Welcome to the IPRO ESRD Network Program

Patient Webinar: *Coping in Uncertain Times: COVID-19 Pandemic*

The webinar will begin promptly at 4:00PM. Thank you for your participation!
Patient Webinar Series: Part 2

Coping in Uncertain Times: COVID-19 Pandemic

Dr. Daniel Cukor, Director of Behavioral Health, The Rogosin Institute, ESRD Network Education Committee Member

Dawn Edwards, Health Ambassador, Patient Advocate/Educator, National SME Network Patient Advisory Committee (PAC) Advisor, Founder/CEO of NYS CKD Champions

April 13, 2020
Welcome/Opening Remarks

Danielle Andrews
Community Outreach Coordinator
IPRO ESRD Network Program
Housekeeping Reminders

• This WebEx will be recorded and slides will be made available on the Network’s 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
Network Program Overview
IPRO ESRD Network Service Areas
(2018 Network Annual Reports)

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

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

Network 9
OH, KT, IN
Patients: 33,890
Facilities: 639
Transplant: 14

Network 6
NC, SC, GA
Patients: 50,539
Facilities: 760
Transplant: 10

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
COVID 19 and Patients

• The COVID-19 pandemic has created a complex and stressful situation for the ESRD community.
• Access to constant news and media coverage, and medical and public health websites have caused information overload and may have increased patients' anxiety.
• Patients have stated having trouble adjusting to
  • Social distancing
  • External Stressors (behaviors of other people)
  • Fear of the unknown
  • Dialysis treatment changes (time, duration, seating)
Dr. Daniel Cukor

Director, Behavioral Health

The Rogosin Institute
Dawn Edwards

Health Ambassador, The Rogosin Institute
NYS CKD Champions Founder/CEO
ESRD Network Patient Advisory Committee (PAC) Advisor
National Patient Advocate/Educator and Subject Matter Expert
Coping with the Uncertain Times of the COVID-19 Pandemic

Daniel Cukor, PhD
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Rogosin Institute

PART 2
Concerns I have heard:

1. COVID-19-specific worries
2. Impact of Social Isolation
3. Instability in the World
4. Coping with Difficult Feelings

} Last Week

} Today
“Everything seems so different than it did just a few weeks ago, the future is so difficult to imagine.”

“I live with my son and his family, what if I lose my savings and he loses his job?”

“Will I be able to get groceries?”
Instability

- Acknowledgement of the stability and infrastructure that is protective for you
- Acceptance of uncertainty and powerlessness
Instability

• Remain Hopeful! Be Active!
  – Be mindful of the positive signs of response
  – Companies will respond to new economic realities
  – The whole world is working to address this
Outline

Concerns I have heard:

1. COVID-19-specific worries
2. Impact of Social Isolation
3. Instability in the World
4. Coping with Difficult Feelings
How are you coping?

HOW I PICTURED MYSELF DURING THE APOCALYPSE

WHAT I REALLY LOOK LIKE!

Me after I eat all of my quarantine snacks in one night
Coping with Feelings - Stress

- Stress
  - Allostatic Load - the cost to the brain and body of continual allostatic response.

McEwan B, Lasley EN, 2002
Coping with Feelings - Stress

- Maladaptive vs. Adaptive coping
  - What ways can you mimic what has worked in the past?
  - Do not turn to unhealthy behaviors
Coping with Feelings

• Stress
  – Breathing
  – Meditation
  – Progressive Muscle Relaxation
  – Use Apps or online resources
Coping with Feelings - Anxiety

- Anxiety
  - Catastrophizing
  - Scheduling worry time
  - Worrying vs. Ruminating
  - Mindful of news intake
Coping with Feelings - Despair

• Despair
  – Negative attributional style – stable, global and internal
  – Survived similar and worse things as a society

• Solution
  – Purposefully include pleasant activities in your schedule
  – Don’t let your negative thoughts spiral you downward
The Importance of Meaning

Forces beyond your control can take away everything you possess except one thing, your freedom to choose how you will respond to the situation.

— Viktor E. Frankl —
Coping with Feelings - Grief

• Normal reaction to abnormal times
• Understand what you are grieving
• Allow yourself to experience your emotions
  – no correct way to grieve/no timetable
• Lean on your social network
• Understand the difference between grief and depression
Final Thoughts

• We are all experiencing a shared trauma
• This is temporary and will get better – choose hope
  – this is a marathon, not a sprint
• Develop a plan
• for active coping

— Maya Angelou

“You may not control all the events that happen to you, but you can decide not to be reduced by them.”
Specific Recommendations

• Limit time spent talking about/content around COVID

• Maintain a regular healthy routine
  - Eat
  - Exercise
  - Sleep

• Socially connect - creatively

• Create Time/Space for your mental health
  (meditate, hobby, read, etc.)

• Develop an active plan for caring for one self
Resources

Coping
• [Cognitive Behavioral Strategies to Manage Anxiety by Massachusetts General Hospital](#)
• Coronavirus Disease 2019 (COVID-19): Manage Anxiety and Stress by the [CDC](#)
• Psychology Today - Dr. Robert Leahy “Anxiety Files” [Blogposts](#)

Yoga
• [NYP Integrative Health](#): 15-minute series for all levels

Relaxation
• [How to reduce stress with the 2:1 breathing technique](#)
• [Progressive Muscle Relaxation](#)

Meditation
• [headspace.com/ny](#)

NY State Hotline For FREE emotional support 1-844-863-9314
Questions or Comments?
Closing Remarks/Next Steps
Next Steps

Please complete the post-webinar survey to provide your feedback!

- **Survey Link:**
  https://forms.gle/PcbY2sFsvQgGqGqW9L6
Thank You!

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