



End-Stage Renal Disease
Network Program



Patient Subject Matter Experts (PSMEs) Bi-Monthly Meeting

November 18, 2020

Patient and Family Engagement Program Team



Laura Rodriguez-Carbone,
MPA, MPP
Community Outreach
Coordinator



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MPH, GCPH
Community Outreach
Coordinator



Jeanine Pilgrim,
MPH, PMP, CPHQ, CHES, CPXP
Network Program Director

ROLL CALL

- Lines will be unmuted, one by one, as we call out your phone number.
- When you hear your phone number, please tell us your name, what state you live in, and what is your favorite holiday tradition.



Welcome/Introductions

Laura Rodriguez-Carbone



Meeting Reminders

- All phone lines are muted upon entry to eliminate background noise/distractions
- If you get disconnected, please don't place the call on hold, instead disconnect your line and rejoin the call when able
- Be present and engaged in our topic presentations
- We will be monitoring our WebEx Q & A throughout the webinar for questions or comments
- All slides will be shared within a week of completion of the meeting



AGENDA



- Patient Insights/Feedback on Transplant Referral Exchange (T-REX) Program APP
- Open Discussion/Patient Input on drafted Patient Educational Resources (see drafts in your mailed packet)
 - COVID Precautions: Dialysis Patient Lives Here Poster
 - Adjusting to Facility Changes During COVID-19
 - Nutrition Tips for Avoiding Fluid Retention During COVID-19
- Open Discussion: Patient Engagement in Facilities during COVID-19
- Brainstorm ideas and tips on how to educate and support others virtually during COVID-19 social distancing.
 - Ideas on a new virtual Jeopardy game for ESRD patients
 - Sharing of Helpful Resources to Pass Along to Patients
- Reminders of upcoming activities to get ready for next PSME Meeting on January 27, 2021

Transplant Referral Exchange (TREX)

Patient Module – Discussion Deck
Rich Mutell – Apex Health Innovations

Objectives and Agenda

TREX Overview – Key Features

- Overview of TREX
 - History
 - Key Features
- Patient-Specific Module

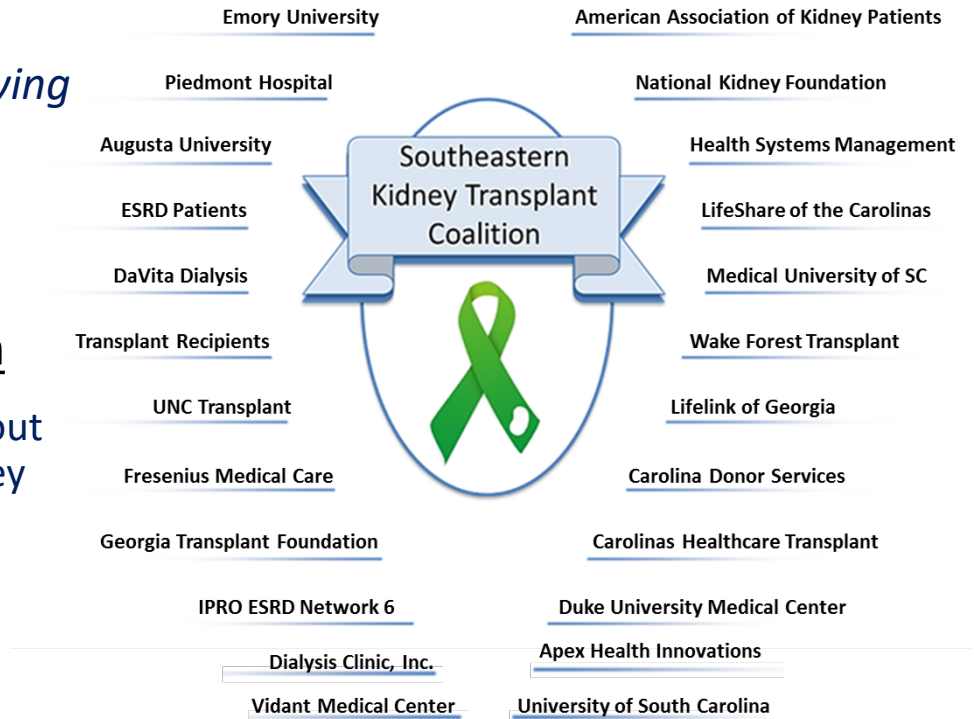
Objectives and Agenda

TREX Network 6 Pilot - History

The Southeastern Kidney Transplant Coalition is a volunteer, non-profit organization whose mission is to increase kidney transplant by identifying and reducing barriers to kidney transplant.

Long-term Goals of the Coalition

- Increase education and awareness about kidney transplant among chronic kidney disease and end-stage renal disease patients, providers, and the public
- Build an alliance of transplant centers
- Increase organ availability and organ donation
- Reduce racial disparities in order to improve the quality of care for all kidney disease patients in Georgia, North Carolina, and South Carolina



Objective and Agenda

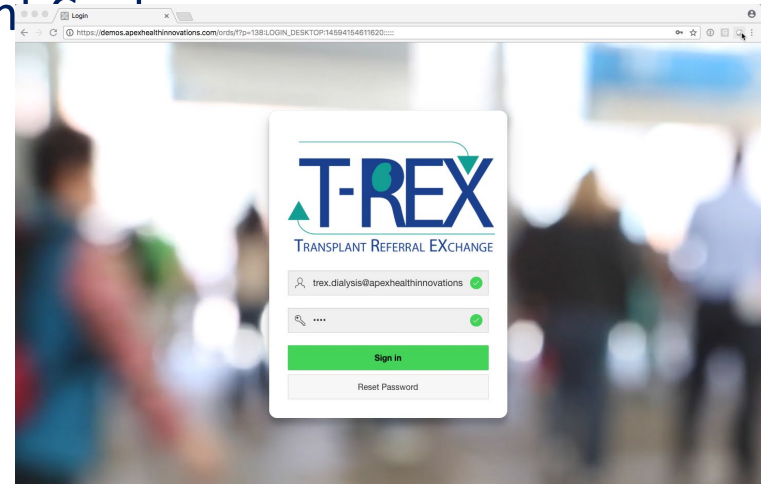
Historic Challenges – Dialysis and Transplant Center

Key Referral Challenges	Resulting Clinical Problems	TREX Benefits and Capabilities
No consistent process for Kidney Referrals across Transplant Centers.	<ul style="list-style-type: none"> Multiple FAX's Incomplete Referral Information Time consuming follow-ups Lost / Delayed Referrals 	<ul style="list-style-type: none"> Dynamic Requirements based on Transplant Center selected Inability to submit an incomplete referral based on Tx Requirements Explicit acknowledgement of Referral Received and Complete
Tracking of Patients through the Transplant Referral Process	<ul style="list-style-type: none"> Slow updates: Once a month or quarterly reporting of status changes from Tx Center Manual collection of information at the Dialysis Center – often outdated and incomplete 	<ul style="list-style-type: none"> Transplant center referral status updates instantaneously available for Dialysis Center staff Time in referral status alerts Comparable metrics on patient progression through the transplant referral process across Centers
Communication between Transplant Center and Dialysis Center	<ul style="list-style-type: none"> Hit and miss telephone calls and emails Patient history lost if SW or coordinator leaves position 	<ul style="list-style-type: none"> Communication about the patient transplant experience captured in a systemic and organized method Ability to alert Dialysis of Transplant Center staff on patient-focused challenges with keeping appointments Ability to share In-Workup schedule with Dialysis Center
Transplant Closeout / Not a Candidate Letter Process and Reporting	<ul style="list-style-type: none"> Reason why a patient is No Longer a Candidate often lost 	<ul style="list-style-type: none"> Historic Not a Candidate letters allows staff to assess previous attempts at patient referrals Improved insight into Referral loss prior to In-Workup Process at Transplant Center
Network Reporting	<ul style="list-style-type: none"> Time consuming process of collecting and reporting Referral Data 	<ul style="list-style-type: none"> Aggregate reporting to Network automatically captured monthly Improved communication with Network QIP Programs
Quality Improvement Process Reporting and Management	<ul style="list-style-type: none"> No systemic method for tracking, monitoring, and reporting QIP opportunities 	<ul style="list-style-type: none"> Ability to respond quickly and completely to survey inquiries Understand the Patient Transplant Journey Identify recurring challenges and opportunities

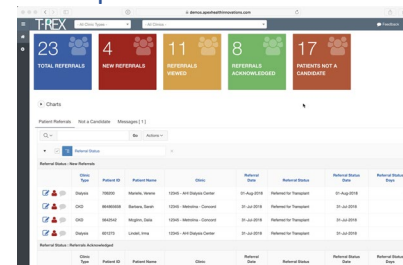
Objective and Agenda

TREX Core Features: Dialysis and Transplant

- Direct Referral Process to Transplant Centers
 - Automatically adjusts to Transplant Center selected
 - Key/Required Fields and Documents ensure a complete referral submission
- Referral Stages/Date Updated by Transplant Center
 - No email/paper-based monthly or quarterly reports
- Open Communication Channel
 - Messages/Documents stored in Communication Channel
 - Transparent tracking
- Evaluation Labs/Outstanding item visible to Dialysis Staff
- On-Hold status and reporting

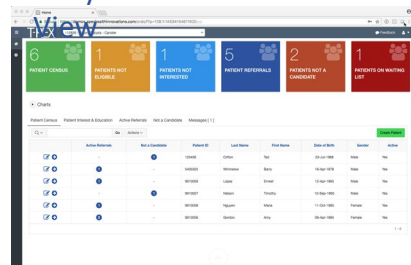


Transplant Center View



Referral ID	Patient ID	Patient Name	Referral Date	Referral Status	Referral Date	Referral Status
10000	10000	John Doe	01-Aug-2018	Referral for Transplant	01-Aug-2018	Referral Status
10001	10001	Jane Smith	01-Jul-2018	Referral for Transplant	01-Jul-2018	Referral Status
10002	10002	John Doe	01-Jul-2018	Referral for Transplant	01-Jul-2018	Referral Status
10003	10003	Jane Smith	01-Jul-2018	Referral for Transplant	01-Jul-2018	Referral Status
10004	10004	John Doe	01-Jul-2018	Referral for Transplant	01-Jul-2018	Referral Status

Dialysis Clinic View

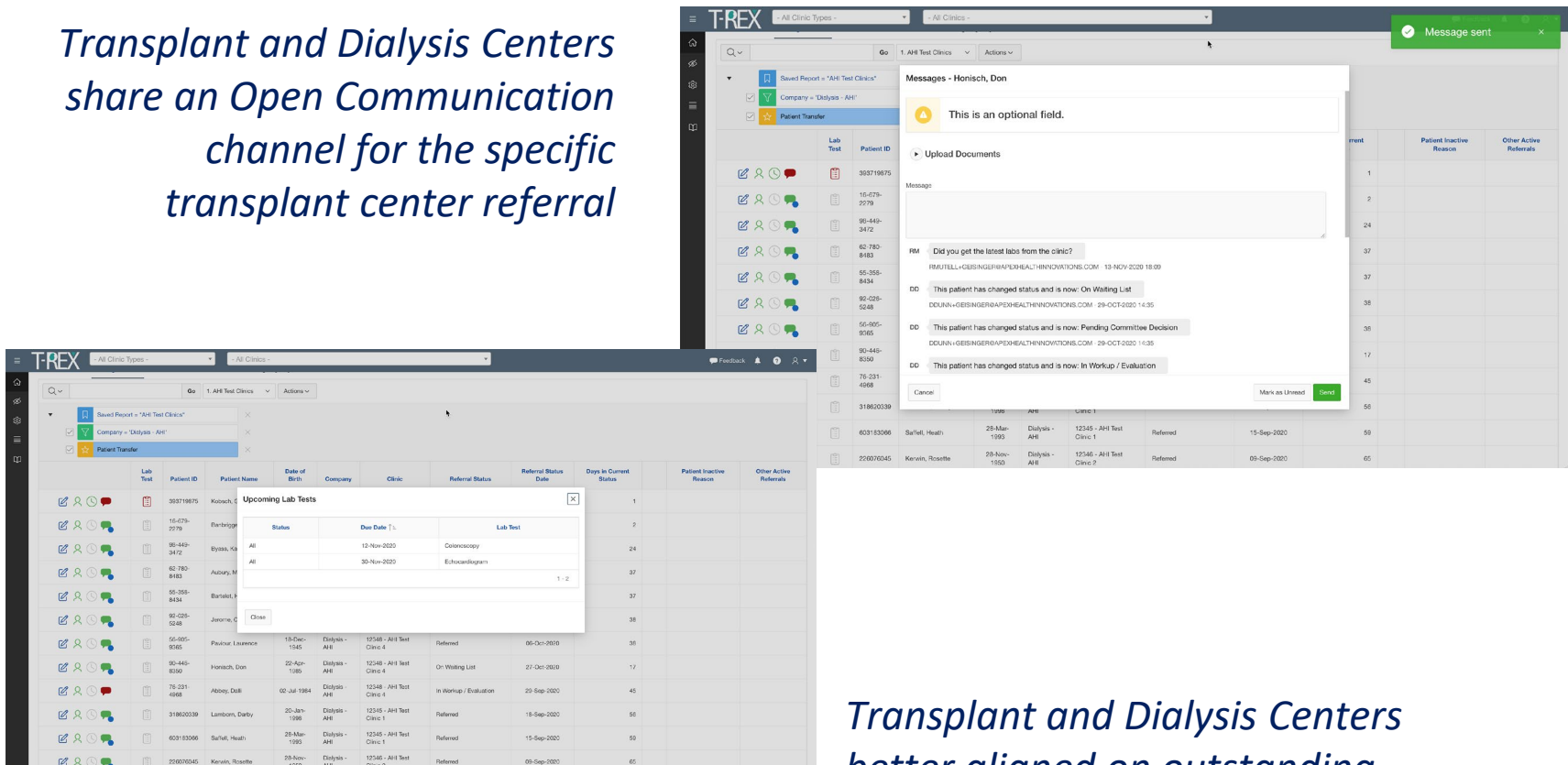


Patient ID	Patient Name	Referral Date	Referral Status	Referral Date	Referral Status
10000	John Doe	01-Aug-2018	Referral Status	01-Aug-2018	Referral Status
10001	Jane Smith	01-Jul-2018	Referral Status	01-Jul-2018	Referral Status
10002	John Doe	01-Jul-2018	Referral Status	01-Jul-2018	Referral Status
10003	Jane Smith	01-Jul-2018	Referral Status	01-Jul-2018	Referral Status
10004	John Doe	01-Jul-2018	Referral Status	01-Jul-2018	Referral Status

Objective and Agenda

TREX Core Features: Communication Channel

Transplant and Dialysis Centers share an Open Communication channel for the specific transplant center referral

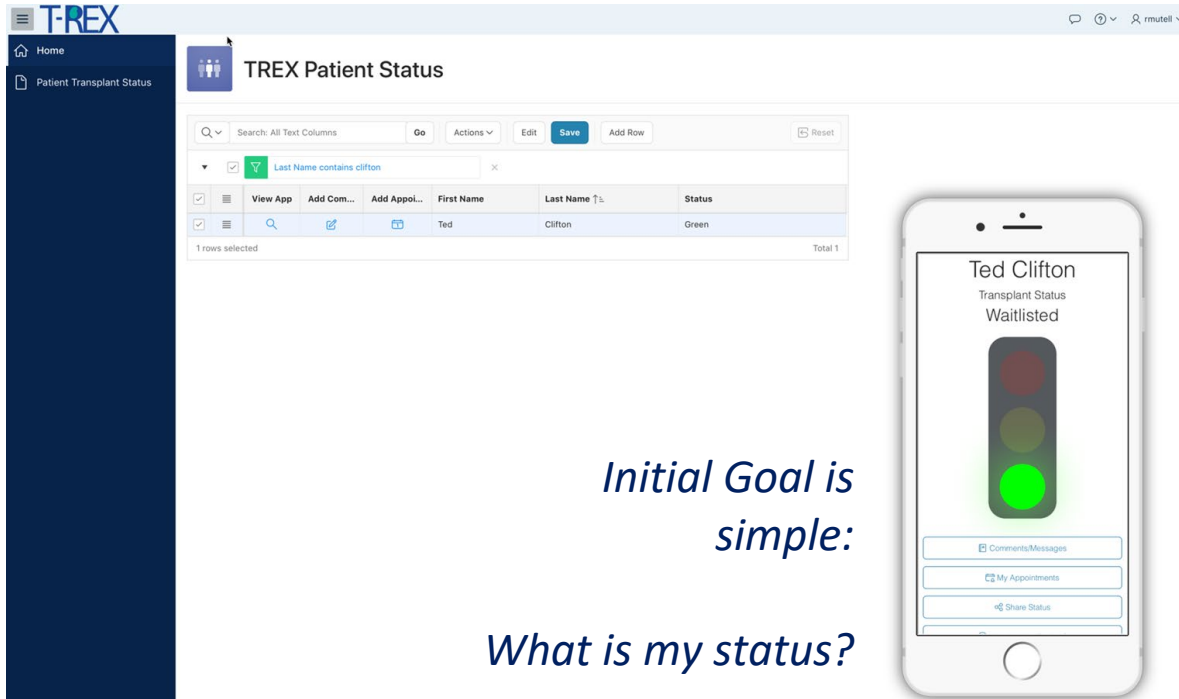


The screenshot displays the TREX software interface. On the left, a sidebar shows navigation options like 'Saved Report - "All Test Clinics"', 'Company - "Dialysis - AHI"', and 'Patient Transfer'. The main area shows a list of patients with columns for Patient ID, Patient Name, Date of Birth, Company, Clinic, Referral Status, Days in Current Status, Patient Inactive Reason, and Other Active Referrals. A modal window titled 'Upcoming Lab Tests' is open, showing a table with columns for Status, Due Date, and Lab Test. The table lists two tests: 'Colonoscopy' due on 12-Nov-2020 and 'Echocardiogram' due on 30-Nov-2020. On the right, a 'Messages - Honisch, Don' window is open, showing a list of messages with details like 'This patient has changed status and is now: On Waiting List' and 'This patient has changed status and is now: Pending Committee Decision'. A 'Message sent' notification is visible in the top right corner.

Transplant and Dialysis Centers better aligned on outstanding labs or test, as well as the duration of how long a patient has been in a specific status

What is Missing?

Patient Perspective



The screenshot shows the T-Rex Patient Status web application. The interface includes a sidebar with 'Home' and 'Patient Transplant Status' links. The main content area displays a table of patient status data. A search filter 'Last Name contains clifton' is applied, resulting in one row: Ted Clifton, Status Green. The table has columns for 'First Name', 'Last Name', and 'Status'. Below the table, it indicates '1 rows selected' and 'Total 1'.

View App	Add Com...	Add Appoi...	First Name	Last Name	Status
			Ted	Clifton	Green

1 rows selected Total 1

*Initial Goal is
simple:*

What is my status?



*... But what else
should we consider
based on your
experience and
feedback?*

Patient Perspective

Brainstorming Topics

- Expand the application to allow for the patient to share the transplant journey with family and friends
 - Example: "I need a ride feature" would automatically text your support structure if help is needed
 - Keep up with Appointment Feature – allow a loved one to see (and pester) about upcoming appointments and key steps
- Support Living Donor Activities
 - "Life without Dialysis" – Share with family and friends what is important
 - Provide snippets of Living Donor education material
- Helpful Tips to Stay on Track
- Notify you when a kidney is offered but not accepted by the Transplant Center

Patient Perspective

Brainstorming Topics

- Would an application such as this be useful?
- Would this compete with any information provided by the Transplant Center? (e.g. the Hospital Patient Portal)
- Would you use the Family and Friend feature to share your journey?
- Are there other features that would help navigate through the process?

Questions or Comments?



Patient Input/Feedback: Resource Development

Danielle Andrews



Resources in Draft Development

- [Door/Window Poster - Kidney Disease Patient Lives Here - COVID Precautions/Reminders](#)
- [Adjusting to Changes in Dialysis Facilities Due to COVID-19 Pandemic](#) (changes previously made)
- [Nutrition Tips for Avoiding Fluid Retention During COVID-19 Pandemic](#)

Upcoming Resources for December Meeting

- Virtual Jeopardy Educational Game (Holiday Game Night)

Questions or Comments?



Patient Spotlights

Danielle Andrews

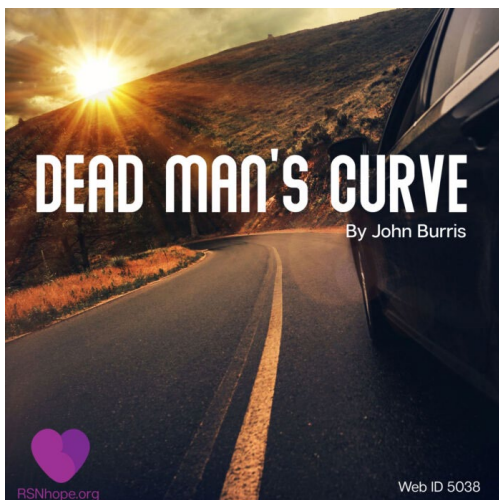
Laura Rodriguez-Carbone



Renal Support Network 18th Annual Essay Contest Feature

John Burris (NW1)

Honorable Mention, "*Dead Man's Curve*"



Great work, John, on your honorable mention, and thank you for all you are doing to educate patients on this very important topic in renal nutrition, phosphorus!

John writes, "To me, the ugliest word in the dialysis dictionary is phosphorous. I've lived for over 40 years as one who picked up not one, not two, but as many as five bottles of my favorite beverage, diet cola, each day. My "survival" depended on that added spike of caffeine. That all changed when I became a dialysis recipient and learned that my favorite drink is high in phosphorous, a nutrient that I would have to limit to stay healthy..."



Read more at rsnhope.org



Rev. Charles H. Paige, Sr.
1944-2011

2020 Charles Paige Patient Advocate Award Kim Pratt (NW1)



In July 2014, Kim was hospitalized with septic pneumonia which ultimately led to ESRD. She was an outpatient dialysis patient for five years at Wakefield Dialysis Center, underwent gastric bypass surgery in 2015, and was eventually transplanted in 2019.

Kim fought many barriers on her road to transplant, but was driven to improve her quality of life and the quality of life of others. In 2019, Kim joined the IPRO ESRD Patient Advisory Committee (PAC) and became a Subject Matter Expert on Transplant. She conducted lobby days, support groups, and served as a voice for patients on the ESRD National Coordinating Center (NCC) National Patient calls.



Kim's passion and strong dedication encourages patients to be engaged and informed about their healthcare, and inspires them to live well with kidney disease. The Network is pleased to recognize Kim's contributions and commitment to the ESRD community.

Featured on Local Media Ken Teasley (NW2)

Ken was recently interviewed by a New York City News Channel during **Minority Donor Awareness Month**. Ken discussed his journey on receiving a life-changing kidney transplant.

“The HOPE Act broke down barriers when it reversed the ban on organ donation between HIV patients in 2013. Teasley became New York's first transplant recipient under the act in 2016. Now, he works closely with various advocacy groups to educate others and raise awareness, including the group that helped coordinate his own transplant, Live On New York.”

-News12



SIGN-UP AS AN ORGAN DONOR

LiveOnNY.org

Ken,
Kidney Recipient



Featured Nationally Lisa Baxter (NW2)

Lisa Baxter was recognized by PKD (Polycystic Kidney Disease) Life (Electronic Magazine) Fall 2020 Edition. As “A Woman With a Mission”. Lisa talks about on “how to make the most of your life”.

Lisa states “It’s important to me to change somebody’s life and get them to realize their needs and be proactive”.

Lisa is an author, motivational speaker, youtube host and is passionate about helping people with PKD live life to the fullest.



Featured Nationally Dawn Edwards (NW2)

“28 Years of Living with Kidney Disease and Thriving”

Dawn was recognized by the World Kidney Day organization as a Kidney Advocate and a long-term dialysis patient.

Dawn Edwards tells the story of her journey with kidney disease on which she has gone from a failed kidney transplant to eventually home dialysis. She also shares her experiences about her advocacy work and the importance of raising awareness, especially in times of pandemic.

-World Kidney Day

28 Years of Living with Kidney Disease and Thriving



Dawn Edwards tells the story of her journey with kidney disease on which she has gone from a failed kidney transplant to eventually home dialysis. She also shares her experiences about her advocacy work and the importance of raising awareness, especially in times of pandemic.

My name is Dawn Edwards and I am a kidney disease advocate from New York City, USA. I was diagnosed with postpartum glomerulonephritis at the age of 23 in 1993. In the past years, I have been on dialysis in a dialysis centre, Peritoneal Dialysis, had a kidney transplant, and now do night haemodialysis at home.

On my journey, I discovered that as a person with kidney disease we need different things at different times in our lives.

It is crucial to be aware of all of the options available to make the best decisions. The more I learned about managing my kidney disease, the more empowered I became.

Throughout my journey, I have experienced many challenges and disappointments, but also many rewarding experiences. One of my biggest challenges was the rejection of my transplanted kidney and I had to resume dialysis. It was a very depressing time in my life: I felt like I failed and wasted a precious gift. The side effects of the medication left me with additional health problems that I still face today. Fortunately, I was able to pull myself together and seek advice to help me manage my feelings, face reality, and move forward. My family, friends, and faith have also played an important role in getting me back on track.

https://www.worldkidneyday.org/28-years-of-living-with-kidney-disease-and-thriving?fbclid=IwAR3XXoaeDYvs8J_tUQEC01BZ8c3juIPf4K-K8jtE8QpDot9zoYa3ogjyKi8

2020 Kathe LeBeau Patient Advocate Award Larry Wilson (NW2)



Kathe LeBeau
1958–2014

The Kathe LeBeau Patient Advocate Award recognizes a single patient's accomplishments in patient advocacy both within and outside of the dialysis clinic. Larry Wilson has demonstrated consistent and effective efforts in providing educational support and advocacy for the ESRD Community.

Larry's strong dedication in the promotion of patient education, assisting the patient community, their caregivers and family members, and galvanizing all individuals diagnosed with ESRD to become active in their healthcare has helped catapult the community towards long-term health success.

Larry has also demonstrated a strong understanding of the needs of the kidney community and has shown his willingness to create initiatives that cater to the unique needs of dialysis patients and transplant recipients.





2020 Outstanding Patient Volunteers (NW9)

Niesha Neil and Philip Fisher



Niesha became a patient advocate and a member of the Network's Medical Review Board in 2019. Niesha readily shares her journey with peritoneal dialysis, promoting improved quality of life and is proud to say at least 3 patients have transitioned to home hemodialysis after talking to her about her journey. Niesha's resolve to go above and beyond to give selflessly of her time, knowledge and expertise is why the Network is pleased to honor her as an outstanding patient volunteer.



Philip is a double transplant recipient, heart and kidney, who has been active in mentoring and educating patients about transplant at multiple dialysis facilities. Immediately following medical clearance post transplant, Philip went back to visit patients at the two facilities where he had received his dialysis treatments. His first-hand knowledge and enthusiasm about the transplant process has helped patients feel supported and empowered to choose transplant as a treatment option, and why the Network is pleased to honor him as an outstanding patient volunteer.

Patient Engagement Resources

Laura Rodriguez-Carbone



OPEN FORUM DISCUSSION GROUP



Challenges with adapting to Virtual engagement formats, using technology and telehealth.



Resources to Share With Other Patients



esrd.ipro.org

Kidney Chronicles

IPRO END-STAGE RENAL DISEASE NETWORK PROGRAM

HELPFUL TIPS TO EMPOWER ESRD PATIENTS AS CONSUMERS

Introducing the IPRO ESRD Network Program

The Centers for Medicare & Medicaid Services (CMS) oversees 18 regional End-Stage Renal Disease (ESRD) Network organizations across the country. Each Network works to improve the quality of healthcare services and the quality of life for patients with ESRD.

Your IPRO ESRD Network works to:

- Empower and engage patients to become educated consumers and partners in their healthcare;
- Improve quality of care for all ESRD patients;
- Collect data from dialysis and transplant facilities to measure quality of care;
- Assist you, your family members and care partners, and ESRD facility staff in understanding the CMS ESRD Quality Incentive Program;
- Provide technical assistance and information to individuals with ESRD and to dialysis facility and transplant center staff; and
- Resolve grievances that cannot be resolved at the dialysis facility level.

continued on page 2

How the Network Serves You

- Advocates for you;
- Answers your questions about treatment, modality choices or other issues;
- Develops and provides educational materials for you and your family;
- Works with renal professionals to improve the care given to you;
- Helps keep you informed and updated to support your involvement in your care and treatment options; and
- Evaluates and resolves grievances.

In an emergency, if you can't reach your facility, contact us.

have questions about your facility or to file a grievance, please contact your local ESRD Network:

End-Stage Renal Disease Network of New England (NH, RI, VT)
 1 Whitney Avenue, 2nd Floor
 Portland, CT 06517
 Toll-Free: (866) 286-3773
 (203) 387-9332
 (3) 389-9902
 esrdnetwork1@ipro.us
 etwork1.esrd.ipro.org

End-Stage Renal Disease Network of New York
 1 Marcus Avenue
 Great Neck, NY 11042-1072
 Toll-Free: (800) 238-3773
 (516) 209-5578
 (6) 326-8929
 esrdnetwork2@ipro.us
 etwork2.esrd.ipro.org

End-Stage Renal Disease Network of the South Atlantic (C, SC)
 1000 Peachtree Parkway, Suite 300
 Atlanta, GA 30328
 Toll-Free: (800) 524-7139
 (404) 463-4500
 (404) 388-9637
 esrdnetwork6@ipro.us
 etwork6.esrd.ipro.org

End-Stage Renal Disease Network of the Ohio River Valley (OH)
 1000 Peachtree Parkway, Suite 210
 Columbus, OH 44122
 Toll-Free: (844) 819-3010
 (614) 593-0001
 (614) 593-0101
 esrdnetwork9@ipro.us
 etwork9.esrd.ipro.org

Know Your Network

- Helps Patients Learn more about the IPRO End Stage Renal Disease Network Program and its services.
- Contains contact info for each Network Program and information on the PAC, technical assistance and grievances.

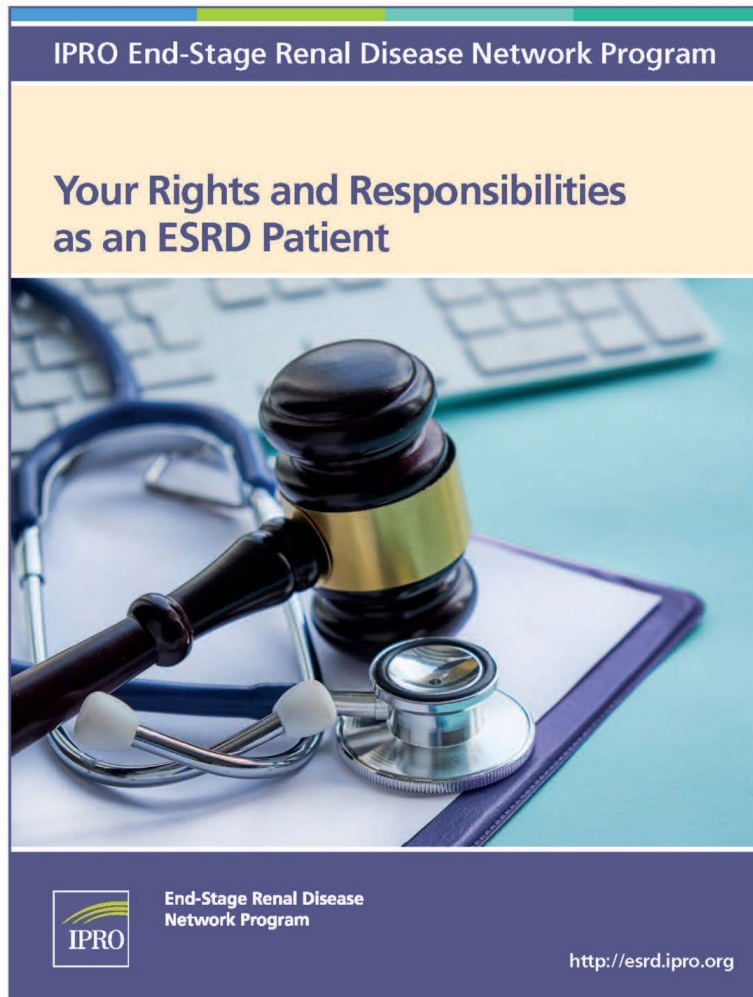
Resources to Share With Other Patients



Patient Advisory Committee Manual - Help us with Recruitment!

- Encourages Patients to learn more about the IPRO Patient Advisory Committee
- Informs patients about volunteer opportunities, roles and responsibilities
- Encourages patients to get involved!

Resources to Share With Other Patients



Patient Rights and Responsibilities

- Overview of Rights and Responsibilities as an ESRD Patients (7 page booklet).
- Right to Information and Quality Care, Individual Treatment, Services Without Discrimination, Emergency Care and Dietary Counseling, Filing a Grievance, etc.

Resources to Share With Other Patients



My Goal—My Roadmap

YOUR LIFE Take Charge!

5: Achieve and sustain!
Did I achieve my goal?
If the answer is “yes” ... how can I make sure that I continue to be able to achieve my goal?
If the answer is “not yet” ... what changes can I make to my plan to help me achieve my goal?

4: Evaluate.
How am I doing in reaching my goal?

3: Take action.
Get started on accomplishing my goal.

2: Assess and plan.
What is blocking me from what I desire?
What will be the benefits of achieving my goal?
What do I need to do to get what I want?
What goals should I set?

1: Find your goal and commit.
What is my desire? What do I want to achieve?

To file a grievance, please contact us:
IPRO End-Stage Renal Disease Network Program
1979 Marcus Avenue, Lake Success, NY 11042-1072
Patient Toll-Free: 800-238-3773 • Web: <http://esrd.ipro.org>

This material was prepared by the IPRO ESRD Network Program, under contract with the Centers for Medicare & Medicaid Services (CMS), an agency of the U.S. Department of Health and Human Services. The contents presented do not necessarily reflect CMS policy.
CMS Contract Numbers: HHSM-500-2016-00019C, HHSM-500-2016-00020C, HHSM-500-2016-00009C, and HHSM-500-2016-00009C.
Rev. 2/19/2020

Your Roadmap to SMART Goals

- Great first resource to share with Mentees (or any patient)!
- Encourages patients to take charge of their life on dialysis and help them map out their path to success.

Resources to Share With Other Patients



End-Stage Renal Disease
Network Program

E-University Reference Guide



What is E-University?

IPRO End Stage Renal Disease Network Program E-University is an online learning system that provides ESRD training for patients and professionals that align with the ESRD Network and CMS quality improvement goals. Once you have created a user account, you will <https://esrdlms.ipro.org> able to take training courses, download supporting materials, and obtain a certificate of completion. Visit the website at <https://esrdlms.ipro.org> to get started.

How Do I Create an Account?

Each person should create their own unique account. Facility staff may assist patients with registering for their own personal account, however sharing user account information is strongly discouraged.

1. Click "Register" from the login screen



Username (required)

Email Address (required)

2. To create an account, you will need to fill out the following information

- a. Username (recommend this be same as your email address)
- b. Email Address
- c. Choose a Password
- d. Confirm Password
- e. First Name
- f. Last Name
- g. Job Title
- h. ESRD Network
- i. ESRD Network CCN/Facility No (This field will appear after you selected your Network number. CCN is the Medicare Provider ID. Your facility can give you the number and name of your facility as it is in the Medicare database.)

V.3. 9/11/2018 E-University Reference Guide Page

End-Stage Renal Disease
Network Program

<http://esrdlms.ipro.org>

PEER MENTORING
Patients for Patients

Alternative Approaches to Peer Mentoring

Virtual Options During COVID-19 Pandemic

As the COVID-19 pandemic continues, direct face-to-face peer mentoring has become more challenging due to state regulations and the need for social distancing. The good news is that there are other ways to stay connected with your peers.

Consider using some of these alternative methods:

- Direct phone calls
- Private online discussion boards
- Secure conference calls
- Video calls and/or messaging
- Social media (i.e., Facebook, Twitter, Instagram, LinkedIn)
- Texting or messaging applications
- Web conferencing

To help you make these connections, these are some examples of online (virtual meeting) tools to consider:

- Zoom <https://zoom.us>
- Google Hangouts <https://meet.google.com>
- GoToMeeting <https://www.gotomeeting.com>
- FaceTime (iPhone Users Only) <https://apps.apple.com/us/app/facetime>
- Skype <https://www.skype.com/en>
- Facebook Groups <https://www.facebook.com>
- WhatsApp <https://www.whatsapp.com>

IMPORTANT
Although the above tools are free, some will require you to create an account and/or download an app. Always read the User Agreement Policy carefully for any chosen tool.

To use these online platforms, here are some equipment and resources you might need:

- Internet service (at home and/or through your phone service provider)
- Mobile phone, tablet and/or computer
- Built-in camera (included with most smartphones and some computers)
- Headset/microphone (if your computer does not have a built-in microphone)
- An active account on the platform of choice
- A downloaded program or app for the platform of choice

continued on next page

Peer Mentor User Guide - E-University and Alternative Approaches Tips

- **Have YOU signed up to be a Peer Mentor?**
- IPRO End Stage Renal Disease Network Program E-University is an online learning system that provides ESRD training for patients to become an official Peer Mentor.
- Once you have created a user account, go to <https://esrdlms.ipro.org> to take training courses, download supporting materials, and obtain a certificate of completion. Visit the website at <https://esrdlms.ipro.org> to get started.
- Course Topics Include: Mentoring to Support Choices, Talking Effectively With Other Patients, Discussing Home Dialysis as an Option, etc.
- Tips for alternative methods to in person mentoring (online and telephone options)

Resources to Share With Other Patients



Kidney Chronicles

IPRO END-STAGE RENAL DISEASE NETWORK PROGRAM

HELPFUL TIPS
TO EMPOWER
ESRD PATIENTS
AS CONSUMERS



Better healthcare,
realized.

Protect yourself. Get the vaccines you need.

Vaccines (also known as vaccinations or shots) are a safe, sure way to protect yourself from serious illness.

A doctor or a nurse "injects" the vaccine into your upper arm or leg. Each vaccine contains a weak version of a bacteria and/or virus. Vaccines help protect your body against infection by acting like an infection, without making you sick. After you receive a vaccine your body's immune system develops the same response as it would to a real infection, and it becomes resistant to the bacteria and/or virus in the vaccine. Some people have a mild fever and slight discomfort, soreness, or a rash around the injection area after they receive a vaccine. If your symptoms are more severe after your vaccine, contact your dialysis healthcare team as soon as possible.

The Importance of Getting Vaccinated

As a dialysis patient or transplant recipient you are more likely than others to develop other diseases, infections, and viruses. This is because your immune system does not work as well as the immune system of a person with healthy kidneys. To avoid these illnesses, people on dialysis MUST receive the following three vaccinations:

I. Annual Flu Shot (Influenza Vaccine)

Influenza ("flu") is a contagious and serious respiratory disease. As a dialysis patient or transplant recipient, if you get the flu you are more likely than others to develop serious problems. According to the Centers for Disease Control and Prevention (CDC), February is the month

continued on page 2

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- Evaluates and resolves grievances.

In an emergency, if you can't reach your facility, contact us.

Kidney Chronicles: Protect Yourself. Get the Vaccines You Need

- Encourages patients to learn more about, and get, vaccines to protect their health.

Kidney Chronicles

Protect Yourself (continued)

when the most people get the flu. However, they point out that flu season can last until late May. It is recommended that you receive a flu shot once a year. To learn more about the flu vaccine, please speak with your healthcare team, contact the Network, or visit www.cdc.gov/flu/index.htm.

2. Pneumonia Vaccine (Pneumovax 23)

Pneumonia is an infection of the lungs that can lead to serious illness. Pneumonia infections are caused by bacteria and can often be prevented and treated. The pneumonia (pneumococcal) vaccine protects your body against 23 different types of infectious bacteria pneumonia. You should receive the pneumococcal vaccine every five years. To learn more about the pneumonia vaccine, please speak with your healthcare team, contact the Network, or visit www.cdc.gov/pneumococcal/vaccination.html.

3. Hepatitis B Vaccine

"Hepatitis" is an inflammation of the liver. It is spread through contact with blood or body fluids from someone who has the virus. Dialysis patients are at greater risk than others for hepatitis because of the repeated access to the bloodstream during treatment. The hepatitis B vaccine is the best protection available against the virus. It also protects against a form of liver cancer caused by hepatitis B. The hepatitis B vaccine is usually given in a series of three to four doses over a six-month period. To learn more about hepatitis B and its preventive vaccination, please speak with your healthcare team, contact the Network, or visit www.cdc.gov/hepatitis/abc/index.htm.

Other Vaccines

Your doctor may recommend other vaccines, depending on your age, the type of treatment you receive, and how long you have been on dialysis. These vaccines may include the herpes zoster (shingles) vaccine and the measles, mumps, rubella (MMR) vaccine. If you are not sure about which vaccines you should be receiving, talk to your dialysis healthcare team or your primary care physician.

The Patient Advisory Committee (PAC) and Vaccinations

What have members of the Network's Patient Advisory Committee (PAC) said about vaccines on the IPRO ESRD Program's Facebook page?



"I get the influenza shot every October.

The staff at my dialysis facility is really good about making sure all of our vaccinations are up to date."

"I have gotten the Influenza, Pneumonia, and Hepatitis B vaccine. I also received the pertussis (whooping cough) vaccine to protect my young children."

If you have questions about your facility or to file a grievance, please contact your local ESRD Network:

IPRO End-Stage Renal Disease Network of New England (CT, MA, NH, RI, VT)
1952 Whitney Avenue, 2nd Floor
Hamden, CT 06517
Patient Toll-Free: (866) 286-3773
Main: (203) 387-9332
Fax: (203) 389-9902
E-mail: esrdnetwork1@ipro.us
Web: network1.esrd.ipro.org

IPRO End-Stage Renal Disease Network of New York
1979 Marcus Avenue
Lake Success, NY 11042-1072
Patient Toll-Free: (800) 238-3773
Main: (516) 209-5578
Fax: (516) 326-8929
E-mail: esrdnetwork2@ipro.us
Web: network2.esrd.ipro.org

IPRO End-Stage Renal Disease Network of the South Atlantic (GA, NC, SC)
909 Aviation Parkway, Suite 300
Morrisville, NC 27560
Patient Toll-Free: (800) 524-7139
Main: (919) 463-4500
Fax: (919) 388-9637
E-mail: esrdnetwork6@ipro.us
Web: network6.esrd.ipro.org

IPRO End-Stage Renal Disease Network of the Ohio River Valley (IN, KY, OH)
3201 Enterprise Pkwy., Suite 210
Beachwood, OH 44122
Patient Toll-Free: (844) 819-3010
Main: (216) 593-0001
Fax: (216) 593-0101
E-mail: esrdnetwork9@ipro.us
Web: network9.esrd.ipro.org

Questions or Comments?



Closing Remarks/Next Steps

Danielle Andrews



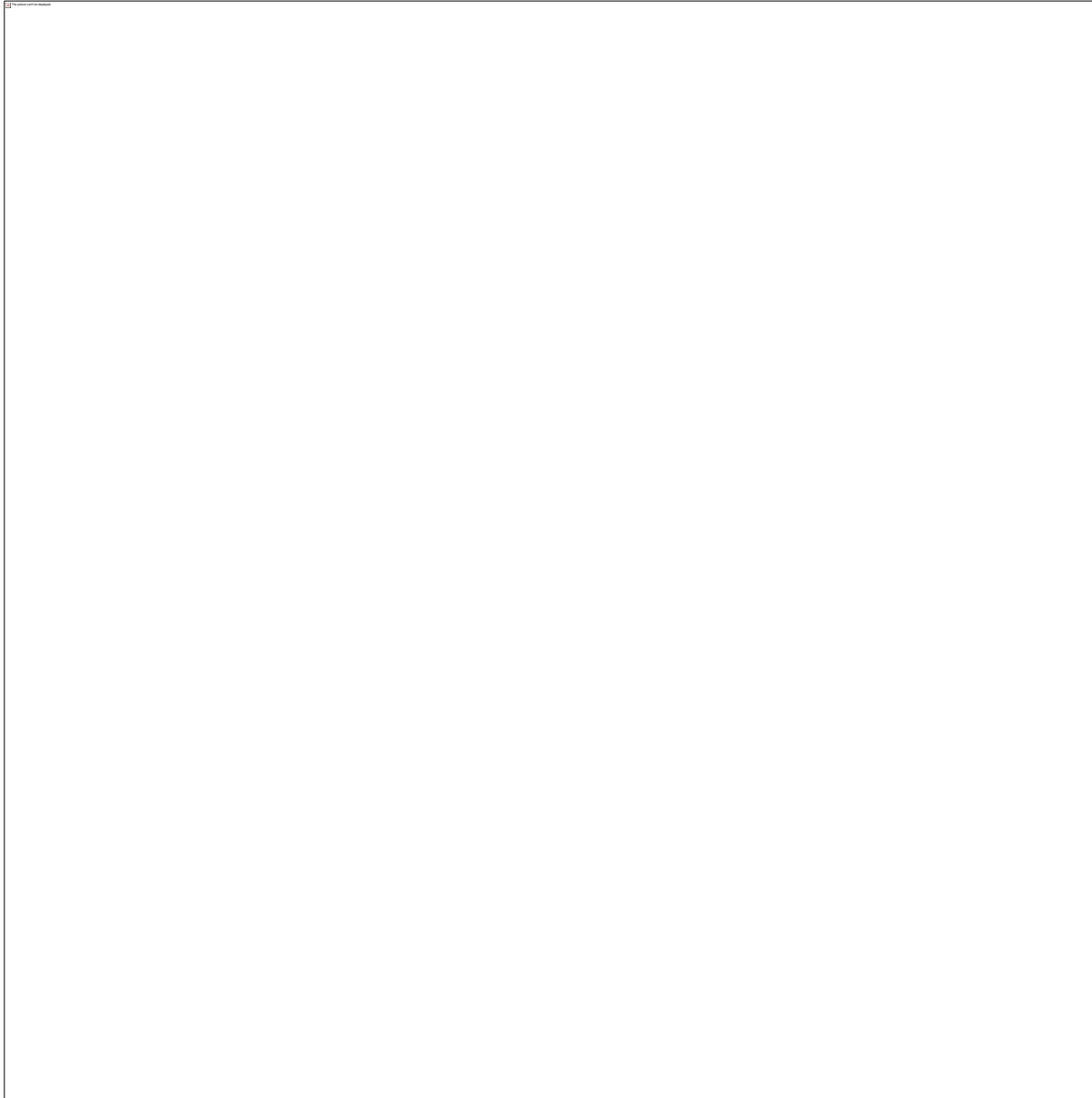
Next Steps



- Complete Post-Event Evaluation – we value your feedback!
- Look out for next issue of PSME Newsletter: Patient Voice-Expert Thoughts
- Follow Us on Social Media:
 - <https://www.facebook.com/groups/IPROESRDPAC>
 - <https://www.facebook.com/ESRDNetwork1>
 - <https://www.facebook.com/ESRDNetwork2>
 - <https://www.facebook.com/NW6ESRD>
 - <https://www.facebook.com/ESRDNetwork9>
 - <https://twitter.com/IPROESRDNetwork>
 - https://www.instagram.com/ipro_esrd_network/
 - https://www.linkedin.com/in/ipro_esrd_network
- Visit the Network Peer Mentoring Training <https://esrdlms.ipro.org>
- Check out Network Program Website <https://esrd.ipro.org/>
- Review Network Educational Resource Library – think of ways to share and spread in your community, we need your help!
- **Save-the-Date! Next Meeting: January 27, 2021**



SAVE THE DATES: UPCOMING WEBINARS



SAVE THE DATES: UPCOMING WEBINARS



IPRO ESRD Network Virtual Patient Support Discussion Group



Every 2nd and 4th Thursday at 5:00PM
Upcoming Meeting Dates: 11/24 and 12/10

[Click here to join the meeting](#)

Password: PAC2020

Call-In Number: 1-855-797-9485

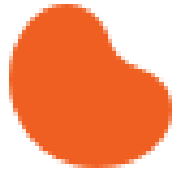
Meeting Number: 616 535 334



NOVEMBER
National DIABETES
AWARENESS
MONTH



SAVE THE DATES: UPCOMING WEBINARS



NATIONAL KIDNEY
FOUNDATION.

Coping with Kidney Disease: Part 1

NKF New England in collaboration with IPRO ESRD Network of New England to present *Coping with Kidney Disease*. This is a 2-part series that will discuss the emotional and mental health impact of dealing with kidney disease. The series will provide coping strategies and help patients navigate the NKF website on how to access resources and support services.

Date: December 4, 2020

Time: 3:00PM- 4:00PM

Speakers: Dr. Jasvinder Bhatia & Lydia Johnson
Reynolds, LICSW

Register:

https://kidney.zoom.us/webinar/register/WN_Yhx_Ofk3SESFXX76GSDmHg



Thank You!



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ESRD Network Program (Entire Program/All Networks)

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