

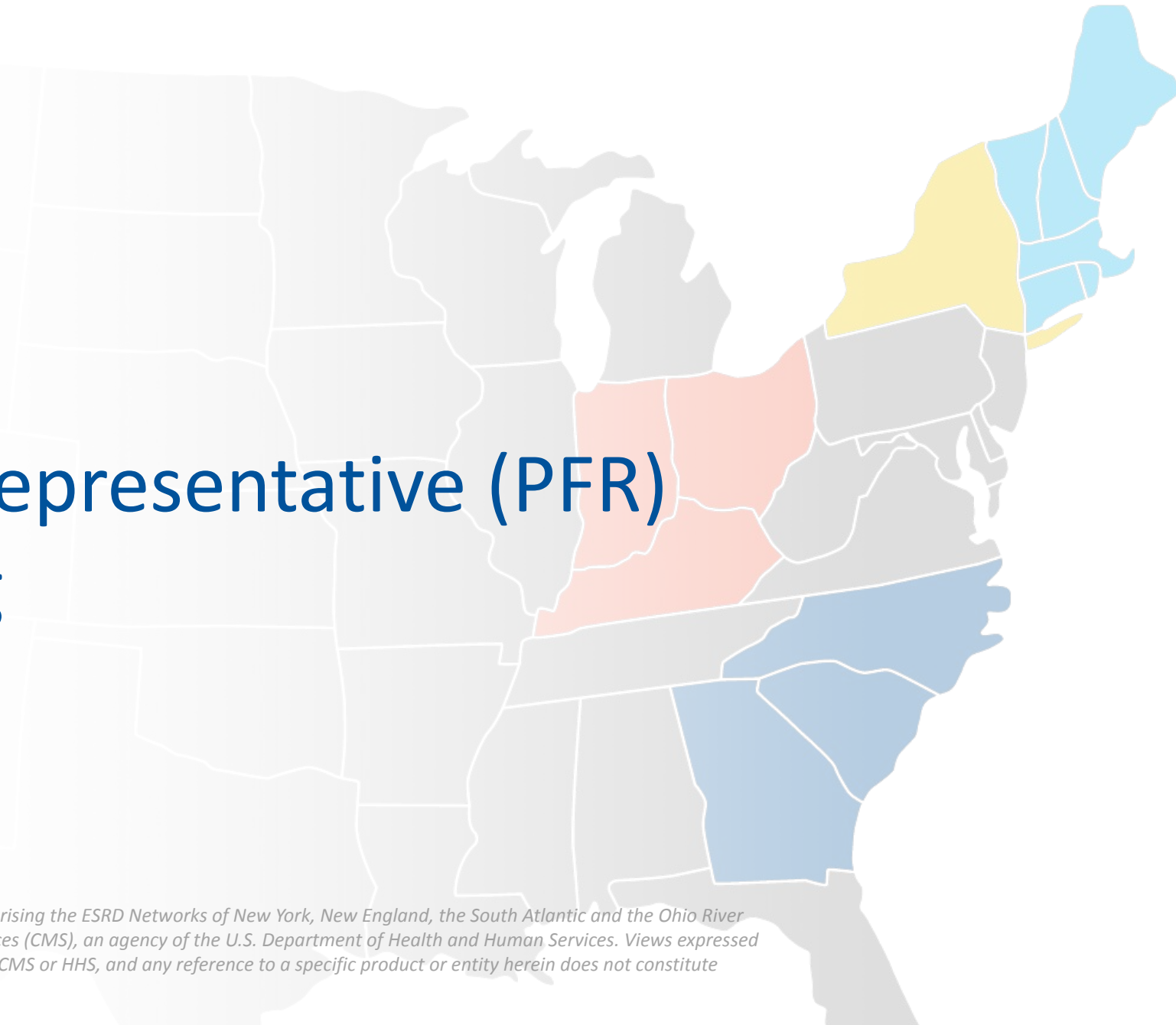


End-Stage Renal Disease
Network Program

Patient Facility Representative (PFR) Alliance Meeting

June 6th, 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



Brooke Andrews, MSW
Patient Services Speaker

Today's Agenda

Topics for Review/Discussion



Meeting Reminders

Patient Services Topic

PFR Check-In

Closing Remarks

Patient Spotlight Recap



Meeting Reminders



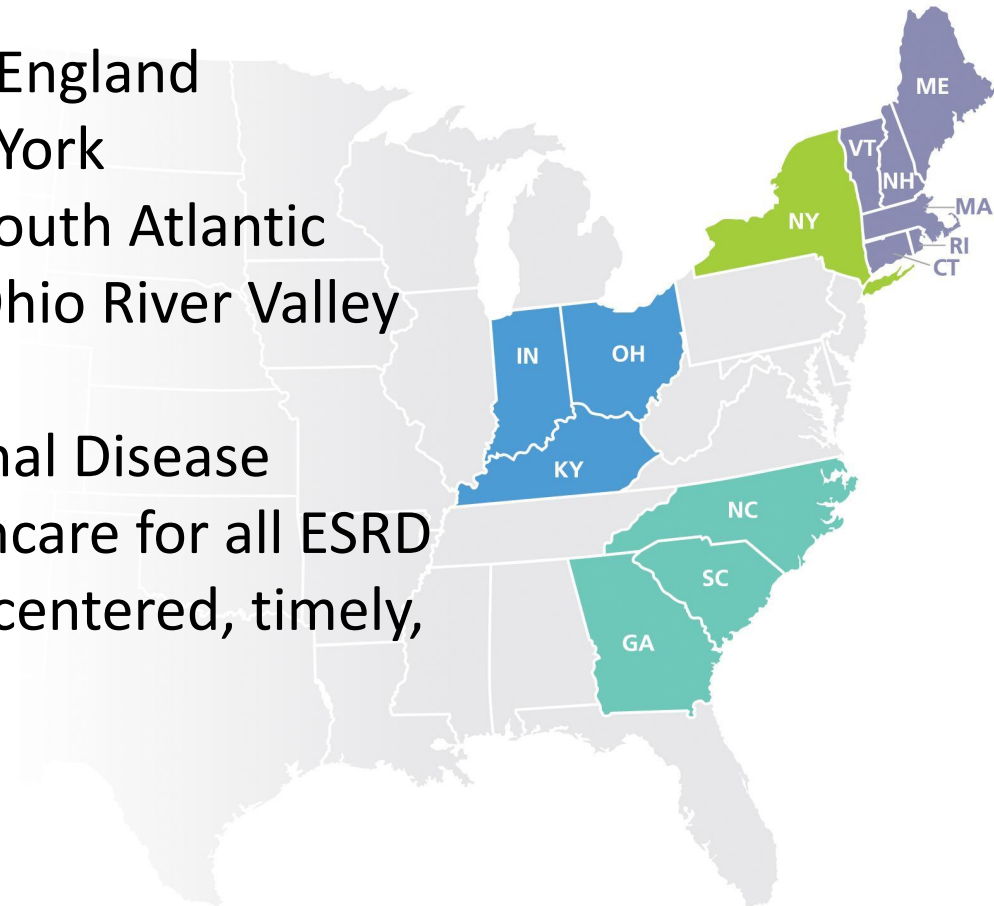
- All phone lines are muted upon entry to eliminate background noise/distractions
- We will be monitoring Chat throughout the meeting for questions or comments
- All slides will be shared within a week of completion of the meeting



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.

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.

 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

Better healthcare, realized.

Developed by the IPRO ESRD Network Program while under contract with the Centers for Medicare & Medicaid Services. Contract # F31CMC100029 Publication # ES01993-CA-NW-3020913-1014-10202022 IPRO, the End Stage Renal Disease Network Program, the Network of New England, Network of New York, Network of the South Atlantic, and Network of the Ohio River Valley, prepared the material under contract with the Centers for Medicare & Medicaid Services (CMS), an agency of the U.S. Department of Health and Human Services. CMS Contract Number: F31CMC100029, CMS Task Order Number: F31CMC100029 (Network 1), F31CMC100029 (Network 2), F31CMC100029 (Network 3), F31CMC100029 (Network 4), F31CMC100029 (Network 5)

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.

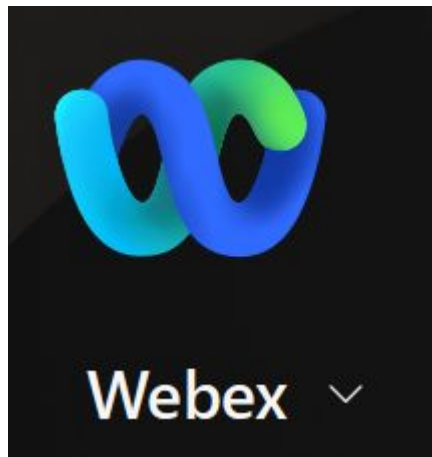


Meeting Updates!!

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!



Microsoft Teams

Microsoft Corporation

4.6★
7.4M reviews

100M+
Downloads

E
Everyone ⓘ

Install

Share

Add to wishlist

How about a NEW TIME!?

Let's talk about it....

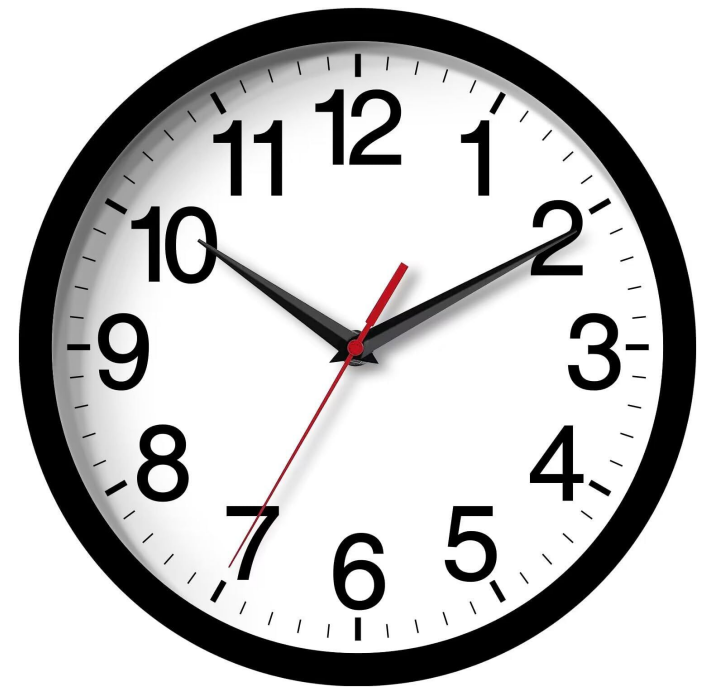


If we were to change the time for our Monthly PFR Meetings, what time works best for you?

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...





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.

For more information or to file a grievance, please contact us:
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Patient Services: (516) 231-9767 • Toll-Free: (800) 238-3773
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Publication # ESRD.IPRO-GA-NW-20240327-294 4/25/2024 v2

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

: [English](#) | [Spanish](#)

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 micronutrients; 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

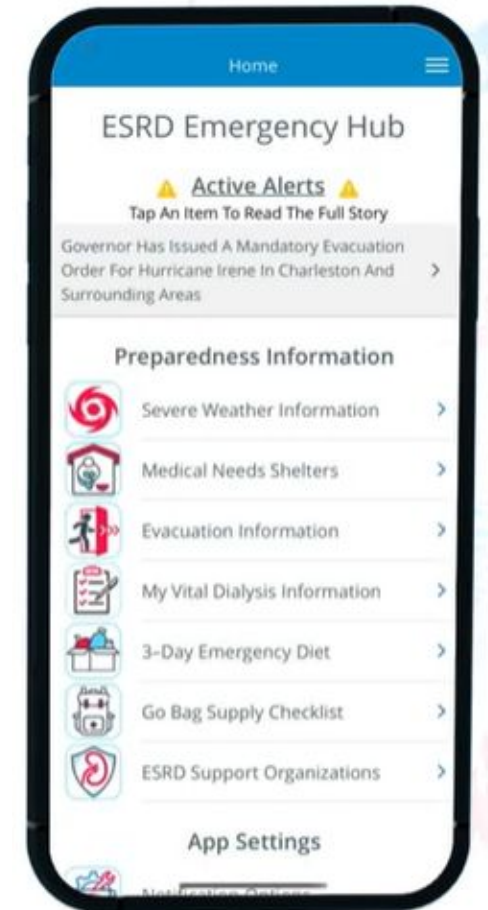


Apple Store

Scan QR Code
for Quick Access

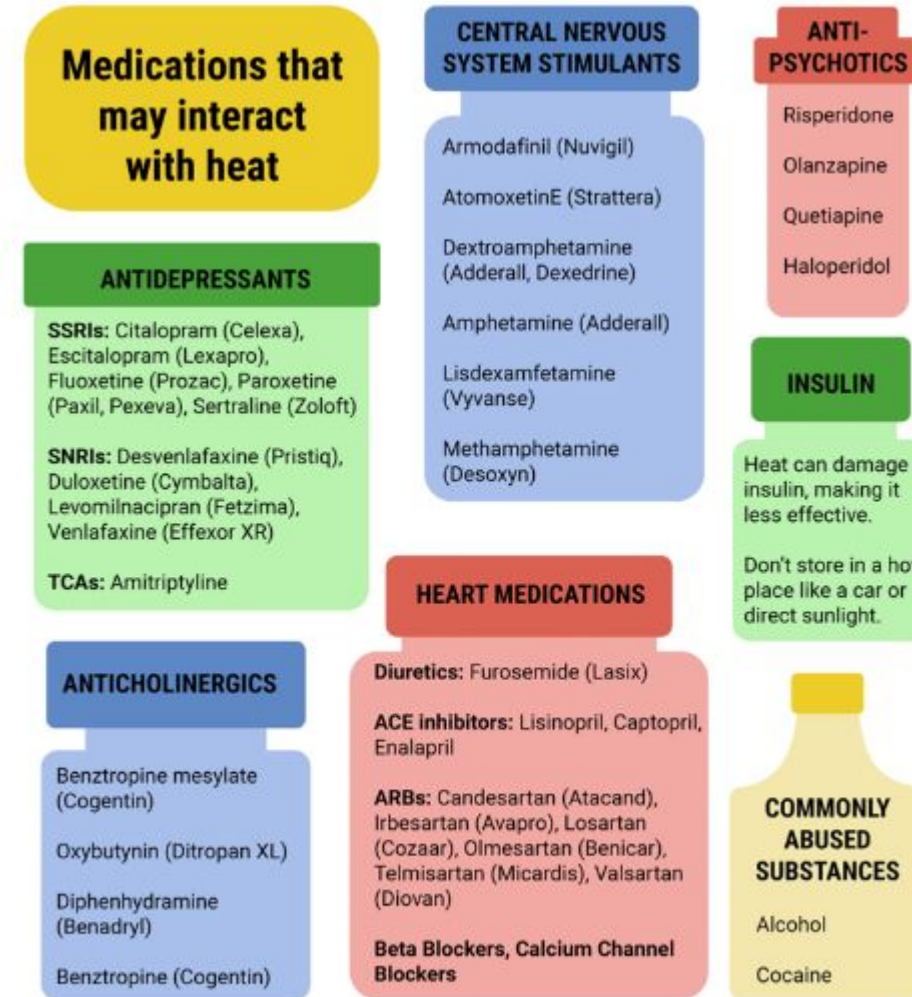


Google Play



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!



Infographic: Samantha Harrington for Yale Climate Connections | Sources: Ebi. (2021). Hot weather and heat extremes: health risks. / Westaway. (2015). Medicines can affect thermoregulation and accentuate the risk of dehydration and heat-related illness during hot weather. / World Health Organization

Tips & Tricks

<https://www.kidneyfund.org/resource/how-beat-heat-safely-when-you-have-kidney-disease>

BEAT THE HEAT! American Kidney Fund®

Stay hydrated without overdoing fluids

FLUID INTAKE

When you are on dialysis, fluid (water) builds up in your blood between treatments. Here's some helpful info on fluid management. Ask your dietitian how much fluid you should have each day.

Things to keep in mind . . .

- Extra fluid in your body can make your dialysis treatments more difficult.
- Too much fluid can cause swelling, high blood pressure, trouble breathing and heart failure.
- Salty foods like chips and pretzels make you thirsty.

ASK your doctor or pharmacist if any of your medications cause dry mouth.

DRINK slowly out of smaller cups.

CHEW sugar-free gum.

CHILL or freeze fruit for a refreshing snack.

FREEZE juice in an ice cube tray and eat it like a popsicle.

CHOOSE unsalted snacks.

SUCK on a lemon slice or sugar-free sour candy.

REMEMBER! Ice cream, Jell-o, soup and other liquid-based foods count as fluids, too--be careful to watch your intake of fluids.

DROPS OF ADVICE



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!

Please join us each month for an IPRO ESRD Network Program hosted **webinar for patients!**



Patient Facility Representative (PFR) Alliance Conference Call
First Thursday of Each Month • 5:30 PM–6:30 PM EST

Please join us in our informative monthly webinars hosted by the Network to help understand quality-of-care expectations for dialysis facilities. Learn about new goals and priorities and how they will affect ESRD patient care.

Scan the QR Code to log onto the meeting!



Topics include:

- Patient and Family Engagement
- Emergency Preparedness
- Health Equity
- Behavioral Health
- Hospitalizations
- Healthy Lifestyles
- Transplant Coordination
- Home Therapies Utilization
- Peer Mentoring

Webinar Access: <https://tinyurl.com/PFRAllianceMeeting>

Meeting ID: 2426 823 7622

Toll-Free Dial-In: 1-855-797-9485

Password: IPROPFR

For more information, please contact the Network at 516-686-9790.

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Patient Services: (516) 231-9767 • Toll-Free: (800) 238-3773
Data Management: (516) 268-6426 • Administration: (516) 686-9790
Support Portal: help.esrd.ipro.org/support/home • Website: esrd.ipro.org/

Developed by the IPRO ESRD Network Program while under contract with Centers for Medicare & Medicaid Services. Contract # 75FCMC19D0029

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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Project Manager: Patient and Family Engagement
Tel: 216-755-3066 | E-mail: aedmondson@ipro.org



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