daily dialysis, limit potassium to 3,500 milligrams per day.

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**Protein:** If you are not on dialysis but have kidney disease, you might benefit from a diet lower in protein. Check with a kidney doctor or dietitian for guidelines.

Northwest Kidney Centers  
<https://www.nwkidney.org/living-with-kidney-disease/recipes/>

National Kidney Foundation  
<https://www.kidney.org/nutrition/recipes>

DaVita's Kidney Diet Cookbook  
<https://www.davita.com/diet-nutrition/kidney-friendly-cookbooks>

FMC Kidney-Friendly Cookbook  
<https://www.freseniuskidneycare.com/recipes-and-nutrition/kidney-friendly-cookbooks>

# Next Steps



**Aisha Edmondson**  
**Patient and Family Engagement**



# Community Awareness Campaigns

## National Influenza Vaccination Week Dec 2nd-6

National Influenza Vaccination Week (NIVW) is a national awareness week focused on highlighting the importance of influenza vaccination. From December 2-6, 2024, we will observe National Influenza Vaccination Week, a reminder for everyone 6 months and older that there's still time to get a flu vaccine this season.

get your  
**Flu**



**Shot**

**NATIONAL  
INFLUENZA**

**VACCINATION**

**WEEK**

FIRST FULL WEEK IN DECEMBER



# Next PRF Meeting - Mark Your Calendar!

Thursday, January 2nd 2024 at 5:30pm ET



- Upcoming Topics: New Year Interventions
  
- Things to Think About: Staying Safe This Winter
  - \*NEW\* Emergency Preparedness Checklist for Patients: [English](#) | [Spanish](#)
  - General Patient Preparedness: [Tips](#)
  - [Why You Should Be #WinterREADY](#)

# 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:

**Aisha Edmondson**  
**Project Manager: Patient and Family Engagement**  
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