Patient and Family Engagement Program Team

Laura Rodriguez-Carbone, MPA, MPP
Community Outreach Coordinator

Danielle Andrews, 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
Objectives and Agenda

TREX Overview – Key Features

• Overview of TREX
  • History
  • Key Features

• Patient-Specific Module
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**

<table>
<thead>
<tr>
<th>Key Referral Challenges</th>
<th>Resulting Clinical Problems</th>
<th>TREX Benefits and Capabilities</th>
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| No consistent process for Kidney Referrals across Transplant Centers. | • Multiple FAX’s  
• Incomplete Referral Information  
• Time consuming follow-ups  
• Lost / Delayed Referrals | • 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 | • 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 | • 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 | • Hit and miss telephone calls and emails  
• Patient history lost if SW or coordinator leaves position | • 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 | • Reason why a patient is No Longer a Candidate often lost | • 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 | • Time consuming process of collecting and reporting Referral Data | • Aggregate reporting to Network automatically captured monthly  
• Improved communication with Network QIP Programs |
| Quality Improvement Process Reporting and Management | • No systemic method for tracking, monitoring, and reporting QIP opportunities | • 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 Centers

• 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

Confidential: Apex Health Innovations, 2020
Objective and Agenda

TREX Core Features: Communication Channel

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

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

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
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
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.
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
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.
“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.

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-World Kidney Day

https://www.worldkidneyday.org/28-years-of-living-with-kidney-disease-and-thriving?fbclid=IwAR3XXoaeDYvs8J_iUQvC01BZ6c9juIPhXK-K8tEBQpDot9zoYa3ogyKil8
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.
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
Challenges with adapting to Virtual engagement formats, using technology and telehealth.
Resources to Share With Other Patients

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.
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 Patient (7 page booklet).
- Right to Information and Quality Care, Individual Treatment, Services Without Discrimination, Emergency Care and Dietary Counseling, Filling a Grievance, etc.
Resources to Share With Other Patients

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.
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)
Kidney Chronicles: Protect Yourself. Get the Vaccines You Need

- Encourages patients to learn more about, and get, vaccines to protect their health.
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/groups/IPROESRDPAC)
  ○ [https://www.facebook.com/ESRDNetwork1](https://www.facebook.com/ESRDNetwork1)
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  ○ [https://www.linkedin.com/in/ipro_esrd_network](https://www.linkedin.com/in/ipro_esrd_network)
● Visit the Network Peer Mentoring Training [https://esrdlms.ipro.org](https://esrdlms.ipro.org)
● Check out Network Program Website [https://esrd.ipro.org/](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
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!

Laura Rodriguez-Carbone, MPA  
*Community Outreach Coordinator*  
*ESRD Network Program (Networks 1 & 9)*  
Tel: (216) 755-3056 | E-mail: Laura.Rodriguez-Carbone@ipro.us

Danielle Andrews, MPH, GCPH  
*Community Outreach Coordinator*  
*ESRD Network Program (Networks 2 & 6)*  
Tel: (516) 209-5549 | E-mail: Danielle.Andrews@ipro.us

Jeanine Pilgrim, MPH, PMP, CPHQ, CHES, CPXP  
*Network Program Director*  
*ESRD Network Program (Entire Program/All Networks)*  
Tel: (516) 209-5365 | E-mail: Jeanine.Pilgrim@ipro.us