IPRO ESRD Network Program
Peer Mentoring
Learning and Action Network (LAN)

March 24th, 2020
Welcome/Opening Remarks

Jeanine Pilgrim, Director
IPRO ESRD Network Program
Housekeeping Reminders

• This WebEx will be recorded and slides made available on the Network Website.
• All lines have been muted to eliminate background noise.

To ask a private question use the Chat section in the bottom right corner of your screen sending to All Panelists

To ask a question for the answer to be shared with all Attendees or Privately, use the Q&A section in the bottom right corner of your screen
Agenda

• Overview of the IPRO ESRD Network Peer Mentor Program
• Guest Speaker Presentations:
  – Diana Clynes, American Association of Kidney Patients (AAKP)
  – Risa Simon, Founder TransplantFirst Academy
  – Lori Hartwell, Renal Support Network (RSN)
• Q&A Session
• Call-to-Action/Next Steps
Learning Objectives

• Provide a clear and concise understanding of the IPRO ESRD Network Peer Mentoring program.
• Understand different ways to implement a peer mentoring program in your facility.
• Hear the patient’s perspective on the benefits of peer mentoring.
• Learn successful strategies from experts in the field and best practices.
Network Program Overview
IPRO ESRD Network 2019 Service Areas
(2018 Network Annual Reports)

Network 1
CT, MA, ME, NH, RI, VT
Patients: 14,856
Facilities: 199
Transplant: 15

Network 2
NY
Patients: 30,337
Facilities: 305
Transplant: 13

Network 3
IN, KY, OH
Patients: 33,890
Facilities: 639
Transplant: 14

Network 4
OH, KT, IN
Patients: 30,337
Facilities: 305
Transplant: 13

Network 5
NC, SC, GA
Patients: 50,539
Facilities: 760
Transplant: 10

NW1
NW2

IPRO ESRD Program
129,662
ESRD Patients
1,903
Dialysis Facilities
52
Transplant Centers
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.
ESRD Network Role/Responsibilities

- Liaison with Department of Health (DoH) and Centers for Medicare & Medicaid Services (CMS)
- Lead State-Wide Quality Improvement Activities (QIAs) to improve quality of care for ESRD patients
- Promote patient engagement, education, and patient experience of care
- Provide technical assistance and grievance management for ESRD patients and providers
- Support ESRD data systems and data collection, analysis and monitoring for improvement
- Support emergency preparedness and disaster response
- Collaborate with Dialysis Facilities and Transplant Centers
Peer Mentoring Introduction
Peer Mentoring

• A peer mentor empowers fellow patients to move forward with their lives after being diagnosed with ESRD.
• Peer mentoring provides support and increases the confidence that many new patients need, and offers patients access to someone who has been through similar experiences and can understand their concerns.
Role of a Peer Mentor

Peer mentors can have several roles, including:

- Providing information,
- Listening to concerns,
- Sharing experiences,
- Promoting positive behavior,
- Offering encouragement, and
- Relieving anxiety.

A positive role model that can encourage and offer hope.

A feeling that peers are not alone in facing their illness.

Understanding and insight based on experience.
Diana Clynes, Executive Director
American Association of Kidney Patients (AAKP)
The Enhanced Patient Engagement to Improve Patient-Centered Outcomes among Chronic Kidney Disease (CKD) Project

Peer Mentorship Training

The Enhanced Patient Engagement to Improve Patient-Centered Outcomes among Chronic Kidney Disease (CKD) Project is supported by a Eugene Washington Engagement Award (AAKP-EADI-14537) from the Patient-Centered Outcomes Research Institute (PCORI).
American Association of Kidney Patients (AAKP)

The AAKP is the **oldest and largest** fully independent kidney patient organization in the U.S. Founded in 1969 by six dialysis patients, with doctor encouragement, our Founders helped create the Medicare ESRD Program, saving more than one million lives since 1973.

Dedicated to improving the quality of life and long-term outcomes for kidney patients through **education, advocacy, patient engagement** and the fostering of **patient communities** – AAKP fights for early detection; increased kidney transplantation and pre-emptive transplantation; full patient choice either at-home or in-center dialysis; protection of the patient/physician relationship; promotion of research and innovation; and the elimination of barriers for patient access to available treatment options.
Purpose of Project

This project connects patients (mentees) to the experiences of similarly situated patients (mentors) which may lead to a mutually supportive and engaged community of patients empowered with coping skills to deal with the challenges of living with chronic kidney disease (CKD) and end-stage renal disease (ESRD). Through the dissemination of strategies like a decision aid to complement existing educational resources, we hope to reduce racial disparities in the utilization of transplant and home dialysis therapies. Furthermore, supporting patients in choosing a dialysis modality that is a better fit for their individual lifestyle increases satisfaction, motivates engagement in care, and ultimately improves overall outcomes. We hope this project will build the infrastructure to continue outreach to susceptible populations on an ongoing basis. Lessons learned from this pilot project will inform the literature on effective outreach strategies that will be applicable to the larger kidney community across the U.S.
Project Goal

This project will pair **150 CKD/non-dialysis and ESKD patients** with AAKP Mentors for a **6-month period**, **one-on-one peer mentoring project**. **23-30 Mentors in Georgia** will each mentor 5-7 CKD/ESKD patients who are diverse with respect to their clinical severity—including earlier stage CKD patients and ESRD patients undergoing dialysis— as well as their level of engagement and reachability.
Projected Project Outcomes

1. Increase the percentage of kidney patients who are engaged with a Mentor

2. Increase the percentage of vulnerable patients that receive kidney disease education

3. Improve knowledge of renal replacement therapy choices and coping strategies among African-American CKD/ESKD patients. Patients targeted are those with CKD/non-dialysis, ESKD, family members, high-risk individuals who have declined previous educational programs, and patients with a history of noncompliance or who have refused transplant referral.

4. Increase the number of trained kidney patient Mentors (i.e. AAKP Ambassador Initiative)

5. Enhance the quality of educational resources to include effective coping strategies and patient values/preferences for dialysis/transplant options
Mentor Training

We have designed a self-guided, online training course.

The training will take approximately 8 hours to complete and will entail:

Five (5) online educational webinars (ranging from 45-90 minutes)

- review of learning objectives,
- competency quizzes completed in order to assess the Mentor’s acquisition and retention of new information, and
- role-playing videos
Mentor Toolkit

Trained Mentors will receive a Mentor Toolkit including:

- Certificate of Training Completion
- AAKP lapel pin
- Mentor Training Guide, including PowerPoint slides from each of the 5 Modules
- Activity Report (Survey Monkey link) *REQUIRED ACTIVITY
- Activity Tracker/Log (Optional)
- Resource checklist by topic
- Portfolio of AAKP materials to be used as resources for your Mentee engagements
Mentor Role & Expectations

- Mentors will engage with 5-7 mentees over a period of six (6) months to provide guidance and resources.
- Help fellow patients understand and navigate the complexities of living with kidney disease.
- Share their own experiences as an individual with CKD, experiences on dialysis, and/or experience with a kidney transplant.
- Share information on kidney disease modality choices with a focus on home dialysis options and kidney transplant.
- Share information and resources about coping with kidney disease diagnoses and treatment requirements.
- Complete activity reports and final project evaluation.
Learn More!

American Association of Kidney Patients

www.aakp.org
info@aakp.org

AAKP Peer Mentor Program

https://aakp.org/center-for-patient-research-and-education/peer-mentorship-program/
Risa Simon, Founder
TransplantFirst Academy
Preemptive Transplant Recipient, Peer Mentor,
Patient Advocate, Speaker, Author & Founder of TFA
Stumbled into a Goldmine
Discovered Endless Pearls & Nuggets

Stepping Stones to Peer Mentoring

Step 1
Fear = Powerful Motivator

Step 2
Explored Beyond Exam Room Walls

Step 3
Patient Conference
Inscribed Me by Secure PKT
Chatted w/ Champions
Discovered Endless Pearls & Nuggets
COMMON DENOMINATOR=
COMMON EXPERIENCES

“She Gets Me!”

“I Felt Understood & Inspired”

“Boy, If She Could Do That Perhaps I Can Too?”

Their Success Inspired My Success
Compelled Me To Sign-Up!
Application Process + Interviews* + Training + Retention Quizzes, Role Play + Confidentiality Commitments

*Extra Credit for Passionate Patients Who Would be a Good Fit: Hill Days / Lobby Days / Patient Advisory Committees

Focus on Communication Guidelines, Empathetic Listening, Personal Values Awareness, Cultural Diversity, Boundaries & Emotional Intelligence
WE GIVE HOPE & INSPIRE MENTEES TO FIGHT FOR A BETTER & LONGER LIFE

OUR EXPERIENCES OFFER HUMAN PERSPECTIVE

OUR EMOTIONAL SUPPORT NORMALIZES FEARS

Function Declines to COVID-19

WE ENCOURAGE "PROACTIVE" SELF-ADVOCACY & PROVIDER ENGAGEMENT
WE DON'T GIVE MEDICAL ADVICE!
MENTORING CONNECTS BEYOND FAMILY SUPPORT

NO REPLACEMENT FOR TALKING TO THOSE WHO HAVE WALKED A MILE IN OUR SHOES

WE'VE BEEN THERE. WE GET IT!
"WE GET THEM!"
"WE ARE THEM!"

ADDED BONUS:
LIGHTEN THE EMOTIONAL BURDEN FOR FAMILY / FRIENDS

+ LIGHTEN THE "EMOTIONAL LOAD" FOR CARE PROVIDERS
POLL

Do you think peer mentoring can support your work as a professional in your facility?

a. Yes
b. No
Engagement Platforms

- Telephone
- Email
- Peer Apps: Chat-Text
- Face to Face - (Live)
- Remote "Skype" Video

* Extremely Valuable w/ COVID19*
HOW PATIENTS DISCOVER PEER MENTORING

- Word of Mouth / Posters / Handouts
- Referred by Mentors / Facility / Staff
- Message Boards / Websites / Social Media
- Nephrology Practices (Vastly Underutilized)
HOW PATIENTS SIGN UP

- Online Application
- Telephone Interview - Establish "Fit"
- Matched = By Area of Interest / Goals
PROGRAM CHALLENGES

- Mentees Unaware of Offering
- Not Fully Committed - (No Fee / No Show)
- Just Want to Complain
- Need Professional Help

\[ +\text{Mentor Challenges} = \text{Time} / \text{Lack of Admin Appreciation} / \text{"Compassion Fatigue"} \]
CLINIC "PUSHBACK"

- Responsibility Overload
- Not Sure How to Approach
- Skepticism *(Can Patients Really Do This Right?)*
- Compassion Fatigue
What could the Network provide to support expanding a peer mentoring program to make it easier to implement?

a. Recruitment Material  
b. Video Demonstration – Mock Role Playing Scenario  
  c. Technical Assistance – One-on-One w/Network  
d. Supplemental Patient Handouts
BOOMERANG = "FEEL GOOD"

When We Help Those Once...

- Paralyzed by Fear = Become Fully-Engaged
- Afraid to Share Story = "Donor Magnets"
- Fearful of Transplant = Request Evaluation

When Mentees Express Genuine Appreciation!
LIVING MY BEST LIFE

- PATIENT ADVOCATE
- MENTOR / COACH
- MOTIVATIONAL SPEAKER
- PUBLISHED AUTHOR
- FOUNDER, TRANSPLANTFIRST

PEER POWER ROCKS!
“There is no better way to express our gratitude.”

than to share our experience with others
Lori Hartwell, Renal Support Network (RSN)
Renal Support Network (RSN) empowers people who have kidney disease to become knowledgeable about their illness, proactive in their care, hopeful about their future and make friendships that last a lifetime.
Lori Hartwell has made it her mission to help people who have chronic kidney disease. Living with kidney disease since age two, having survived 50 plus surgeries, 13 years of dialysis and now living with her fourth kidney transplant. In 1993, because of her struggle to find social and peer support to manage her condition, Lori founded the Renal Support Network (RSN) and coined the mottos “An illness is too demanding when you don’t have hope” and “One friend can make a difference” to reflect her belief that people can live joyfully despite having a chronic illness. She is the author of Chronically Happy – Joyful Living in Spite of Chronic Illness, an inspirational guidebook for handling lifestyle and numerous other non-medical issues that come up in the course of chronic disease. She also is the Host of KidneyTalk Podcast.
ONE FRIEND CAN MAKE A DIFFERENCE
**SIGNS OF HOPE**

- Looking forward to a new day
- Feeling joyful
- Feeling positive
- Finding it easy to smile and laugh
- Sleeping through the night
- Being able to finish projects
- Feeling comfortable with one’s decisions
- Having a healthy appetite
- Being accepting and patient
- Being able to remain calm
- Feeling content
- Feeling energetic, ready to go
- Feeling appreciated
- Having a healthy interest in sex
- Excited about being alive

**SIGNS OF DEPRESSION**

- Loss of interest in normal daily activities
- Feeling sad or down
- Feeling hopeless
- Crying spells for no apparent reason
- Problems Sleeping
- Trouble focusing or concentrating
- Difficulty making decisions
- Unintentional weight gain or loss
- Irritability
- Restlessness
- Being easily annoyed
- Feeling fatigued or weak
- Feeling worthless
- Loss of interest in sex
- Thoughts of suicide or suicidal behavior
BENEFITS OF SUPPORT GROUPS

POSSIBLE RISKS

PROS AND CONS OF A ONLINE SUPPORT GROUP

ENSURING SAFE BOUNDARIES

MAKING CONNECTIONS

OUR NEW WORLD OF COVID 19
POLL

Which of the following ways do you think you can assist patients in using alternative ways to peer mentoring?

a. Phone Calls  
b. Video Chats  
c. Online Discussion Boards  
d. Social Media  
e. Conference Calls  
f. Email  
g. Text  
h. Web Conferencing
KIDNEY COMMUNITY ON FACEBOOK

These Kidney Disease Facebook groups are focused on supporting and providing information as well as the sharing of individual experiences. Members include dialysis and kidney patients, people who have had transplants, people who work in dialysis centers and people who have friends or family who have been effected by kidney disease.

- DIALYSIS DISCUSSION UNCENSORED
  14K+ Members

- KIDNEY SUPPORT: DIALYSIS, TRANSPLANT, DONORS AND RECIPIENTS
  24K+ Members

- DIALYSIS DISCUSSION
  12K+ Members

- DIALYSIS & KIDNEY DISEASE
  12K+ Members

- LIFE WITH CHRONIC KIDNEY DISEASE
  5K+ Members

- LIVING WITH KIDNEY FAILURE - END STAGE RENAL DISEASE (ESRD) SUPPORT GROUP
  17K+ Members

- FRIEnds SHARING A POSITIVE CHRONIC KIDNEY DISEASE TOGETHER
  2K+ Members

- I HATE DIALYSIS
  6K+ Members

- POLYCYSTIC KIDNEY DISEASE AND KIDNEY DISEASE
  4K+ Members

- CHRONIC KIDNEY DISEASE SUPPORT GROUP
  17K+ Members

- PARENTS OF KIDNEY KIDS
  2K+ Members

- PEDIATRIC KIDNEY DISEASE AWARENESS AND SUPPORT
  120+ Members

RSNhope.org
With its 22nd year approaching, the Renal Teen Prom has helped thousands of young people who have kidney disease get to know each other, support each other and make an empowered transition to young adulthood in spite of their chronic illness.
RSN'S PROGRAMS

RSN's hopeful and life-enriching, non-medical programs help people who have kidney disease and their families, whether they are in the early stages of the disease, are on dialysis, or have received a transplant.

1.9MM+
ANNUAL REACH
ANNUAL ESSAY CONTEST

RSN's essay contest is one the most prolific sources of patient produced editorial content within the kidney community.

For over 17 years the Annual Essay Contest has received hundreds of entries from across the country.
There are currently over 279 KidneyTalk™ shows available to stream or download. 20+ shows are added each year.
The KidneyTalk™ bi-annual news magazine (est. in 2004 as Live&Give) provides information, stories of hope and suggestions on how patients and family members can navigate kidney disease.
Patient Outreach via RSNhope.org, HOPEline, Annual Patient Education Meeting, Monthly Support Group, the RenAlert E-Newsletter, Studio Hope Workshops and social media help people learn that there are choices available that they might not have considered and that they are not alone in their quest to live as healthy a life as possible.
PLEASE JOIN US TODAY! THERE ARE NO FEES.

Visit RSNhope.org/Join
Open Forum Discussion
Questions or Comments?
Closing Remarks/Next Steps
Alternative Peer Mentoring Approaches

• As the COVID-19 pandemic continues to evolve, direct face-to-face peer mentoring interaction maybe become difficult to pursue to the social distancing guidelines.

• Alternative Platforms:
  – Social Media (private pages)
  – Discussion Boards
  – Dedicated Conference Calls
  – Video Messaging
  – Texting or Messaging Application
  – Web Conferencing
Summary

• Peer Mentoring programs are intended to connect patients to other patients that have experienced similar situations.
• Peer Mentoring allows mentees to identify with mentors.
• This connection can potentially lead to a reciprocal relationship based on mutual support and increasingly engaged patients.
• Patients can become empowered and can create or enhance coping skills. These coping skills can be used and adjusted for current and future challenging situations.
Next Steps

- Next Peer Mentor LAN Call
  - **July 28th at 3:00PM**
- Please complete the post-webinar survey to provide your feedback!
For more information contact your Network Project Lead

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Thank You!

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