



2023 Forum of ESRD Networks Annual Meeting

December 7, 2023

The webinar will begin momentarily...

Microphone

- Please keep your microphone muted unless you are participating in the discussion.

Chat

- If you would like to ask a question, you may use the Chat function.

Recording

- This session is being recorded and will be available, along with the slide deck, after the webinar.

Feedback Requested

A **survey link** to an evaluation will be included in the email you receive after the webinar.



We would very much appreciate your feedback.



2023 Forum of ESRD Networks Annual Meeting

December 7, 2023

Today's Presenters



Kam Kalantar-Zadeh, MD, MPH, PhD

President, Forum of ESRD Networks

Mary Baliker

Interim Co-Chair, Kidney Patient Advisory Council (KPAC)

Vicky Cash, MBA, BSN, RN

Chair, Executive Director Advisory Council (EDAC)

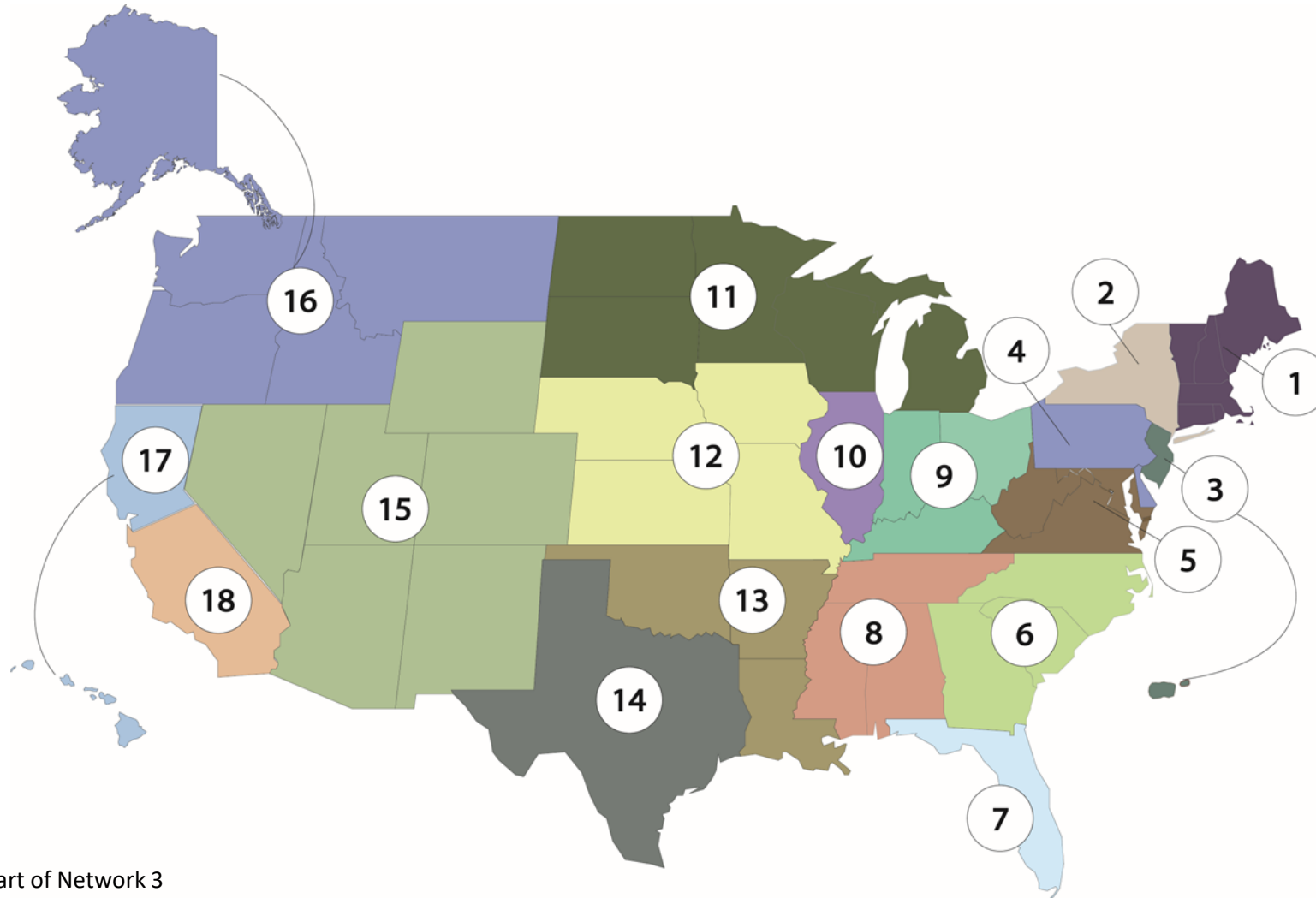
Dan Landry, DO, FASN

Chair, Medical Advisory Council (MAC)

Stephanie (Hutchinson) Counter, MBA

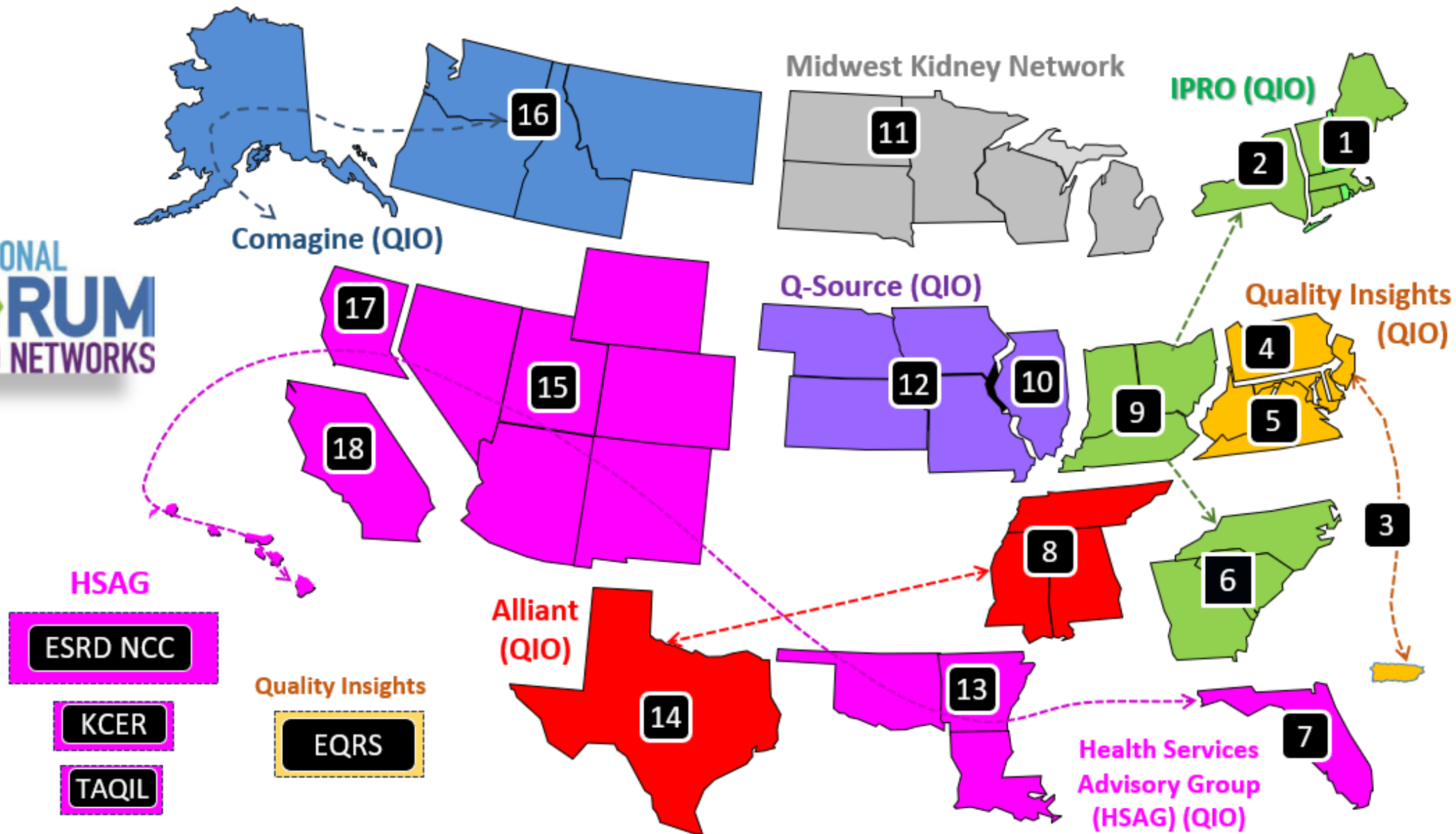
Treasurer

18 ESRD Network Organizations 2021-2026



Puerto Rico and Virgin Islands are part of Network 3
Hawaii, Guam, American Samoa are part of Network 17

The 18 ESRD Network Contracts and Affiliates (2021-2026)



Our Mission



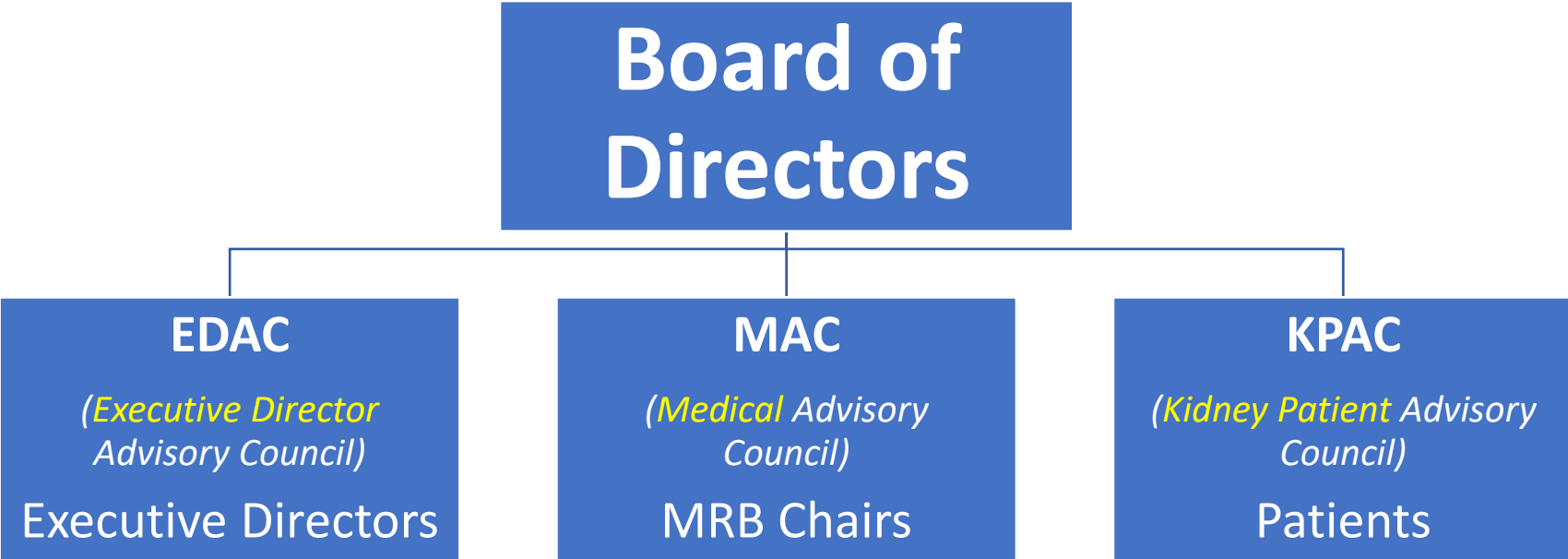
All ESRD Networks are members of the Forum of ESRD Networks, which is a not-for-profit organization that advocates on behalf of its membership and coordinates projects and activities of mutual interest to ESRD Networks. The Forum facilitates the flow of information and advances a national quality agenda with CMS and other renal organizations.

The **MISSION** of the Forum is to support and advocate on behalf of the ESRD Networks in promoting methods to improve the quality of care to patients with renal disease.

CORE VALUES:

- Volunteerism
- Collaboration
- Innovation and Flexibility
- Spread of Knowledge
- Integrity
- Autonomy of Individual ESRD Networks
- Person (Patient & Family) Centeredness

Organizational Chart



- Assisting the Networks
- Council Activities: MAC, EDAC KPAC
- Regular Communication with CMS
- Quality Conference Webinars
- Facilitate flow of information between the Forum and Network Staff/BOD/MRB/PAC
- Relationships with other organizations (i.e., RHA, RPA, LDOs, NKF, AAKP, CDC, ASN, KHI, etc.)

Forum Presidents



Elbert P. Tuttle, Jr.

(1976-1978)

Robert J. Soberman

(1978-1980)

Frederick Westervelt

(1980-1982)

Dominick E. Gentile, MD

(1982-1984)

William W. Pfaff, MD

(1984-1986)

Sidney Baskin

(1986-1989)

John L. Bengfort, MD

(1989-1992)

John D. Bower, MD

(1992-1994)

Louis H. Diamond, MB, ChB, FACP

(1994-1998)

Jay B. Wish, MD

(1998-2001)

Alan S. Kliger, MD

(2001-2004)

Derrick L. Latos, MD, MACP

(2004-2006)

Richard S. Goldman, MD

(2006-2009)

Cynthia Kristensen, MD

(2009-2011)

Klemens Meyer, MD

(2011-2012)

Andrew D. Howard, MD, FACP

(2012-2015)

John Wagner, MD, MBA

(2015-2017)

Donald Molony, MD

(2017-2019)

Ralph Atkinson III, MD

(2019-2021)

David Henner, DO

(2021 - 2023)

Kam Kalantar-Zadeh, MD, MPH, PhD

(2023-Present)

Forum Board of Directors (December 2023)



Executive Committee:

President: Kam Kalantar-Zadeh, MD, MPH, PhD

President-Elect: Dan Landry, DO, FASN

Past President: David Henner, DO

Treasurer: Stephanie Hutchinson, MBA

Secretary: Chris Brown

MAC Chair: Dan Landry, DO, FASN

MAC Vice-Chair: Preethi Yerram, MD, MS, FASN

EDAC Chair: Vicky Cash, MBA, BSN, RN

EDAC Vice-Chair: Mary Albin, BS, CPHQ

KPAC Co-Chair: Dawn Edwards

Interim KPAC Co-Chair: Mary Baliker

Members-at-Large:

Christine Logar, MD, FASN

Kelly M. Mayo, MS

Keith Norris, MD PhD

Stephen Pastan, MD

Maria Regnier, MSN, RN, CNN

Dee LeDuc

Debra Hain, PhD, APRN, AGPCNP-BC, FAAN, FAANP, FNKF

Ad Hoc:

Andrew Howard, MD, FACP

Donald Molony, MD

John Wagner, MD, MBA

Emeritus:

Louis Diamond, MB, ChB, FACP, FCP (SA)

Welcome New Board Members



Dee LeDuc

- Executive Director, Midwest Kidney Network (ESRD Network 11)
- Former Coordinator, Forum of ESRD Networks
- Executive Director Advisory Council liaison to the Kidney Patient Advisory Council
- Secretary, Board of Directors, Superior Health Quality Alliance

Debra Hain, PhD, APRN, AGPCNP-BC, FAAN, FAANP, FNKF

- Member, Forum Medical Advisory Council
- Adult/gerontological nurse practitioner and psychiatric mental health nurse practitioner
- Tenured professor and DNP program director at Florida Atlantic University, College of Nursing
- Peer Reviewer, American Journal of Nursing
- Active with numerous organizations, including but not limited to the National Kidney Foundation, the Gerontological Advanced Practice Nurses' Association, the American Nurses Association, and the American Nephrology Nurses Association

Forum Leadership Calls & Meetings

Forum Executive Committee:

- Monthly conference calls

Forum Board of Directors:

- Quarterly conference calls
- 2023 Meetings: March 7 & 10 (virtual); September 22-23, 2023 (Denver, CO)

CMS/Forum Leadership Calls

- Monthly conference calls
- In-person meetings at CMS Quality Conference *(2020, no in-person meeting in 2021, 2022, or 2023)*

Medical Advisory Council (MAC)

- Quarterly conference calls
- Annual MAC Meeting: November 1, 2023 (Philadelphia, PA)

Executive Director Advisory Council (EDAC)

- Monthly conference calls
- Meeting with CMS & Division of Kidney Health/iQIIG Leaders
- Periodic calls with FMC, DaVita, RHA

Kidney Patient Advisory Council (KPAC)

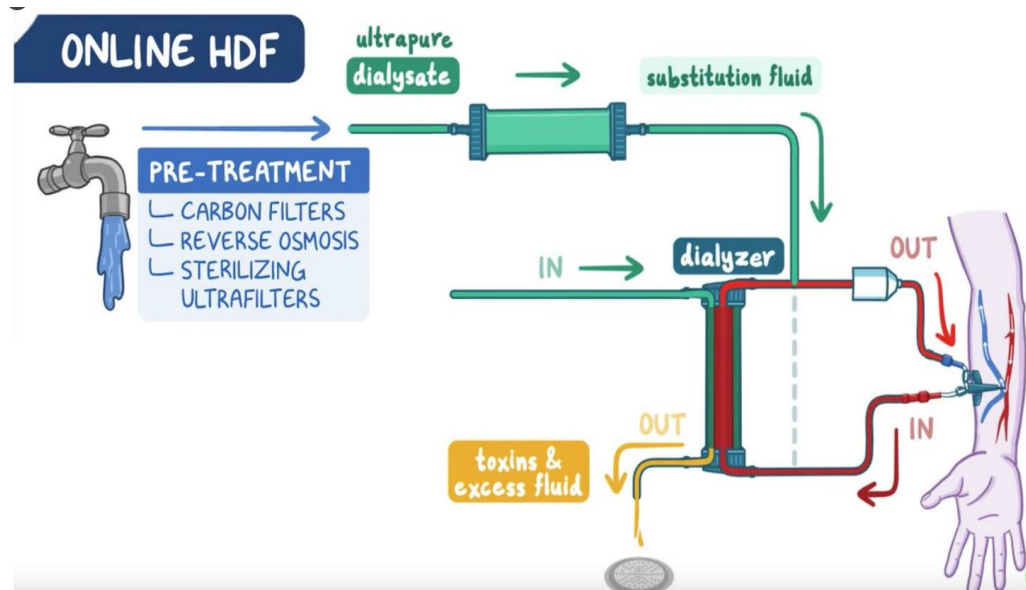
- Monthly conference calls

Highlights from September 22-23, 2023, Meeting in Denver, CO

- Open Session
 - **President's Hot Topics** including 50 years of ESRD, the California Dialysis Council annual conference and dialysis patient and facility trends (including facility closures)
 - **Implicit Bias** and Impact on Kidney Care – Keith Norris, MD
 - KPAC Report and **Dawn's Hot Topics**, including obesity and dialysis, adequacy measures, vascular access, and dialysis staffing shortages – Dawn Edwards
 - **Practicing Health Equity**, and Forum Toolkits – Dan Landry, DO, FASN, and Dawn Edwards

Highlights from September 2023 Meeting in Dener, CO

- Online Hemodiafiltration – George Aronoff, MD
 - Dr. Aronoff provided a deeper understanding of HDF technology as compared to standard HD.
 - He shared a 2023 meta-analysis study comparing HDF to HD, as well as the 2023 CONVINCe study which showed improvement in mortality over time with HDF.
 - He discussed the potential for improved quality of life for patients in HDF.



Let's think seriously: Why is the USA the only country, where outpatient online hemodiafiltration (HDF) is not provided to patients on dialysis, especially if there is such a massive survival benefit? Let's team up and modernize US dialysis practice

nejm.org
Effect of Hemodiafiltration or Hemodialysis on Mortality in...
Original Article from The New England Journal of Medicine
— Effect of Hemodiafiltration or Hemodialysis on Mortalit...

2:20 AM · Jun 18, 2023 · 13.1K Views

- **ESRD PPS QIP Proposed Rule and Update to the ETC – Andy Howard, MD**
 - Dr. Howard shared information on the 2024 Proposed Rule and the Forum’s comments, including but not limited to:
 - Transitional payment for new and innovative technology, including the Buzzy Pro to control pain during needle insertion for HD,
 - Changes to the low volume payment adjustment,
 - Comments re: “time on machine” so that facilities are not penalized by providing more time on the machine or extra supplies to patients,
 - The new health equity measures to which facilities must attest, and
 - Concerns that CMS will keep the COVID vaccination measure at 90% for patients and staff now that the CDC’s definition of “up-to-date” has changed.
 - Shared the goals of the ETC which include:
 - Greater use of home dialysis and transplantation
 - Reduction in Medicare spending
 - Preserving/enhancing quality of care
 - Addressing health equity
 - Also discussed payment adjustments and achievement benchmarks.

Strategic Planning Priorities and Updates

- Strategic Partnerships
 - Continued collaboration with CMS, NKF, RPA, and other stakeholders
 - Continued development of new toolkits and updates to existing toolkits
- Board Development
 - Began development of member questionnaire to gauge areas of interest/expertise
- Customer Outreach, Sharing, & Engagement
 - Implemented social media plan for 2023
 - Grew social media audience
 - Posted *Forum Matters* to the Forum website
- Resource Identification
 - Continued work on fundraising plan to diversify revenue sources
 - Established the Derek Forfang Memorial Fund to support KPAC activities

CMS Organizational Chart

Chiquita Brooks-LaSure,
Administrator, CMS

Liz Fowler
Director, Center for
Medicare and Medicaid
Innovation

iQuality Improvement & Innovation Group

Anita Monteiro, Director
Shane Illies, Deputy Director
Shalon Quinn, PhD, Special Advisory-Data Initiatives
Vacant, CMS Chief Medical Officer for Quality
Improvement



DHHS/CMS Organizational Chart:

https://www.cms.gov/about-cms/agency-information/cmsleadership/downloads/cms_organizational_chart.pdf

Regularly scheduled calls to discuss programmatic/strategic issues:

- **Anita Monteiro**, Director, iQuality Improvement & Innovation Group (iQIIG)
- **Shane Illies**, Deputy Director, iQIIG
- **Vacant**, CMS Chief Medical Officer for Quality Improvement
- **Shalon Quinn**, Special Advisor – Data Initiatives
- **Melissa Dorsey**, Director, Division of Kidney Health, iQIIG
- **Ann Turner**, Acting Deputy Director, Division of Kidney Health, iQIIG
- **Mitzi Christ**, Regional Program Manager, Division of Kidney Health, iQIIG
- CORs, ARAs, Central Office staff

2023 Calls: 2/13, 4/17, 6/12, 7/10, 8/14, 9/11, 12/11

Highlights from 2023

- CMS/Forum leadership calls moved from every other month to monthly to allow for more frequent interaction.
- The November leadership call served as a memorial for Board member and KPAC co-chair Derek Forfang, with many sharing their memories and condolences.
- Ann Turner has been named Acting Deputy Director of DKH; Melissa Dorsey will remain Director of DKH for at least one year.
- The Forum and CMS discussed the Network obesity measure throughout the 2nd quarter. Dr. Kalantar presented data on the “obesity paradox,” which has strong data to support it; higher BMI in dialysis patients demonstrates survival advantages.
- Involuntary discharge and the Second Chance Program were discussed; of the 18 ESRD Networks, 8 have Second Chance Programs, 3 have similar programs, and 7 have no programs.
- The Forum shared information on its numerous toolkits, including the newly updated home dialysis toolkit and upcoming health equity toolkit.
- Discussion continued on staffing shortages. Of note, for the first time in its 50-year history, more dialysis facilities are closing vs. opening.
- The Forum has requested to have further discussions about the QIP measures and the Performance Score Certificates.
- Dr. Howard continued to share transplant metrics, including new data on high KDPI kidneys showing benefits for pre-emptive transplants.
- Mr. Brown continued to share COVID updates, noting data lags making it difficult to track the current vaccination status of patients.

What Else Has the Forum Been Doing?

- The Forum established the Derek Forfang Memorial Fund in memory of KPAC Co-Chair Derek Forfang. Donations will support KPAC activities and can be made at <https://esrdnetworks.org/donate/>.
- The Forum released an updated Home Dialysis Toolkit in August, available at <https://esrdnetworks.org/toolkits/professional-toolkits/home-dialysis-toolkit/>. Members of the MAC are currently working on a Health Equity Toolkit, which will be available in 2024.
- The Forum hosted its first-ever Open Session at its September Board meeting. Over 65 individuals attended virtually or in-person, including Network staff, MAC and KPAC members, and CMS colleagues.
- In August, the Forum submitted comments to CMS on the 2024 Proposed Rule. Comments can be read in full at https://media.esrdnetworks.org/documents/Attachment1_ForumofESRDNetworksCMS1782PCommentsAugust2023.pdf
- Two new Sharing Highly Effective Practices (SHEP) initiatives have been approved and posted to the Forum website at <https://esrdnetworks.org/education/sharing-highly-effective-practices-in-the-kidney-community/approved-highly-effective-practices/>. More highly effective practices are in review.

Forum Members in the Community

- P. Bologna. Transplant Living Community Ambassador. Henry Ford Health. (Ongoing)
- D. Forfang, P. Gee, L. Custer. Webinar: Perspectives: Treating Depression in Dialysis Patients. (January 2023)
- D. Henner, D. Forfang, P. McCowan. SMarRT-HD Study Stakeholder Panel Meeting (PCORI). Chapel Hill, NC. (February 2023)
- M. Baliker, et al. A national registry for people with all stages of kidney disease: The National Kidney Foundation (NKF) Patient Network. *Am J Kidney Dis.* 81(2):210-221. (February 2023)
- P. Gee. National Kidney Foundation Central Virginia Lunch and Learn. Richmond, VA. (March 2023)
- D. Edwards. Chronic Kidney Disease, Education, and Peer Mentorship. Rogosin Institute Kidney Care Innovation Virtual Symposium. (March 2023)
- P. Gee. Advancements in Medications for Diabetic Kidney Disease. American Kidney Fund. Virtual. (March 2023)
- P. Gee. Understanding the Priorities for the Use of Digital Health Technologies (DHTs) to Support Clinical Trials for Drug Development and Review. FDA/Duke/Margolis Virtual Meeting. (March 2023)
- D. Forfang, M. Baliker, J. Nelson. National Kidney Foundation on Capitol Hill Patient Advocacy Committee. Washington, DC. (March 2023)
- P. Gee. Panelist, Patient Summit. National Kidney Foundation Spring Clinicals. Austin, TX. (April 2023)
- P. Gee. Panelist, Eye Movement Desensitization and Reprocessing: Treating Trauma. National Kidney Foundation Spring Clinicals. Austin, TX. (April 2023)
- P. Gee. Panelist, Effective Patient Engagement with Telehealth. National Kidney Foundation Spring Clinicals. Austin, TX. (April 2023)

Forum Members in the Community

- P. Gee. American Heart Association's Cardio-Kidney Metabolic Health Meeting. Dallas, TX. (April 2023)
- P. Gee. American Kidney Fund. Patient Access Initiative Summit. Washington, DC. (April 2023)
- P. Gee. International Society of Medical Publications and Professionals (ISMPP) Conference. Washington, DC. (April 2023)
- M. Baliker. Featured in UNOS article about pediatric kidney transplant. (April 2023)
- L. Custer, D. Forfang. Hemodialysis Infection Prevention Simulation. Tennessee Department of Health. Virtual. (April 2023)
- D. Edwards. Advancing Patient Safety through Patient and Family Engagement. CMS Quality Conference. Virtual. (May 2023)
- D. Henner. Health Equity in Action - A Game Plan for Success for End Stage Renal Disease Care. CMS Quality Conference. Virtual. (May 2023)
- S. Hutchinson. Home Dialysis ECHO: Leveraging National Experts to Address Facility Barriers. CMS Quality Conference. Virtual. (May 2023)
- Kidney Patient Advisory Council. Poster: Patient Resources: Toolkits Created BY Patient FOR Patients. CMS Quality Conference. (May 2023)
- Medical Advisory Council. Poster: Forum of ESRD Networks Toolkits: Valuable Resources for Patients and Providers. CMS Quality Conference. (May 2023)

Forum Members in the Community

- D. Edwards, D. Forfang, M. Baliker, P. McCowan. A Scientific Workshop on Post-Dialysis Fatigue. National Institute of Diabetes and Digestive and Kidney Diseases. Virtual. (May 2023)
- D. Edwards, et al. ISPD Catheter-related infection recommendations: 2023 update. *Peritoneal Dialysis International*. May 26, 2023;43(3):201-219. Available at <https://journals.sagepub.com/doi/10.1177/08968608231172740>.
- P. Gee (Interview). Dialysis was hell to me: A minister's injustice in his own medical care creates his passion for patient advocacy. *ASN Kidney News*. May 2023.
- D. Edwards, S. Dixon. Living Your Best Life with Kidney Disease. Decatur, GA. (June 2023)
- L. Custer. Video: Home Dialysis: Possible Barriers to Overcome available at
- <https://youtu.be/8cUMZDJhAXM?si=wFixPxxCrFQh1 ug>. (July 2023)
- D. Edwards, S. Dixon. Making Dialysis Safer Coalition. Virtual. (July 2023)
- T. Nelson. Radio Interview: Transplanting Hope. (July 2023)
- L. Hall. Depression: Barriers to Treatment and Some Solutions. Pacific Northwest Council of Nephrology Social Workers Workshop. (July 2023)
- P. Gee. Graduation Speaker and Graduate: Patients Professor Academy. University of Maryland School of Pharmacy. (August 2023)

Forum Members in the Community

- D. Henner. Transitional Dialysis Care. Visonex Annual User Group. (August 2023)
- M. Baliker, et al. Chronic active antibody-mediated rejection: Opportunity to determine the role of interleukin-6 blockade. *Transplantation*. Accepted 16 August 2023.
- P. Gee. Gut PD Workshop: Patients' and Caregivers' Perspectives on Gut Health Outcomes in Peritoneal Dialysis. University of Sydney/University of Queensland, Australia. (August 2023)
- L. Hall. Who You Gonna Call? Getting Your Dialysis and Transplant Care Concerns Addressed. National Kidney Foundation Virtual Education Series. (August 2023)
- D. Edwards, M. Baliker, P. McCowan. Kidney Health Initiative Innovations. Washington, DC. (September 2023)
- D. Edwards, M. Baliker. Appointed to the Editorial Board (Patient Voices) of the *Clinical Journal of the American Society of Nephrology*. (September 2023)
- D. Edwards. Financial Constraints of ESRD Patients Along the Kidney Journey. SUNY Downstate. Brooklyn, NY. (October 2023)
- D. Edwards. Importance of Patient Advocates and How to Utilize Them to Achieve a Better Standard of Care. University of Pennsylvania. (October 2023)
- J. Starling. Dealing with Sepsis. American Kidney Foundation. (October 2023)

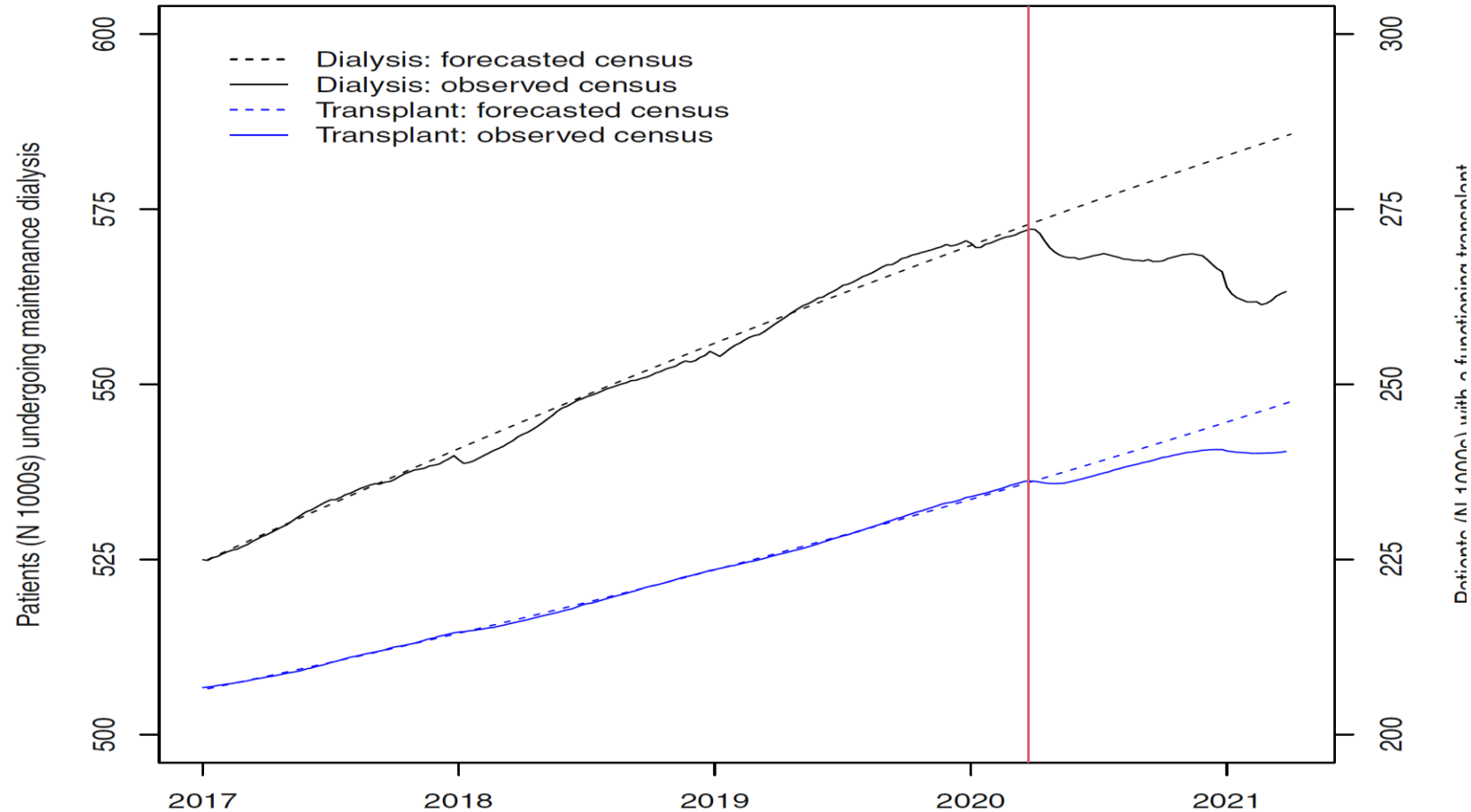
50 Years of ESRD 1973–2023



- **The Medicare End Stage Renal Disease (ESRD) Program**, a national health insurance program for people with kidney failure, was established in **Oct 1972** with the passage of Section 299I of Public Law 92-603, enacted **July 1973**.
- **The formation of ESRD Network Organizations was authorized in 1978 by Public Law 95-292 which amended Title XVIII of the Social Security Act by adding section 1881. → 32 ESRD Network areas were initially established.**
- In 1986, the Omnibus Budget Reconciliation Act of 1986 (P.L. 99-509) amended section 1881c of the Social Security Act to establish at least 17 ESRD Network areas and to revise the Network Organizations responsibilities.
- Today, **18 ESRD Network Organizations** exist under contract to CMS and *serve as liaisons between the federal government and the providers of ESRD services.*
- The ESRD Network Organizations' responsibilities include:
 - the quality oversight of the care ESRD patients receive,
 - the collection of data to administer the national Medicare ESRD program, and
 - the provision of technical assistance to ESRD providers and patients in areas related to ESRD.
- **Since 1976 The National Forum of ESRD Networks: All ESRD Networks are members of the Forum, which is a not-for-profit organization that advocates on behalf of its membership and coordinates projects and activities of mutual interest to ESRD Networks.**
- ***The Forum facilitates the flow of information and advances a national quality agenda with CMS and other renal organizations***

What Else Happened in 2023?

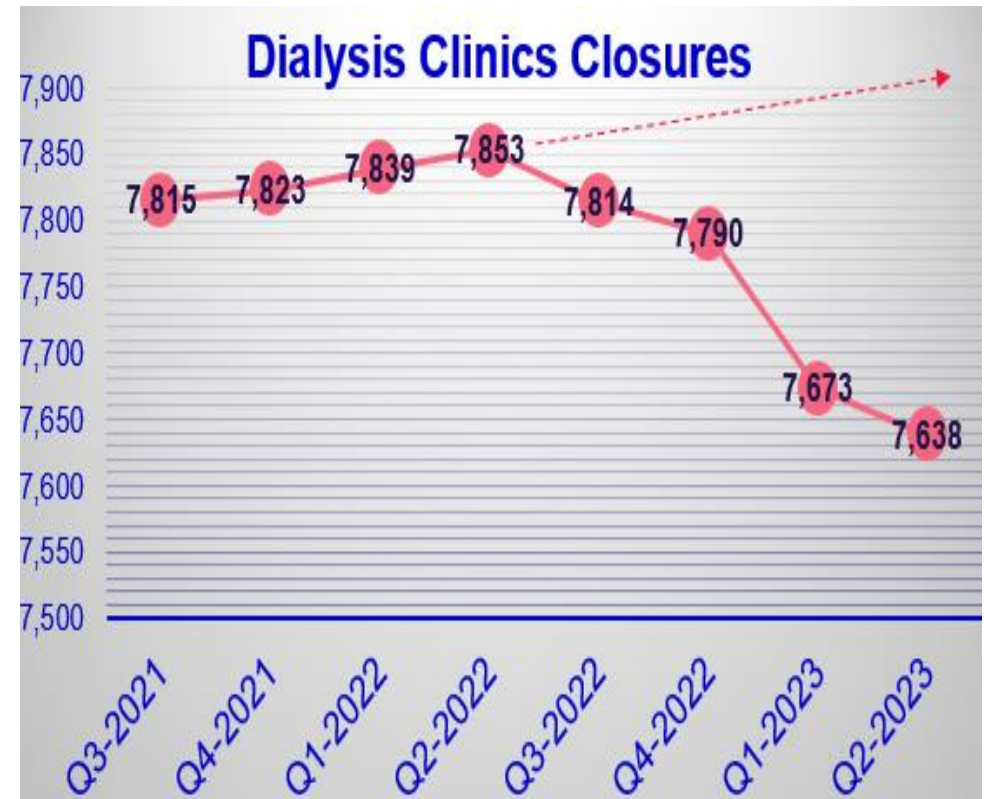
COVID Death in among CKD and ESRD Patients



Net Closure of >200 Dialysis Clinics 2023

Potential Causes of Clinic Closures:

1. COVID deaths in 2020-2021 affected ESRD population in 2023?
 - ND-CKD Stages 4-5 exhibit high COVID mortality
2. More than 25,000 kidney transplantations in 2022 and likely more in 2023
3. Later transition to dialysis:
 - Is this an emerging culture?
 - Role of VBC models?
 - New medications and diet, e.g., SGLT2i
4. More home dialysis at the expense of in-center HD?
5. Fiscal and workforce factors:
 - Shortage of dialysis staff, high wages, inflation
 - Budget neutrality
6. Other unknown factors



Measures Review in 2023



Kam Kalantar-Zadeh, MD, MPH, PhD
@kamkalantar

Promote

...

Public Comment Period for 2023 [#MeasureSetReview](#) [#MSR](#) @CMS [#ESRD](#) Quality Incentive Program ESRD-QIP Report Now Open Guidebook Available for Download p4qm.org/msr-material/p... click on File MSR-Report-ESRD-QIP-20230911.pdf
Deadline for comment: 11:59 pm ET 9/25/23
[@ESRDNetworks](#)



National Consensus Development and Strategic Planning for Health Care Quality Measurement

2023 Measure Set Review (MSR): End Stage Renal Disease Quality Incentive Program (ESRD-QIP)

Public Comment Period for 2023 Draft MSR Report Now Open and Guidebook Available for Download

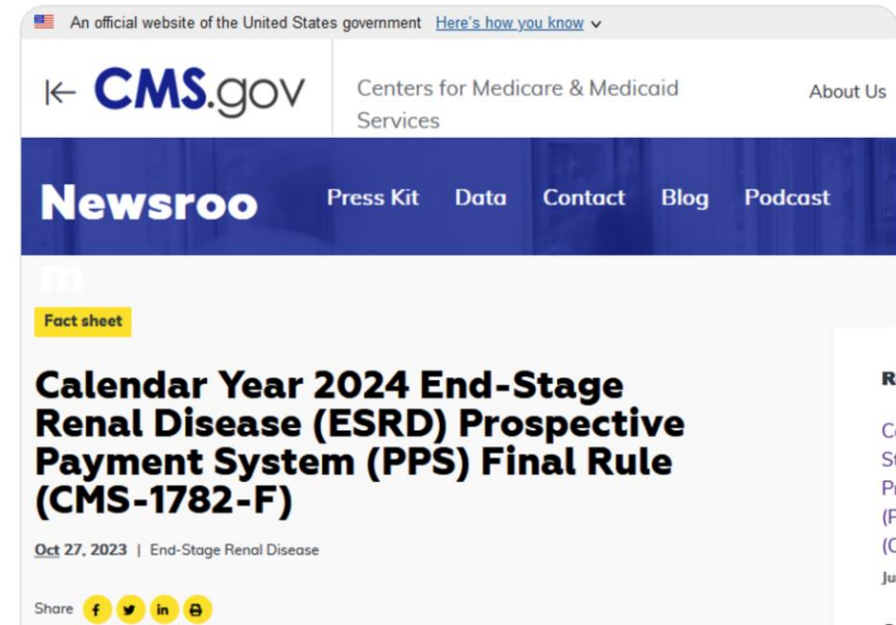


Kam Kalantar-Zadeh, MD, MPH, PhD
@kamkalantar

Promote

...

ESRD Medicare Program 2024 Prospective Payment System Final Rule CMS-1782-F released. Select QIP highlights:
1) Standardized AV Fistula rate is removed
2) UF rate reporting removed
3) Time on chair data to be collected
4) Health equity attestations added
cms.gov/newsroom/fact-...



Donate Online!



Home x +
https://esrdnetworks.org

THE NATIONAL FORUM OF ESRD NETWORKS

Advocating for the organizations that monitor the quality of chronic kidney disease, dialysis and kidney transplant care in the USA.

Home About Us Membership Toolkits Resources & News Education Contact

Donate

The National Forum of ESRD Networks, Inc. is a registered 501(c)(3) non-profit organization #13-3246354. Your donation is tax deductible to the extent allowable by law. No goods or services will be provided by the Forum in return or consideration for this contribution. Donations can also be mailed to the Forum Office at PO Box 203, Birchwood, WI 54817.

Donate now

What's new on the Forum website?

Learn about the new Transplant Toolkit for Patients

This 12-minute video provides an overview of the Toolkit

Is A Kidney Transplant Right for Me?

ESRD Networks - contact information

Welcome to the Forum of ESRD Networks website



Advocating for the organizations that monitor the quality of chronic kidney disease, dialysis and kidney transplant care in the USA.

- Home
- About Us
- Membership
- Toolkits
- Resources & News
- Education
- Donor Wall**
- Contact



Donor Wall

A gracious "Thank you" to all of our donors, big and small, are making a difference in the life of a kidney patient!

With more than 75 engaged volunteers actively involved in identifying gaps in care and filling those gaps, the Forum has developed both patient and provider centered resources. Through the generous donations from the community, we will continue this work. What is the community saying about these resources?

- "Good info graphics and something for every staff member in the dialysis clinic." ~Corporate VP in Dialysis, about the Kidney Transplant Toolkit
- "The information is geared to improving the health and safety of patients with ESRD." ~Dialysis Social Worker, about the Kidney Transplant Toolkit
- "It gives a new way to look at things. We need to make sure we continue to meet patient needs." ~Dialysis Nurse, about the Transitions of Care Toolkit

Thank You to all of our Generous Donors in 2021
[Read more...](#)

Thank You to all of our Generous Donors in 2022
[Read more...](#)

Donor Recognition Levels
[Read more...](#)

esrdnetworks.org/donor-wall/

Donate

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[Donate now](#)

What's new on the Forum website?

[Learn about the new Transplant Toolkit for Patients](#)

This 12-minute video provides an overview of the Toolkit

[Is A Kidney Transplant Right for Me?](#)

[COVID-19 vaccination flyer for Dialysis patients](#)

Please share this flyer with your dialysis patients

[Resources & Links for Kidney Patients](#)



esrdnetworks.org



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<https://www.linkedin.com/company/national-forum-of-esrd-networks-inc>



<https://www.youtube.com/channel/UC9Vp4Hfu7VmSTbSwG7-6e2g>

Sharing something about the KPAC? Use #KPACPatientVoice

Questions / Comments:
Kelly Brooks, Forum Coordinator
kbrooks@esrdnetworks.org
804-390-9822

Questions?

Kam Kalantar-Zadeh, MD, MPH, PhD
kkalantar@lundquist.org



KPAC Report

Mary Baliker
Interim Co-Chair, KPAC
ESRD Network 11

Mission:

To support and advocate on behalf of the ESRD Networks and to improve the **standard** of care to patients with renal disease.

Vision:

Being the patient eyes, ears and voice for CMS bridging the gap between patient experience and provider performance.

November 2023

Kidney Patient Advisory Council (November 2023)



- | | | | |
|-------------|-----------------------------------------------------|-------------|---------------------------------------------------------|
| Network 1: | Laurie Pease
Sherrie Shively | Network 11: | Jeff Nelson
Mary Baliker (Interim Co-Chair) |
| Network 2: | Stephanie Dixon
Dawn Edwards (Co-Chair) | Network 12: | Shane Blanchard |
| Network 3: | Bill Senior
Anthony Abbate | Network 13: | Yazzi Bishop |
| Network 4: | Timmy Nelson | Network 14: | Precious McCowan
Abby Ruiz |
| Network 5: | Virna Elly
Patrick Gee | Network 15: | VACANT |
| Network 6: | Jamall Wimberly
Eric Dolby | Network 16: | Bob Crabtree
Lisa Custer |
| Network 7: | Janice Starling | Network 17: | Doris Lew |
| Network 8: | VACANT | Network 18: | VACANT |
| Network 9: | Evan Coaker
Laura Wilcox | EDAC Rep: | Dee LeDuc (NW 11) |
| Network 10: | VACANT | PSD Reps: | Yessi Cubillo (NW 3)
Lisa Hall, MSSW, LICSW (NW 16) |

Welcome New KPAC Members!

- Laurie Pease – ESRD Network 1
- Sherrie Shively – ESRD Network 1
- Anthony Abbate – ESRD Network 3
- Jamall Wimberly – ESRD Network 6
- Eric Dolby – ESRD Network 6
- Laura Wilcox – ESRD Network 9
- Yazzi Bishop – ESRD Network 13

Thank You Former KPAC Members!



The following KPAC members rotated off this year. We thank them for their service.

- Gerald “Jerry” Calabritto – ESRD Network 1
- Joy Solomon, MSN, RN, PNP – ESRD Network 3
- Dolores McGrath – ESRD Network 6
- Marquita Kirk – ESRD Network 8
- Quin Taylor – ESRD Network 10
- Patti Bologna – ESRD Network 11
- Bobby Walker – ESRD Network 13
- Lynne Hall – ESRD Network 15
- Terry McCallum – ESRD Network 18

In Memory of Those We Lost in 2023



Derek Forfang



Terry Peeler



Jacqueline Bland

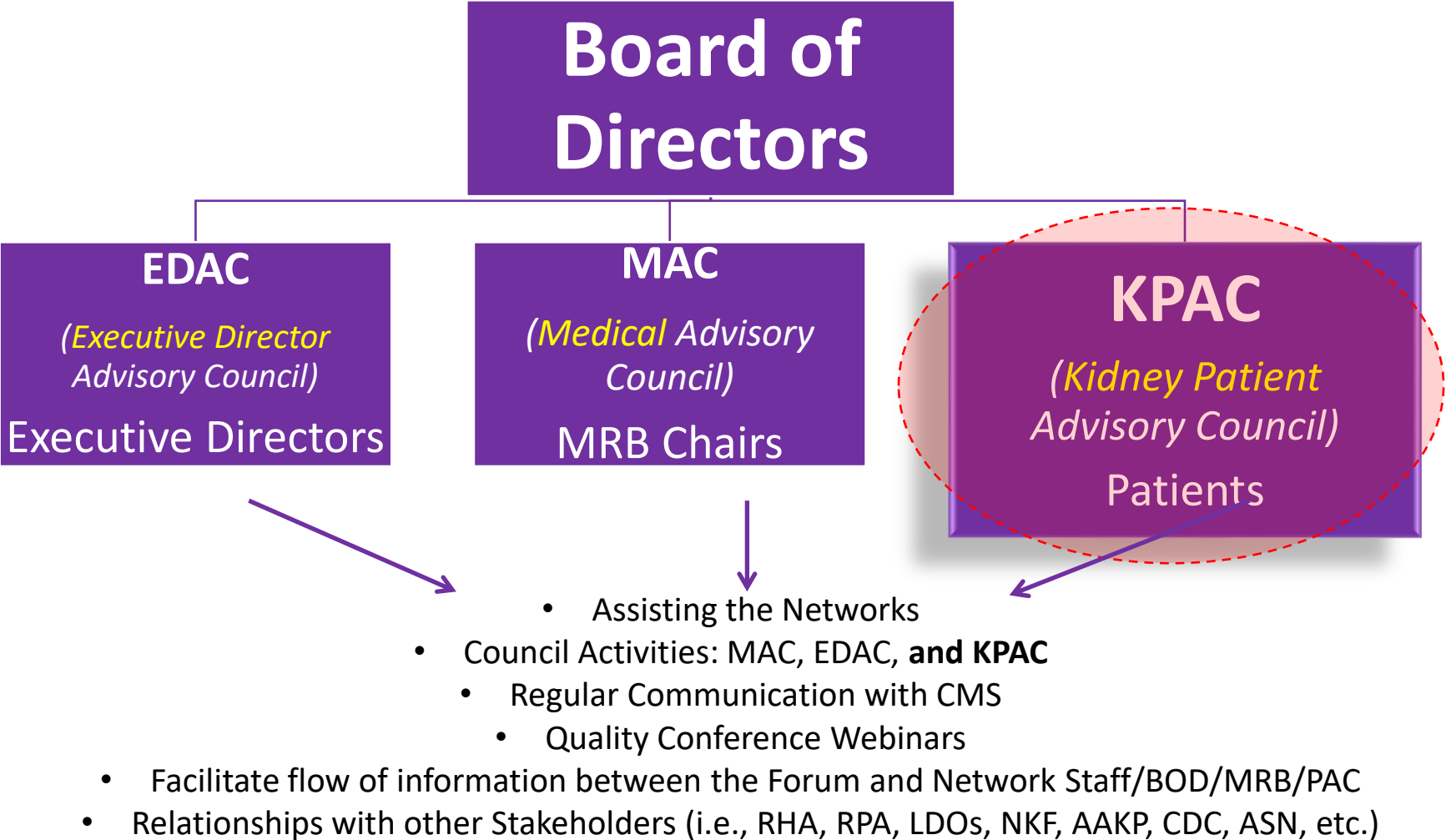


Nielkje Gedney



Dawn Goertz

Forum Organizational Chart



Integration of Geriatric Care into Dialysis Clinics



- NIH-funded grant project run by Rasheeda Hall, MD, MBA, MHS, FASN, Duke University
- KPAC members Dawn Edwards and Bill Senior serving on the Stakeholder Advisory Board (SAB)
- Project will refine and pilot test a geriatric care model for dialysis clinics.
- The SAB members will play a critical role by providing feedback on study design, patient-facing materials, and implementation, as well as ensuring that the care model meets the needs and expectations of patients and care providers alike.

Identifying Goals of Care and Concerns in ESKD Patients

- Study conducted by Don Molony, MD, Jacob Galan, MS-2, and others.
- This qualitative study will include a national sample of ESRD patients, both male and female adults (ages 18-85), who are currently receiving incenter HD or who have been treated with in-center HD in the past prior to kidney transplant or transition to home dialysis.
- Investigators will interview patients to identify important questions that need to be addressed to improve patient quality of life, experience of care, and safety.
- The goal of the study is to foster a patient-centered approach to improve quality of care and ensure that patient concerns are addressed regarding their dialysis treatment.
- Results will be summarized and submitted for national/international publication in a peer-reviewed journal.

KPAC Member Activities



- NKF Policy and KAC member participation
- AAKP Board and member participation
- DPC Board member
- UNOS
- Philadelphia OPO Board
- UCSF Kidney Project Patient Board
- New York State CKD Champions
- ASN: Kidney Health Initiative & Kidney X Reviewers, DKD Diabetic Kidney Disease Collaborative
- Kidney X judges panel
- CDC: Making Dialysis Safer Coalition
- KCER
- ESRD NCC/MEI, NEPOP

KPAC Member Activities



- Forum MAC
- SONG, PD Expert Working Groups for Technique Survival, Infection, and Life Participation, HD CVD MI Expert Working Group paper published in *Kidney International*, "Defining Myocardial Infarction in trials of people receiving hemodialysis: a consensus report from the SONG-HD MI Expert Working group" June 2023
- OPPUS aspects of peritonitis-related practices and outcomes Derek
- PDOPPS Webinar OPPUS dashboard update, STATUS OF PD in the US
- NIH / NIDDK Advisory Board, Dawn
- Docola <https://www.doco.la/#/Home>
- PCORI Grant Activities
- NCC Legacy Members
- TAQIL ETCLC – Mary
- KDIGO Workgroups – Dawn & Mary
- HDU (Home Dialyzors United) Board Members - Dawn & Patrick

KPAC Member Activities



- P. Bologna. Transplant Living Community Ambassador. Henry Ford Health. (Ongoing)
- D. Forfang, P. Gee, L. Custer. Webinar: Perspectives: Treating Depression in Dialysis Patients. (January 2023)
- D. Henner, D. Forfang, P. McCowan. SMarRRT-HD Study Stakeholder Panel Meeting (PCORI). Chapel Hill, NC. (February 2023)
- M. Baliker, et al. A national registry for people with all stages of kidney disease: The National Kidney Foundation (NKF) Patient Network. *Am J Kidney Dis.* 81(2):210-221. (February 2023)
- P. Gee. National Kidney Foundation Central Virginia Lunch and Learn. Richmond, VA. (March 2023)
- D. Edwards. Chronic Kidney Disease, Education, and Peer Mentorship. Rogosin Institute Kidney Care Innovation Virtual Symposium. (March 2023)
- P. Gee. Advancements in Medications for Diabetic Kidney Disease. American Kidney Fund. Virtual. (March 2023)
- P. Gee. Understanding the Priorities for the Use of Digital Health Technologies (DHTs) to Support Clinical Trials for Drug Development and Review. FDA/Duke/Margolis Virtual Meeting. (March 2023)
- D. Forfang, M. Baliker, J. Nelson. National Kidney Foundation on Capitol Hill Patient Advocacy Committee. Washington, DC. (March 2023)

KPAC Member Activities



- P. Gee. Panelist, Patient Summit. National Kidney Foundation Spring Clinicals. Austin, TX. (April 2023)
- P. Gee. Panelist, Eye Movement Desensitization and Reprocessing: Treating Trauma. National Kidney Foundation Spring Clinicals. Austin, TX. (April 2023)
- P. Gee. Panelist, Effective Patient Engagement with Telehealth. National Kidney Foundation Spring Clinicals. Austin, TX. (April 2023)
- P. Gee. American Heart Association's Cardio-Kidney Metabolic Health Meeting. Dallas, TX. (April 2023)
- P. Gee. American Kidney Fund. Patient Access Initiative Summit. Washington, DC. (April 2023)
- P. Gee. International Society of Medical Publications and Professionals (ISMPP) Conference. Washington, DC. (April 2023)
- M. Baliker. Featured in UNOS article about pediatric kidney transplant. (April 2023)
- L. Custer, D. Forfang. Hemodialysis Infection Prevention Simulation. Tennessee Department of Health. Virtual. (April 2023)
- D. Edwards. Advancing Patient Safety through Patient and Family Engagement. CMS Quality Conference. Virtual. (May 2023)
- Kidney Patient Advisory Council. Poster: Patient Resources: Toolkits Created BY Patient FOR Patients. CMS Quality Conference. (May 2023)
- Medical Advisory Council. Poster: Forum of ESRD Networks Toolkits: Valuable Resources for Patients and Providers. CMS Quality Conference. (May 2023)
- D. Edwards, D. Forfang, M. Baliker, P. McCowan. A Scientific Workshop on Post-Dialysis Fatigue. National Institute of Diabetes and Digestive and Kidney Diseases. Virtual. (May 2023)
- D. Edwards, et al. ISPD Catheter-related infection recommendations: 2023 update. *Peritoneal Dialysis International*. May 26, 2023;43(3):201-219. Available at <https://journals.sagepub.com/doi/10.1177/08968608231172740>.
- P. Gee (Interview). Dialysis was hell to me: A minister's injustice in his own medical care creates his passion for patient advocacy. *ASN Kidney News*. May 2023.
- D. Edwards, S. Dixon. Living Your Best Life with Kidney Disease. Decatur, GA. (June 2023)

KPAC Member Activities



- D. Edwards, S. Dixon. Making Dialysis Safer Coalition. Virtual. (July 2023)
- T. Nelson. Interview. Gift of Life. Philadelphia, PA. (July 2023)
- L. Custer. Video: Home Dialysis: Possible Barriers to Overcome available at <https://youtu.be/8cUMZDJhAXM?si=wFixPxxCrFQh1 ug>. (July 2023)
- L. Hall. Depression: Barriers to Treatment ad Some Solutions. Pacific Northwest CNSW Workshop. (July 2023)
- P. Gee. Gut PD Workshop: Patients' and Caregivers' Perspectives on Gut Health Outcomes in Peritoneal Dialysis. University of Sydney/University of Queensland, Australia. (August 2023)
- L. Hall. Who You Gonna Call?: Getting Your Dialysis & Transplant Care Concerns Addressed. NKF Virtual Education Series. (August 2023)
- M. Baliker, et al. Chronic active antibody-mediated rejection: Opportunity to determine the role of interleukin-6 blockade. *Transplantation*. Accepted 16 August 2023.
- D. Edwards, M. Baliker, P. McCowan. Kidney Health Initiative Innovations. Washington, DC. (September 2023)
- D. Edwards. Appointed to the Editorial Board (Patient Voices) of the *Clinical Journal of the American Society of Nephrology*. (September 2023)
- D. Edwards. Financial Constraints of ESRD Patients Along the Kidney Journey. SUNY Downstate. Brooklyn, NY. (October 2023)
- D. Edwards. Importance of Patient Advocates and How to Utilize Them to Achieve a Better Standard of Care. University of Pennsylvania. (October 2023)
- J. Starling. Dealing with Sepsis. American Kidney Foundation. (October 2023)

2023 TEP Participation

- PCORI 5-Diamond Stakeholder TEP (Mary Baliker)
- Quality Measure Development Plan & Quality Measure Index (Mary Baliker)
- ESRD PPS TEPs
 - MIPS TEP: Preventing and Delaying the Progression of Kidney Disease (Derek Forfang)
 - Acumen Wave 5 Post-Transplant Care (Derek Forfang)
- Impact Assessment Report 2024 of CMS Quality and Efficiency Measures (Derek Forfang)
 - Focus on health equity

Congratulations!



Dawn Edwards and Mary Baliker

have been appointed to serve on the

Clinical Journal of the American Society of Nephrology's

Patient Voices Editorial Board!

Upcoming KPAC Activities

- Complete patient videos for MAC Home Dialysis Toolkit
- Develop a Cardiovascular Disease & CKD Toolkit
- Develop short videos/webinars about KPAC resources and orientation materials for new KPAC members
- Explore financial resources to help support the Forum
- Develop a “Success on All Modalities” video
- Participate in MAC Toolkit Project, June 2024, Honolulu, HI

Thank You to the Forum



For all your support and encouragement.

We couldn't do what we do without you!

Questions?

Dawn Edwards, Co-Chair

dawnedwards@gmail.com

Mary Baliker, Interim Co-Chair

mbaliker@gmail.com



EDAC Report

Vicky Cash, MBA, BSN, RN
Chair, EDAC
ESRD Network 9

Executive Directors Advisory Council (July 2023)



Chair:	Vicky Cash, MBA, BSN, RN
Vice-Chair:	Mary Albin, BS, CPHQ
Networks 1/2	Sue Caponi, MBA, RN, BSN, CPHQ
Networks 3/4	Chris Brown
Network 5	Brandy Vinson
Network 6	Danielle Daley, MBA
Networks 7/13/15/17/18	Helen Rose, MSW, BSW, LCSW
Networks 8/14	Mary Albin, BS, CPHQ
Network 9	Vicky Cash, MBA, BSN, RN
Network 10	Audrey Broaddus
Network 11	Dee LeDuc
Network 12	Stephanie Smith
Network 16	Stephanie Hutchinson, MBA

ESRD Network Contract Updates



- Technical Direction Received
 - Depression treatment goal measure removed
 - BMI measure removed
 - There are now 24 QIA goals in Option Year 2, including the same four PFE goals
- On site visits by DKH began November and occurring through February
 - Visiting organization main corporate offices and an ESRD or transplant facility
 - Focus on how Networks are working to overcome barriers

Measures Summary 2023-24

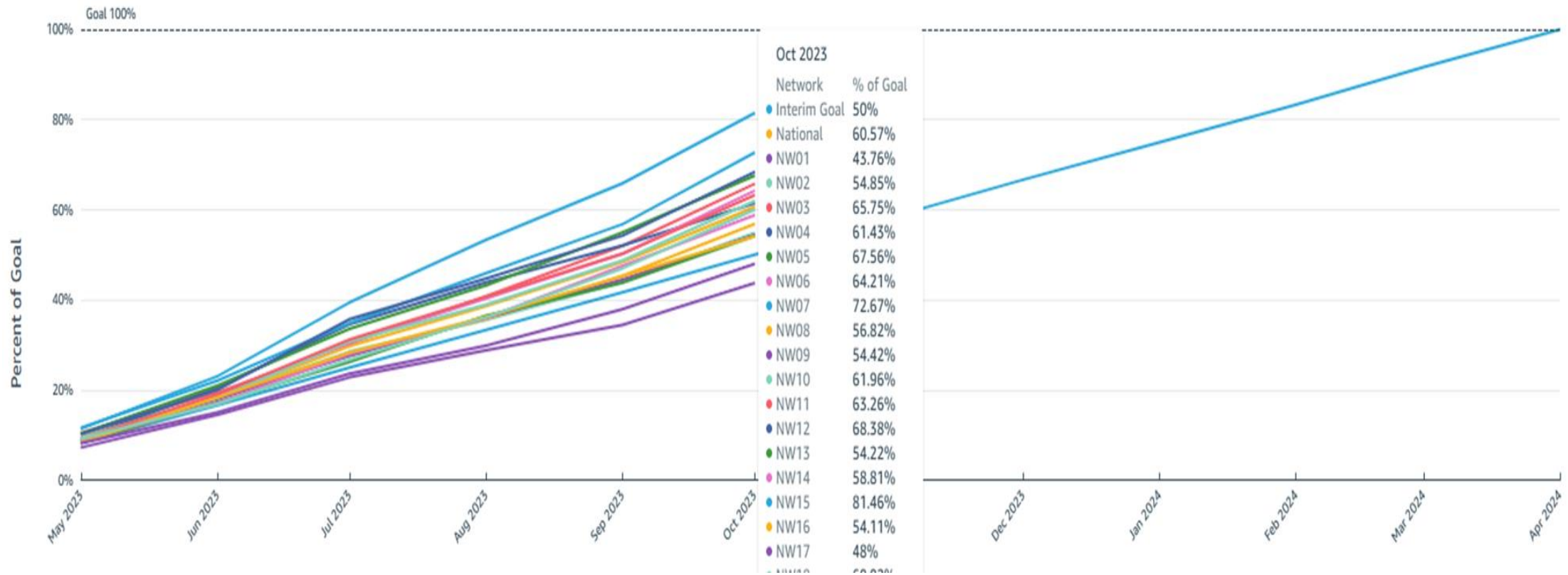
- Vax-COVID19 Pt Fully Vaccinated (80% Of Pt)
- Vax-COVID19 Staff Fully Vaccinated (95% Of Pt)
- Pneumonia Vaccination Up to Date (+7% Over BL)
- Hosp-Inpatient (-4% Below BL)
- Hosp-Unplanned(-4% Below BL)
- Hosp-ED Visit(-4% Below BL)
- NH-Alt Blood Transfusions (-7% Below BL)
- NH-Alt Infection (-14% Below BL)
- NH-Blood Transfusions (-3% Below BL)
- NH-Infection (-6% Below BL)
- NH-Peritonitis (-3% Below BL)

Measures Summary 2023-24

- PFE-QAPI (30% Over BL)
- PFE-Life Plan (+30% Over BL)
- PFE-Peer Mentor (+15% Over BL)
- NPFE-LAN Attendance (60% attendance)
- DQQIA-Form_2746 (+5% Over BL)
- DQQIA-Form_2728 (+4% Over BL)
- Home-Incident (+30% Over BL)
- Home-Transitions (+12% Over BL)
- Telemedicine (+3% Over BL)
- Txp-Waitlist (+9% Over BL)
- Txp-Transplant (+12% Over BL)
- Vax-Influenza Pt (90% Of Pt)
- Vax-Influenza Staff (90% Of Staff)

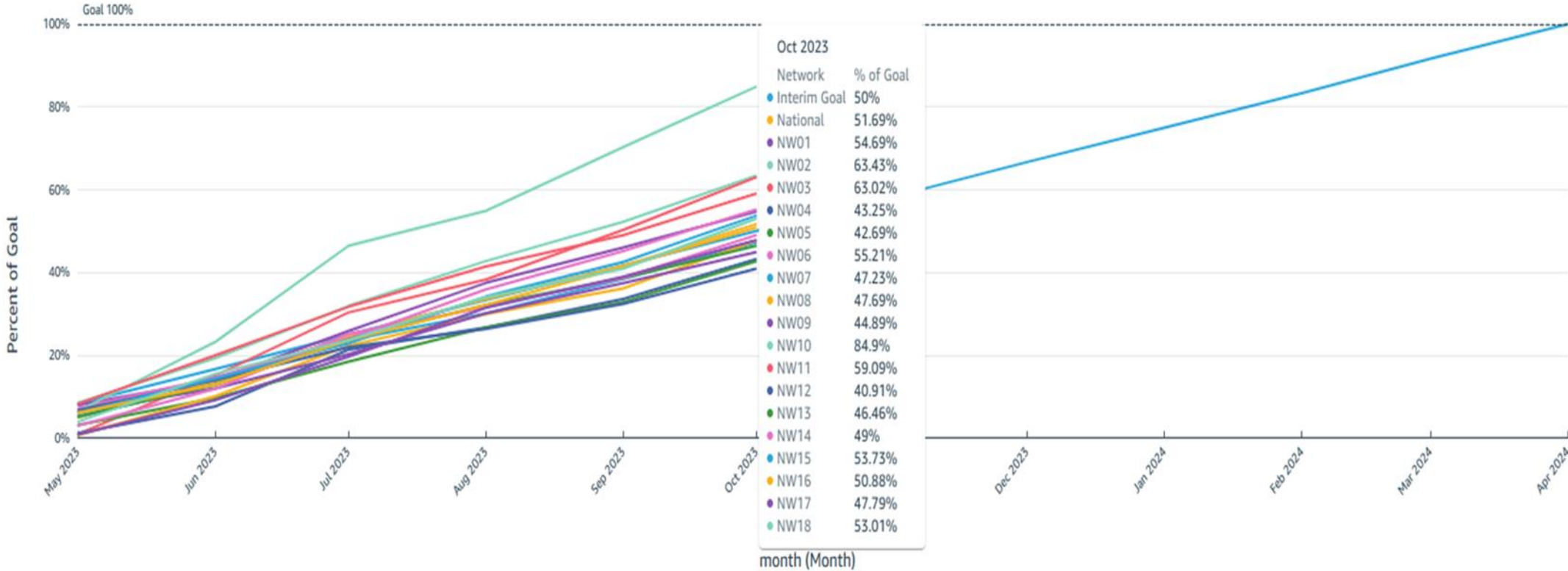
Transplant – Added to Waitlist

Added to Waitlist Relative Increase Percent of Goal



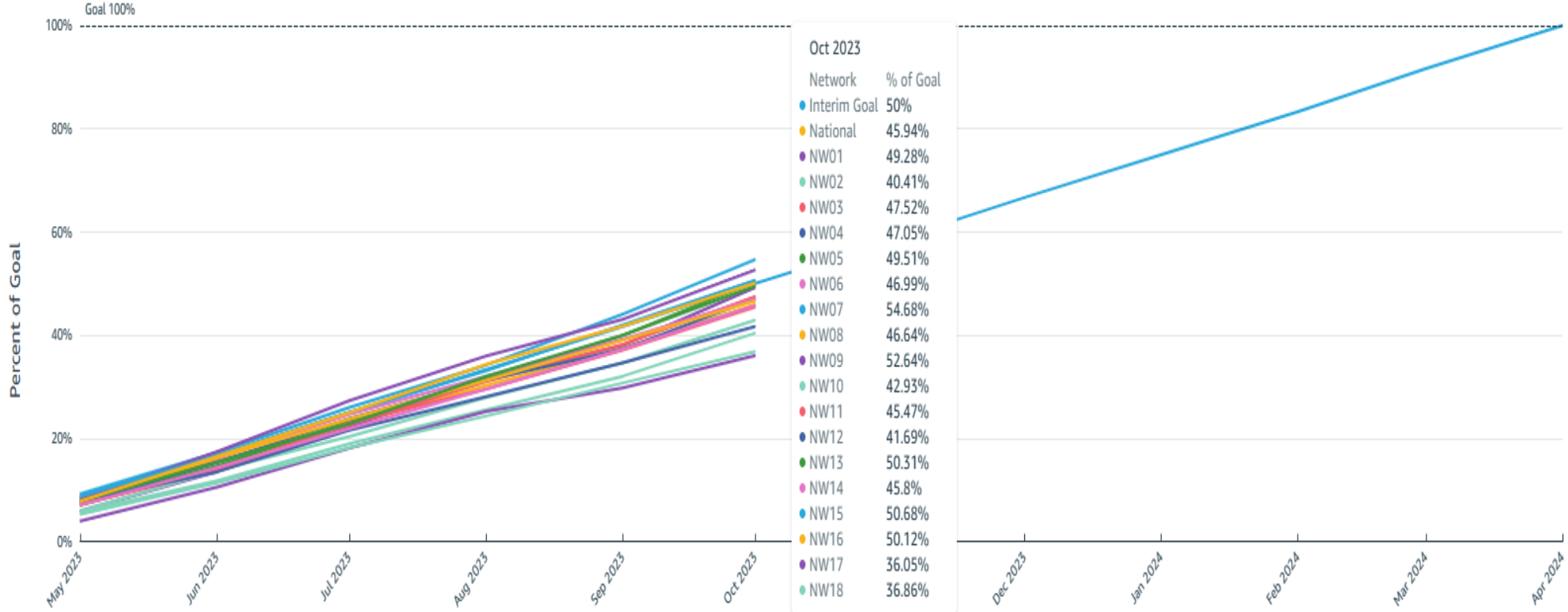
Transplant – Actual Transplanted

Transplanted Relative Increase Percent of Goal



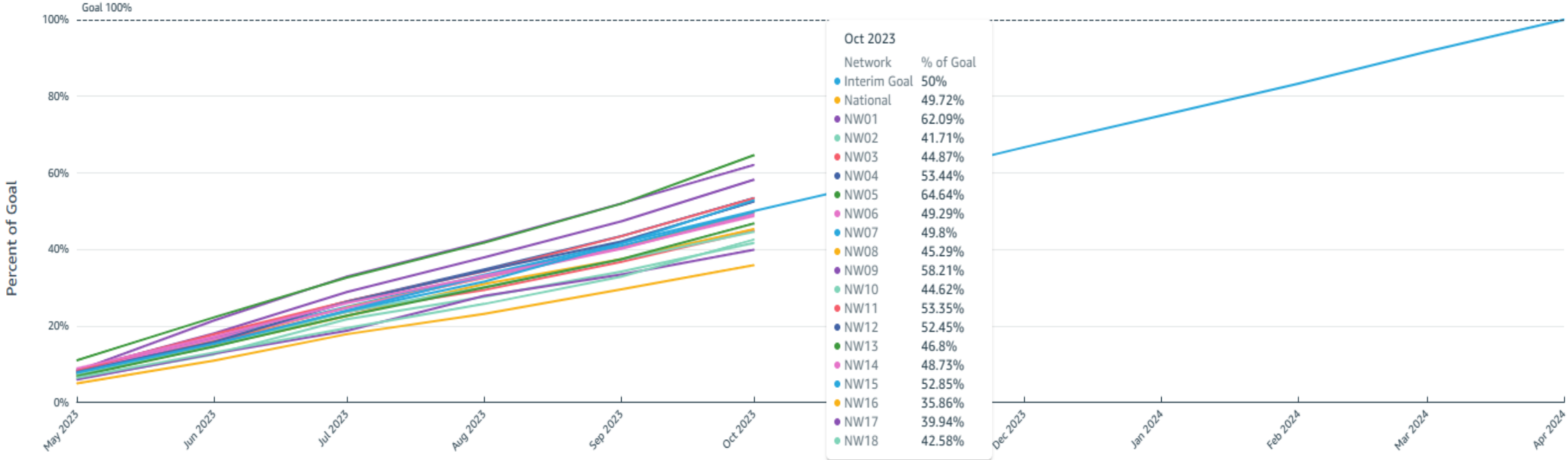
Home - Incident

Incident to Home Relative Increase Percent of Goal



Home - Transition

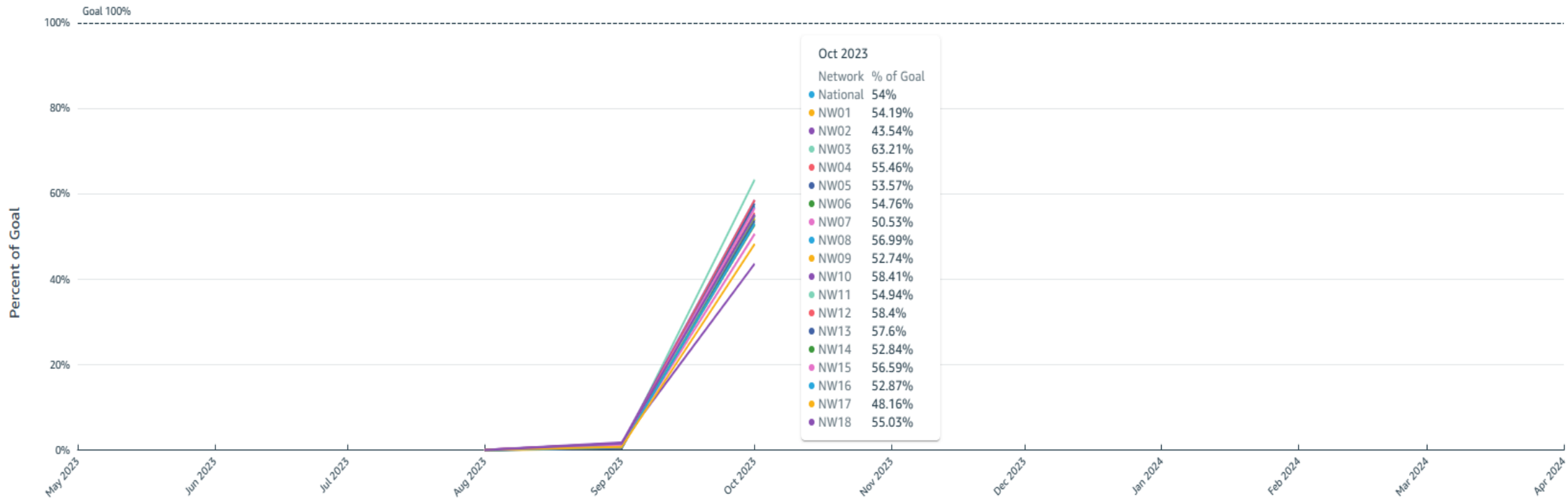
Transition to Home Relative Increase Percent of Goal



Transition to Home Data Table

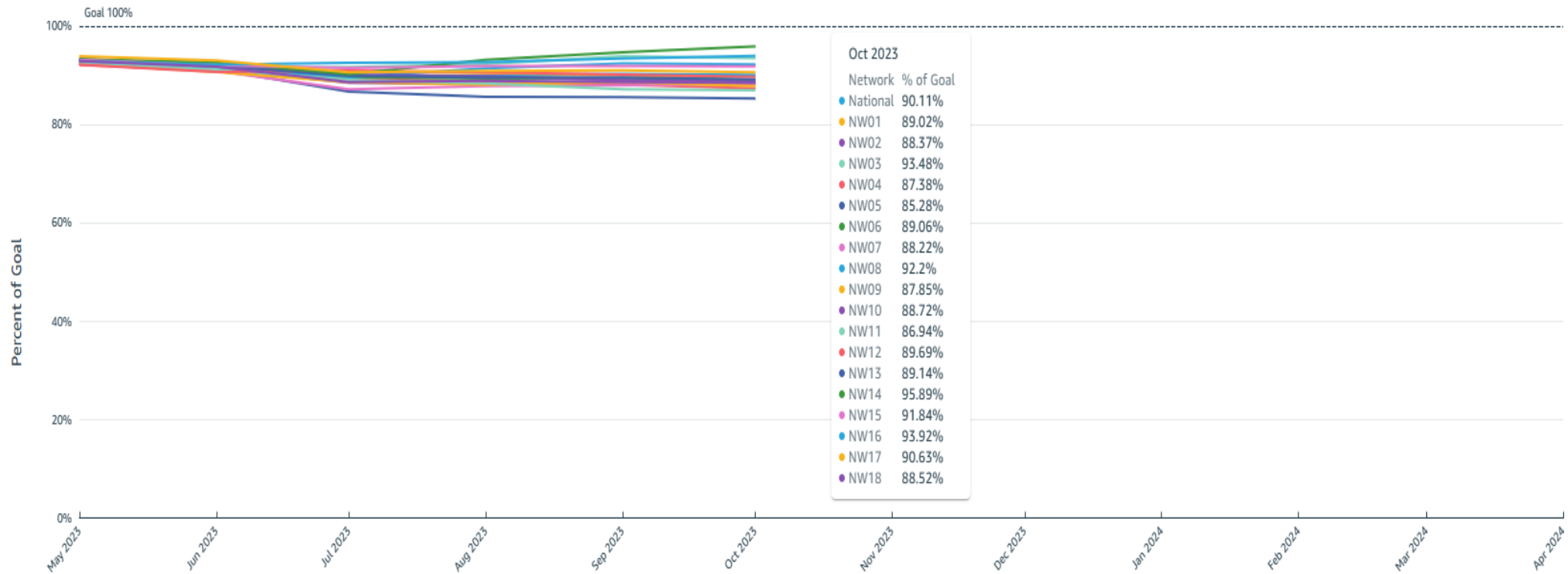
Vaccine – Influenza Patients

Vaccination - Influenza Patients Percent of Goal - By Month Option Period 2



Vaccinations – Pneumococcal

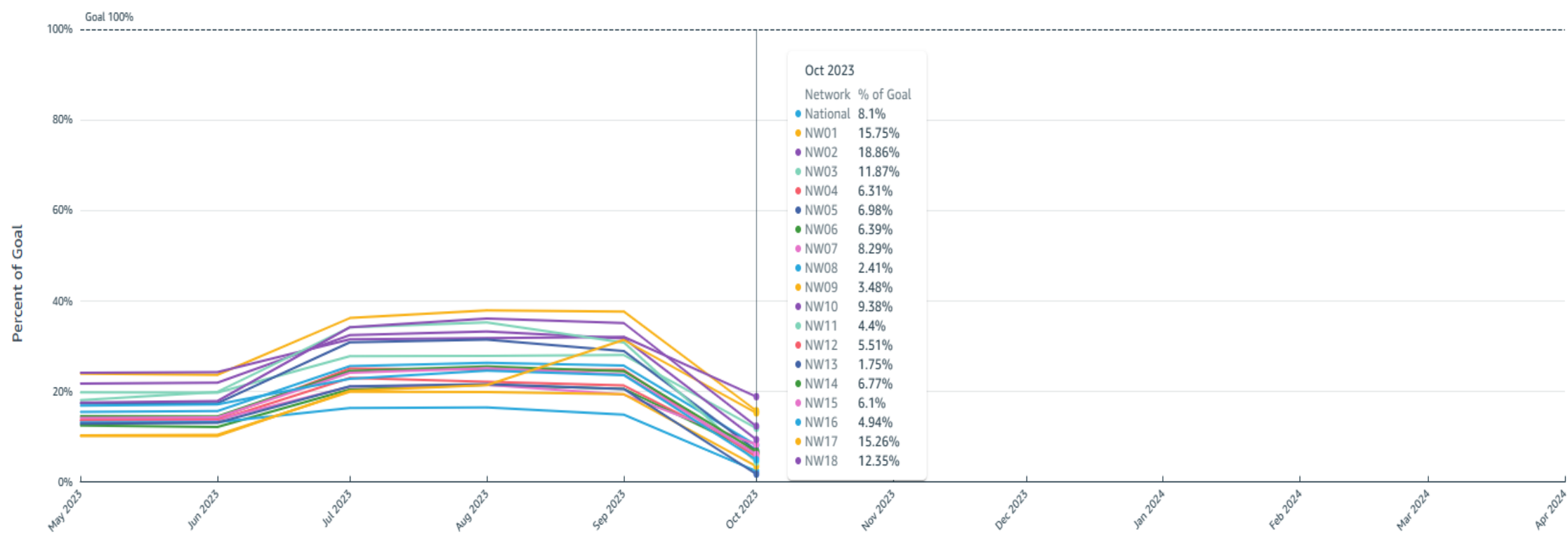
Vaccination - Pneumococcal Percent of Goal - By Month Option Period 2



* COVID and Influenza data unavailable

Vaccinations – COVID19 Patients

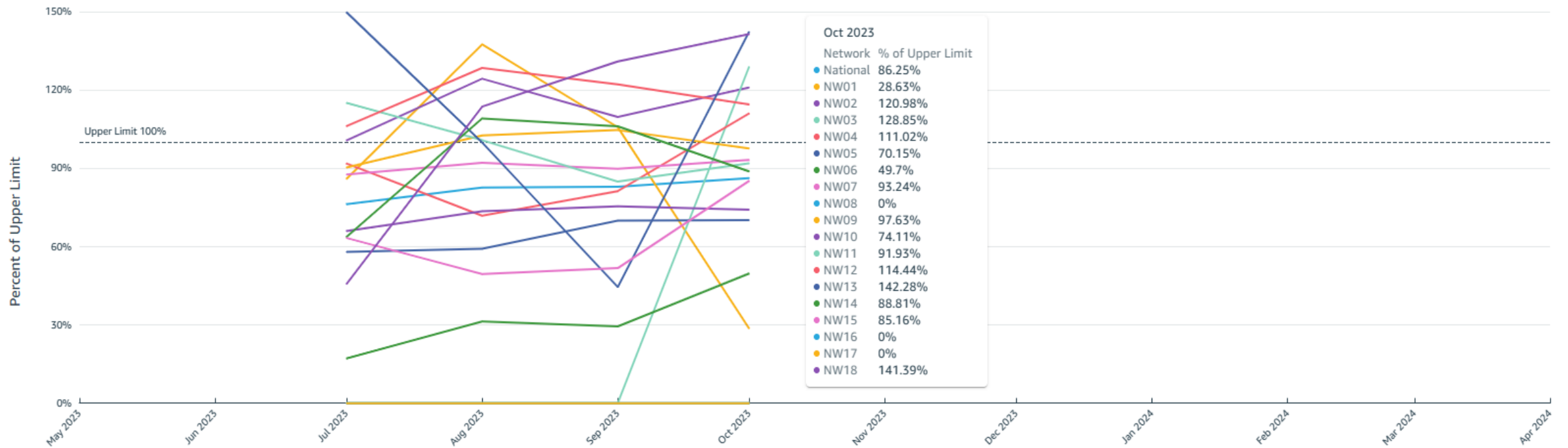
Vaccination - COVID-19 Patients Percent of Goal - By Month Option Period 2



* COVID and Influenza data unavailable

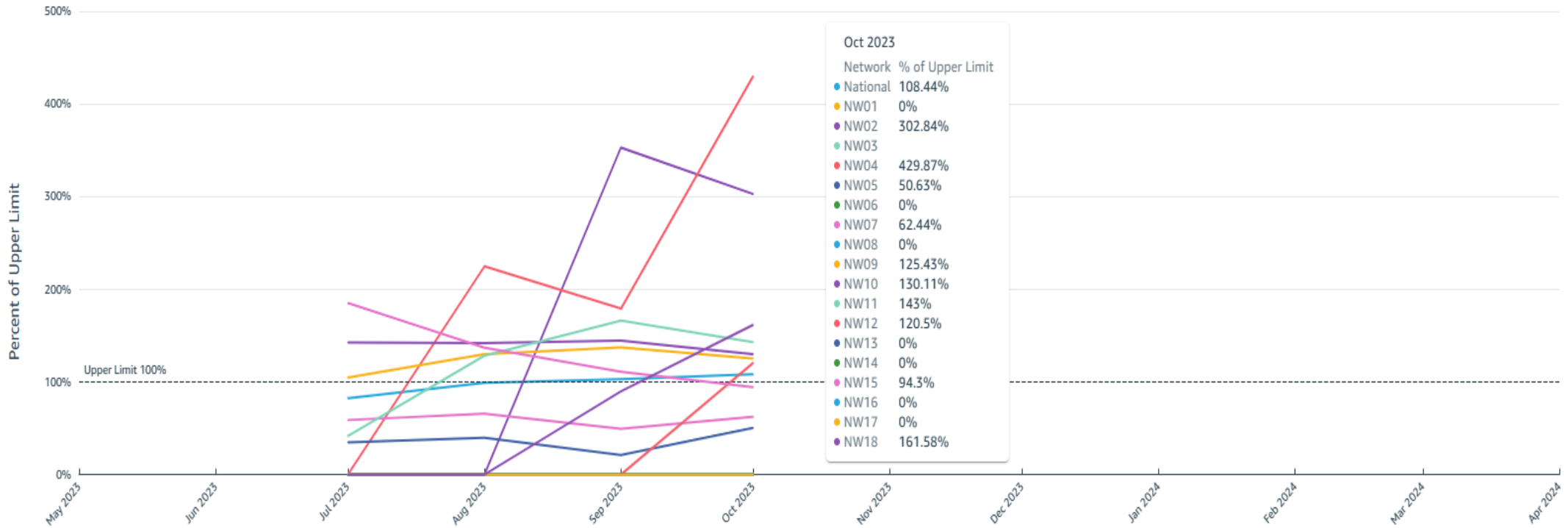
Nursing Home – Blood Transfusions

Blood Transfusion Relative Decrease Percent of Upper Limit



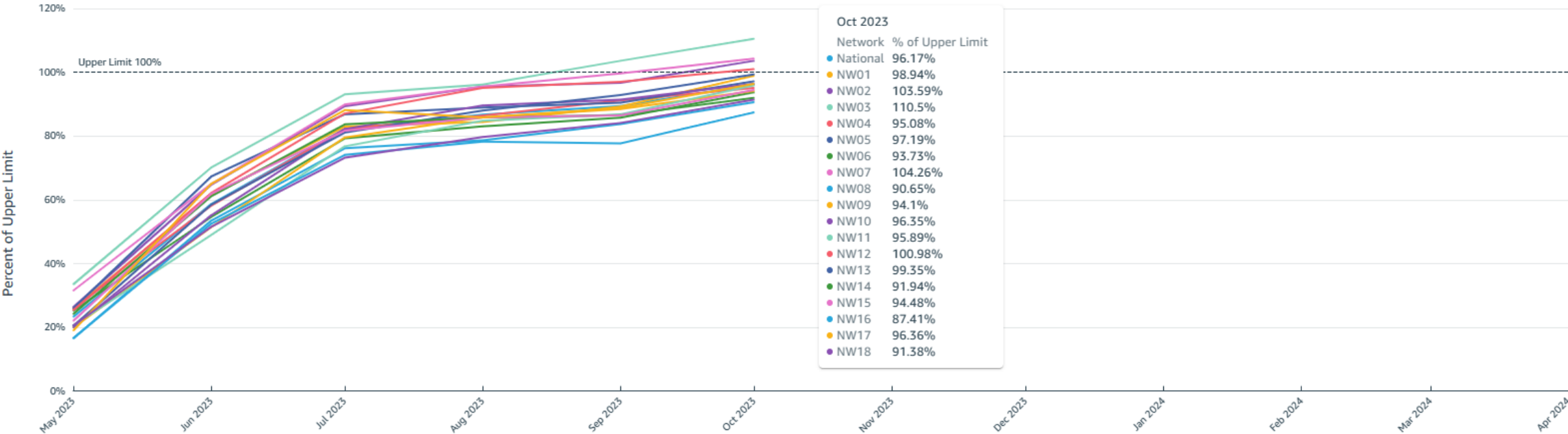
Nursing Home – Infections

Catheter Infection Relative Decrease Percent of Upper Limit



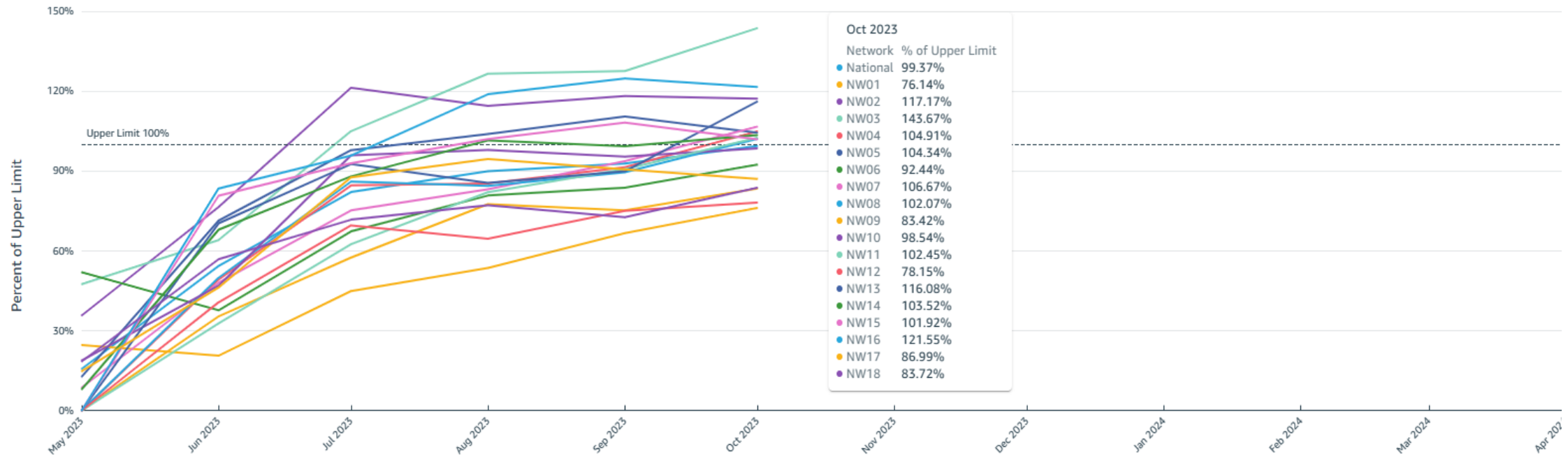
Hospitalization – Inpatient ESRD Admissions

ESRD Admissions Relative Decrease Percent of Upper Limit



Hospitalization – Unplanned Readmissions

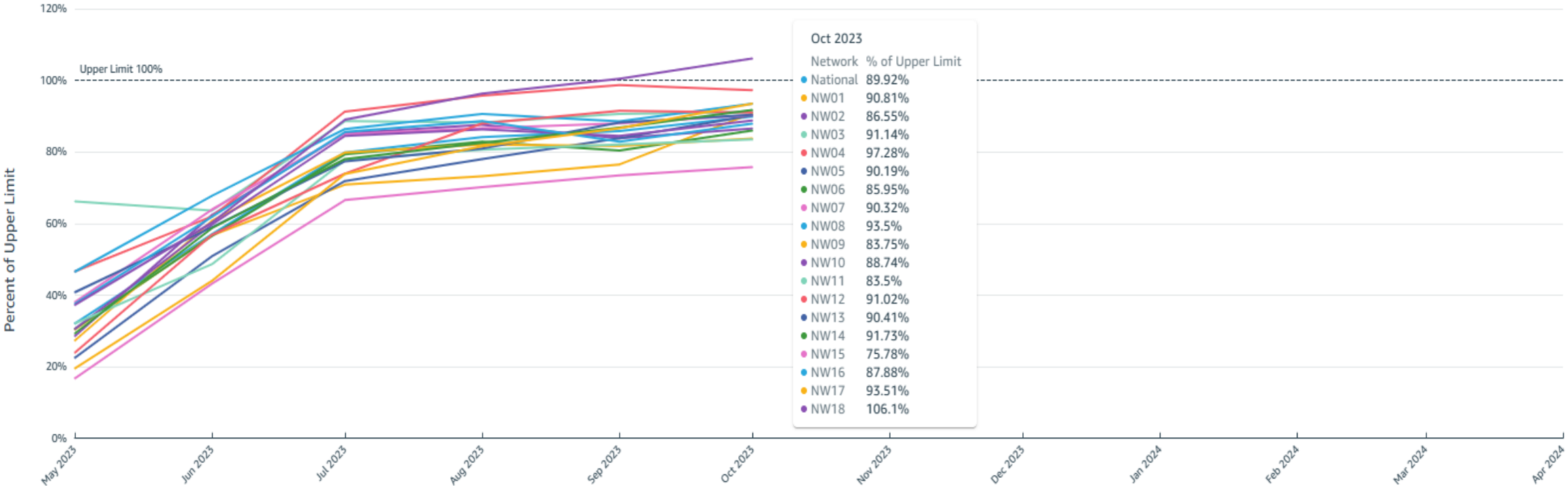
Unplanned Readmissions Relative Decrease Percent of Upper Limit



Unplanned Readmissions Data Table

Hospitalization – ED Visits

ED Visits Relative Decrease Percent of Upper Limit



EQRS Data Challenges & Barriers Unchanged



- New CDC definition of COVID-19 “up-to-date” vaccination
- Nursing home/date patient indicator does not capture history so infections/transfusions from past settings being added into data set
 - Networks suggested a date verification process of event to eliminate those incidents that occurred prior to nursing home placement. Temp solution; working with CMS on long-term solution
 - Nursing home baseline data has inaccuracies. If baseline zero, need to not exceed zero in OY2
- EQRS vaccination module moved, LDO EMRs just catching up. Monitor with influenza season.
- High home incident goal, while home programs keep closing
- 2728 forms older than 1 year past due difficult to track/complete

Summary

- Six months into contract and home incident, vaccination, nursing home, and hospitalization goals are not aligning with 6-month goals.
- EDs having ongoing discussions with CMS on vaccination and nursing home indicators due to ongoing data issues and changing goal indicators.
- DKH has started a measures committee to evaluate quality measure issues.
- EDAC/CMS meetings have been more engaging and focused on collaboration.
- On-site visits have been going well!

Questions?

Vicky Cash
vcash@ipro.org



MAC Report

Dan Landry, DO, FASN
Chair, MAC
ESRD Network 1

Medical Advisory Council (October 2023)



Chair: Daniel L. Landry, DO, FASN

Vice Chair: Preethi Yerram, MD, MS, FASN

Immediate Past Chair: Kam Kalantar-Zadeh, MD, MPH, PhD

Network 1: Daniel L. Landry, DO, FASN

Network 2: George Coritsidis, MD

Network 3: Keith Norris, MD, PhD

Network 4: Paul Palevsky, MD

Network 5: Marc Brazie, MD

Network 6: John J. Doran, MD, FASN

Network 7: Debra Hain, PhD, APRN, AGPCNP-BC, FAAN, FAANP, FNKF

Network 8: Martha Tankersley, MSN, RN

Network 9: Anne Huml, MD, MS

Network 10: Daniel Roseman, MD

Network 11: Louis Raymond, MD

Network 12: Preethi Yerram, MD, MS, FASN

Network 13: Laura Rankin, MD

Network 14: Donald Molony, MD

Network 15: Harmeet Singh, MD

Network 16: Christine Logar, MD

Network 17: Ramin Sam, MD

Network 18: Kam Kalantar-Zadeh, MD, MPH, PhD

Ad Hoc Member: Stephen Pastan, MD

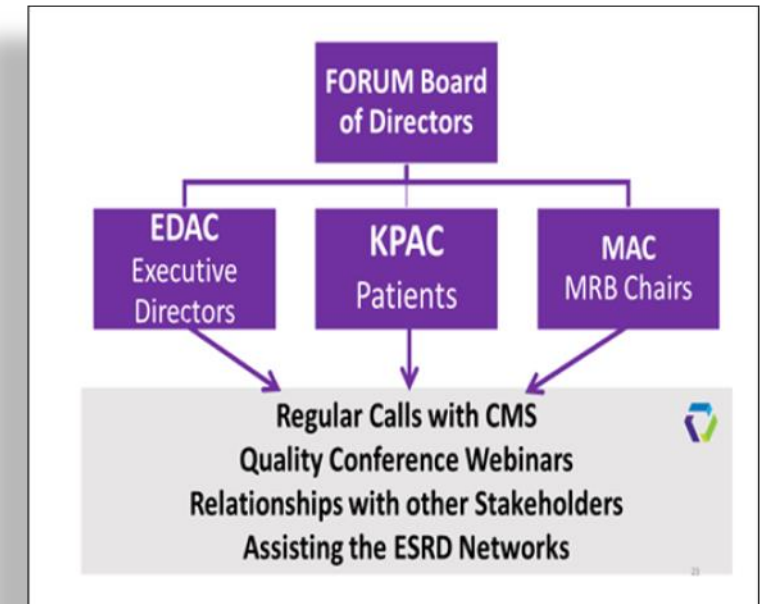
EDAC Rep: Sue Caponi, MBA, RN, BSN, CPHQ (1/2)

QID Rep: Barbara Dommert-Breckler, RN, BSN, CNN (16)

KPAC Rep: VACANT

MAC Mission & Scope

- The Medical Advisory Council (MAC) of the National Forum of the ESRD Network:
 - Provides a consistent interpretation from the *provider* perspective of the challenging issues faced by the ESRD Networks, Forum Board, and other stakeholders
 - Works with and through the ESRD Networks to generate QA/QI initiatives aimed at improving care of kidney patients



Annual MAC Conference: Philadelphia

Topic	Presenter
Welcome & Updates (5 min) <ul style="list-style-type: none"> Approval of 9/14/23 MAC Call Minutes 	Daniel Landry, DO
Guest Presentation (30 min) <ul style="list-style-type: none"> Improving Dialysis Care for Undocumented ESRD Patients 	Lilia Cervantes, MD
KPAC Report (15 min)	Dawn Edwards
MAC Vice-Chair: Meeting QIP Metric Goals at the Unit Level (15 min)	Preethi Yerram, MD
Open Discussion and Break (20 min)	MAC Members
EDAC Report (15 min)	Chris Brown
Forum's President and Board of Directors Updates (15 min)	Kam Kalantar-Zadeh, MD, MPH, PhD
2024 ESRD PPS Final Rule (15 min)	Andrew Howard, MD
MAC Chair Updates and Goals for 2024 (15 min)	Daniel Landry, DO
Open Discussion and Planning for 2024 (30 min)	MAC Members
Review of Assignments & Adjournment (5 min)	Daniel Landry, DO

- Q1 MAC Quarterly Conference Call: Thursday **March 1, 2023**
- Q2 MAC Quarterly Conference Call: Thursday **June 7, 2023**
- Q3 MAC Quarterly Conference Call: Thursday **Sep 14, 2023**
- Forum BOD Meeting: Fri/Sat **Sep 23-24, 2023**, Denver, CO
- Q4/Annual MAC Conference: Wed **Nov 1, 2023**, Philadelphia, PA
- ASN Kidney Week Meeting: **Nov 2-5, 2023**, Philadelphia, PA

Guest of Honor



Lilia Cervantes, MD, MSCS

- Undergraduate training at Colorado University, Boulder
- Medical degree and internal medicine residency at the University of Colorado School of Medicine
- Director of Immigrant Health
- Associate Professor for the Department of Medicine at the University of Colorado, Anschutz Medical Campus



Meeting QIP Metric Goals at the Unit Level

Preethi Yerram, MD

Forum MAC Meeting

November 1, 2023

MAC Mission & Vision for 2022-23

- Communication: with CMS, Networks
- Education: Toolkits, KPAC collaboration, RPA
- Delivery: Reaching our Network audience and other organizations (ASN, RPA, NKF, NCC)
 - Get to the training program directors and early-career nephrology providers
 - Value-based care through education and advocacy with CMS
 - Take back what we are doing to Network level

Updates from MAC Leadership

- Home Dialysis Toolkit 2nd edition publication
- Updates regarding Practicing Health Equity & Patient-Provider Collaboration in Kidney Care Toolkit
- Review of toolkit work over the last 4 years
- Response to CMS Proposed Rule
- Dialysis unit closures update
- Sharing Highly Effective Practices (SHEP)

Professional Toolkits

- Inpatient Medical Director Toolkit
- Kidney Transplant Toolkit
- Transitions of Care Toolkit
- Vaccination Toolkit
- Outpatient Medical Director Toolkit
- Home Dialysis Toolkit (2nd edition published online!!!)
- Catheter Reduction Toolkit
- QAPI Toolkit

Patient Toolkits:

- Health Equity Toolkit (in progress)
- Dialysis Patient Depression Toolkit
- Dialysis Patient Grievance Toolkit
- Financial Help Resources
- Kidney Patient Transplant Toolkit
- *Patient video providing an overview of the toolkit available at https://media.esrdnetworks.org/documents/Is_A_Kidney_Transplant_Right_For_Me.mp4; consider sharing with your patients!*

Congratulations to Dr. Sam

Oct 02, 2023

Dear Dr Sam,

Thank you for providing a revised version of "Vaccination for Patients Receiving Dialysis" to *Kidney Medicine*. We are pleased to inform you that we are satisfied that the concerns raised in the letter requesting revision have been appropriately addressed, and we have accepted this Review for publication, with the assumption

Congratulations to Dr. Palevsky

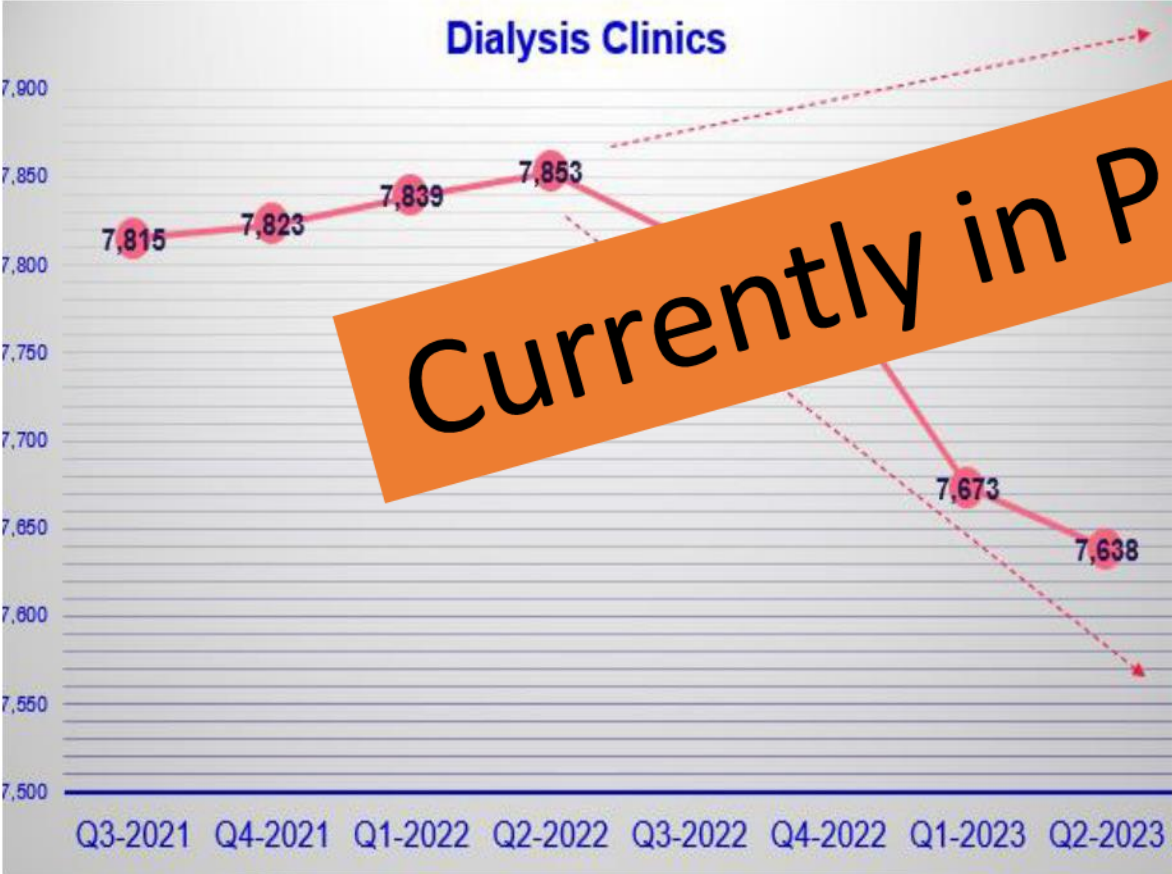
Needs and Considerations for Standardization of Kidney Disease Education in Patients with Advanced CKD

Ashutosh M. Shukla ^{1,2} Kerri L. Cavanaugh ^{3,4} Huanguang Jia ¹ Jennifer Hale-Gallardo ⁵
Anuradha Wadhwa ^{6,7} Michael J. Fischer,^{8,9} Scott Reule ^{10,11} Paul M. Palevsky ^{12,13} Linda F. Fried,^{12,13}
and Susan T. Crowley^{14,15}

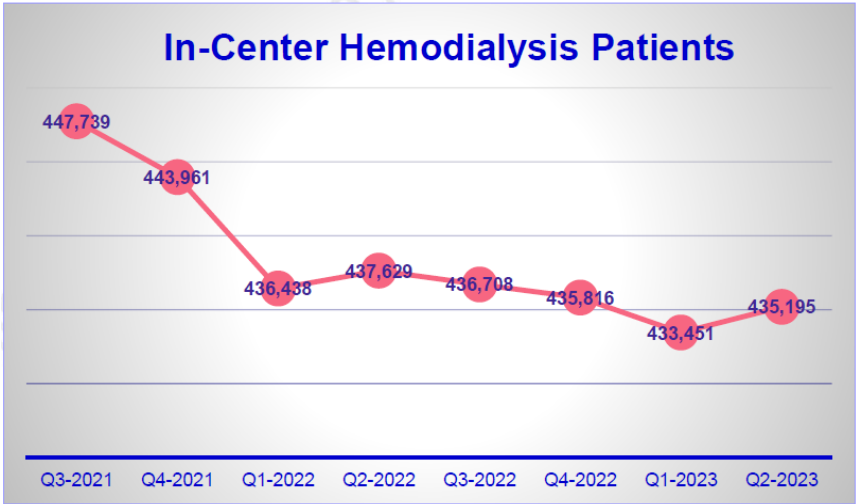
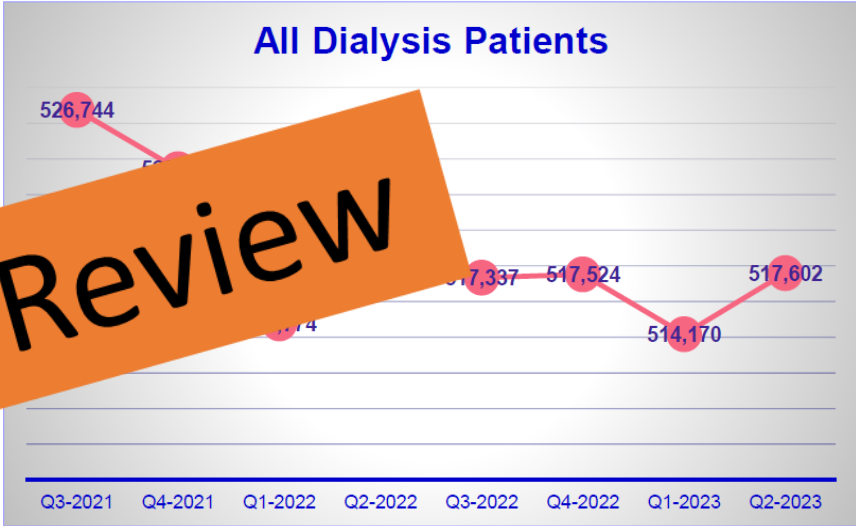
Dialysis Unit Closure Data

Clinical Journal of the American Society of Nephrology
 Closure of Dialysis Clinics in the USA: An Unprecedented Trend in the History of
 ESRD Program
 --Manuscript Draft--

Appendix Figure 1. Net growth vs closure of dialysis clinics, 2021-2023



Currently in Peer Review



Massachusetts State House - LDPA



2023

Home Dialysis Toolkit

Developed by the Forum of ESRD Networks
Medical Advisory Council (MAC)

This toolkit for health providers and practitioners is a reference tool that gives information about overcoming barriers to starting or growing a home dialysis program.

Thank You to Our Dedicated Authors



Daniel Landry, DO, FASN - Committee Chair

Baystate Medical Center
Kidney Care & Transplant Services of New
England
Springfield, Massachusetts
ESRD Network 1

Dawn Edwards

Kidney Patient Advisory Council Co-Chair
New York, New York
ESRD Network 2

David Henner, DO

Berkshire Medical Center
Pittsfield, Massachusetts
ESRD Network 1

Kam Kalantar-Zadeh, MD, MPH, PhD

Harbor-UCLA Medical Center
Los Angeles County Department of Health
Services
Los Angeles, CA
ESRD Network 18

Donald Molony, MD

University of Texas McGovern Medical
School
Houston, Texas
ESRD Network 14

Brianna Smith

Quality Improvement Coordinator
Comagine Health
Seattle, Washington
ESRD Network 16

Barbara Dommert-Breckler, RN, BSN, CNN

Quality Improvement Director
Comagine Health
Seattle, Washington
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Maria Story, MD, FACP, CHS

Southeast Iowa Regional Medical Center
West Burlington, Iowa
ESRD Network 12

Carry Holtkamp, RN, BSN

Southeastern Renal Dialysis
Mount Pleasant, Iowa
ESRD Network 12

Home Dialysis Toolkit Update

A Call to Action for Better Home Dialysis Support: A Wish List from the Kidney Patient Advisory Council

1. Make home dialysis programs accessible to all; if home therapies are truly to be an equitable option, they should be in underserved communities as well as affluent neighborhoods.
2. Training materials need to be translated into multiple languages.
3. Assistance for patients with financial needs should be provided for chairs, storage containers, minor adjustments to the home (e.g., 3-pronged outlets, sink adapters).
4. Every home program should have trained PCTs to assist nurses with
 - a. Patient training to reduce wait times
 - b. Patients adjusting to home therapy post training
 - c. Troubleshooting machine malfunctions
 - d. Performing equipment maintenance and testing
 - e. Providing emergency respite care after hospitalizations and illness
 - f. Staff-assisted treatment to patients who have been at home for years, and are now elderly and unable to perform treatments themselves
5. Treatment options education should be standardized and mandatory for *every patient* in a way that is measurable for every facility, even facilities without home therapy programs on-site. Home dialysis programs should be encouraged to partner with such facilities in order to make sure patients are able to receive these dialysis modality education options from experienced staff.
6. Every home patient should be provided with a peer mentor they can reach out to if the patient should so choose.
7. Home therapies should be a mandatory subject for all nephrologists and taught to all PCTs and in-center dialysis staff. Reassure staff that promoting patient modality choice is not only good for patients but also good for those who care for them. Given the ongoing growth of chronic kidney disease, job security for staff with your specialized skills is a certainty!
8. Home dialysis training rooms should not be in backrooms of in-center facilities. They should be clearly visible to in-center patients while providing the privacy and sanitation required.
9. For patients transitioning from in-center to home, some training should begin immediately after consent on the treatment floor to shorten training times and to keep the patient enthusiastic about going home.
10. Train physicians to provide “precision home dialysis,” as not all patients require the same prescription.

Chapter 1: Making Home Dialysis Success a Reality by Learning from the Life Experiences of our Patients



Dawn Edwards has had end-stage renal disease (ESRD) since 1992 and has been a devoted patient advocate to others on dialysis for decades. She joined the National Forum of ESRD Networks in 2018 and currently serves as co-chair of its Kidney Patient Advisory Council (KPAC). As the Forum discussed updating the home dialysis toolkit, we felt that a patient-centered approach was essential to helping providers and staff appreciate the life experiences of our patients to better serve them as we strive to make sure everyone is given the opportunity to be asked the question: “why not home”? This chapter is dedicated to the patient voice. Dawn Edwards shares her personal story of several different kidney disease transitions in her life and also offers a list of patient “demands” which she and her fellow KPAC colleagues felt must be met if we are to provide our patients with the best support.

Home Dialysis Toolkit Update

Table 2: Attainment of Entrustable Clinical Skills and Core Knowledge Recommended for Nephrologists Managing Kidney Patients on Home Dialysis (adapted from Gupta et al)

Peritoneal Dialysis	Home Hemodialysis
PD Catheter Management; Pre- and Post-Insertion: <ol style="list-style-type: none"> 1. Understand proper catheter insertion and location; and complications 2. Diagnosing and managing catheter failures 3. Diagnosis and management of failure to instill or drain PD fluid 4. Diagnosis and management of exit site, tract, or catheter infections / abscesses 	Procedural Skills: Understanding Key Components of Patient Training <ol style="list-style-type: none"> 1. Hemodialysis machine set up 2. Actions to be taken when alarms sound 3. Vascular access care and optimal techniques for cannulation 4. Physical examination of / clinical measures to monitor vascular access 5. Certification of patient skills to conduct HD
Prescription and Management of PD Procedure: <ol style="list-style-type: none"> 1. Understand the goals and limitations of CAPD /CCPD; tidal versus regular PD 	Prescription and Management of HD <ol style="list-style-type: none"> 1. Initiation of HD / or transition from in-center dialysis 2. Adjustment of prescription
Management of PD Prescription: <ol style="list-style-type: none"> 1. PD fluid volume, fluid composition and duration for: Initiation, Urgent start, maintenance PD 2. Urea Kinetics Measurement and Interpretation and adjustment of prescriptions to meet goals 3. Peritoneal equilibration Test 4. Management of patient volume and BP with PD net UF 5. Understand the role of alternate PD solutions 	Management of HD Prescription: <ol style="list-style-type: none"> 1. UF goals (UF rate), dialysate composition and duration for: Initiation, maintenance HD 2. Urea Kinetics Measurement and Interpretation and adjustment of prescriptions to meet goals 3. Home dialysis water treatment 4. Nocturnal Home dialysis
Diagnosis and Management of Complications of ESKD in Patient Managed with PD: <ol style="list-style-type: none"> 1. Dietary control of protein and electrolyte abnormalities; measurement and management 	Diagnosis and Management of Complications of ESKD in Patient Managed with HD: <ol style="list-style-type: none"> 1. Dietary control of protein and electrolyte abnormalities; measurement and management 2. Management of BP and intravascular/ total body fluid volume
Diagnosis and Management of Complications of PD: <ol style="list-style-type: none"> 1. Peritonitis and catheter site infections / prevention, diagnosis, and management 2. Management of exit site for proper maintenance of PD 3. Hypoalbuminemia and protein malnutrition 4. Hyperglycemia especially complicating diabetes management 5. Unintentional weight gain or loss 6. Hernia prevention, surveillance, and treatment 	Prevention, Diagnosis, and Management of Complications of HD <ol style="list-style-type: none"> 1. Calcium and mineral metabolism 2. Potassium mass balance and removal

Chapter 3: Overcoming the Barriers to Starting or Growing a Home Dialysis Program: Educating Clinicians and Medical Directors

Chapter Synopsis

- The Advancing American Kidney Health (AAKH) initiative was established by the federal government in 2019. It places a strong focus on home dialysis and transplantation.
- Home dialysis training during nephrology fellowship has not been a priority until more recently. This sub-specialized area of nephrology is critical to improving the quality of care provided by the nephrology community going forward in order to ensure that all patients are educated and offered access to all kidney replacement therapies.
- In this chapter, we identify and discuss how to overcome the many barriers to training nephrologists in home dialysis therapies, in addition to discussing different approaches that may help reduce physician burnout.
- We also discuss different programmatic and personnel considerations (which include staffing and administrative issues) that all nephrologists and home dialysis medical directors should consider when starting or maintaining a home dialysis program.

Home Dialysis Toolkit Update

Chapter 4: Emergency Management for the Home Dialysis Program

Chapter Synopsis

- Emergency preparedness for home dialysis requires communication and planning for both patients and staff.
- CMS Emergency Preparedness Requirements state that each program should include 4 major elements: risk assessment and emergency planning, policies and procedures, communication planning, and training and testing
- For home dialysis staff, emergency preparedness training, back-up communication planning, and coordination of patient care are critical aspects that must be provided to at both the general and individual level.
- For home dialysis patients, emergency preparedness means involvement with training and preparation with the home dialysis unit, continuous readiness with emergency and dialysis supplies, and planning for scenarios of when one *cannot* leave their home as well as when *must* leave their home.
- The National Forum of ESRD Networks works closely with the Kidney Community Emergency Response (KCER) during emergencies and are both important resources for up-to-date information, communication, and directed support.

Figure 6: KCER Coalition’s “Are You Prepared?” Emergency Go Bag Checklist

**Are You Prepared?
Get Your Go-Bag Ready Now!**

Hurricane, earthquake, flooding, fire, or even a pandemic like Coronavirus 2019 (COVID-19) can strike at any time. Take steps now to prepare yourself if disaster hits your home!

<p>Water and Food</p> <ul style="list-style-type: none"> <input type="checkbox"/> Emergency 3-Day Diet (see reverse) <input type="checkbox"/> Bottled water, cranberry, or apple juice <input type="checkbox"/> Non-perishable foods, canned: <ul style="list-style-type: none"> • Carrots, green beans, peas, corn, yellow squash • Unsalted peanut butter • Vanilla wafers • Applesauce • Fruit cup, drained • Low-sodium or no-salt added tuna, crab, chicken, salmon, or turkey 	<p>Health Documents</p> <ul style="list-style-type: none"> <input type="checkbox"/> Picture ID <input type="checkbox"/> List of medications <input type="checkbox"/> Treatment prescription details <input type="checkbox"/> Insurance/Medicare card <input type="checkbox"/> Copy of monthly lab results <input type="checkbox"/> Contact list of healthcare members/facility staff <input type="checkbox"/> Personal emergency contacts 	<p>Emergency Tools</p> <ul style="list-style-type: none"> <input type="checkbox"/> Face coverings <input type="checkbox"/> Disinfectant wipes <input type="checkbox"/> Flashlight <input type="checkbox"/> Manual can-opener <input type="checkbox"/> Spare glasses <input type="checkbox"/> Battery-powered radio <input type="checkbox"/> Cell-phone <input type="checkbox"/> Cell-phone charger <input type="checkbox"/> Warm blanket <input type="checkbox"/> Hand sanitizer <input type="checkbox"/> Whistle <input type="checkbox"/> Note pad and pencil <input type="checkbox"/> Disposable gloves <input type="checkbox"/> Medications (allergy) 	<p>Clothes and Toiletries</p> <ul style="list-style-type: none"> <input type="checkbox"/> Change of clothes appropriate for your climate <input type="checkbox"/> Sturdy shoes <input type="checkbox"/> Towel <input type="checkbox"/> Toilet paper <input type="checkbox"/> Toothbrush/toothpaste <input type="checkbox"/> Feminine personal hygiene supplies <input type="checkbox"/> Sunscreen
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Home Dialysis Toolkit Update

Chapter 6: Overcoming Barriers to Patient Success with Home Dialysis

Urgent Start

“Urgent start” PD (USPD) refers to the practice of initiating dialysis within two weeks of catheter placement. In patients requiring unplanned dialysis, it allows for the avoidance of central venous catheters, facilitates uptake of a home-based modality, and is considered cost-effective in both the short and long term (Liu 2014, Lok 2016). Use of PD as a first modality choice in patients newly dependent on chronic dialysis, most often in the hospital setting, also allows patients without other resources immediate coverage by Medicare. Urgent placement of PD catheters can be performed either by open-surgical or laparoscopic techniques or percutaneously using peritoneoscopic or fluoroscopic guidance depending on local expertise. Patients are generally initially dialyzed with low volumes (500 to 1000 mL) every 1-2 hours in the supine position. Gradual increases to full volume and postural freedom are usually achieved within two weeks (Ghaffari, 2013). PD can be done with a cycler or by manual exchanges. Because of the low volume of dialysis, patients typically need to produce at least 500 mL of urine per day and a residual urea clearance of 5 mL per minute in order to avoid complications of underdialysis.

If PD is urgently started in the hospital, the patient is immediately referred to the home training program upon discharge; initial outpatient PD “runs,” usually CCPD-driven, are performed during working hours in the home training center, and the patient can be simultaneously or intermittently instructed in the performance of his own dialysis. Planning for an urgent start program requires nursing input for staff training and protocol/procedure development (Ghaffari, 2013). The accepting program needs to have sufficient staff, as well as a fully reclining chair or bed, along with the room to offer PD and training with little advance notice, while meeting the needs of previously scheduled patients for training and outpatient visits.

Starting a Rural Home Hemodialysis Program

Maria Story, MD, FACP, CHS, and Carry Holtkamp, RN, BSN

Rural home dialysis programs face multiple challenges, especially when one considers issues regarding patient accessibility and access to services. Both patients and staff may drive many miles to dialysis clinics. For patients who qualify for transportation assistance, coordinating transportation to and from rural homes (which may be on gravel roads and in poor condition during winter months) to the dialysis clinic is another challenge.

Home hemodialysis (HHD) can help reduce many of these barriers. For the appropriately selected patient, performing hemodialysis at home can be life changing. For the purposes of our experience (which only offers one specific home modality), HHD significantly reduces travel time to and from the dialysis clinic while also helping decrease the chance of missed treatments due to inclement weather, poor road conditions, or other unforeseen circumstances. For instance, prior to our opening a HHD program, there was an alternate HHD program approximately 75 miles away from our clinic, but this was not accessible to the vast majority of patients due to the amount of time required to travel to and from the clinic for training and monthly doctor visits.

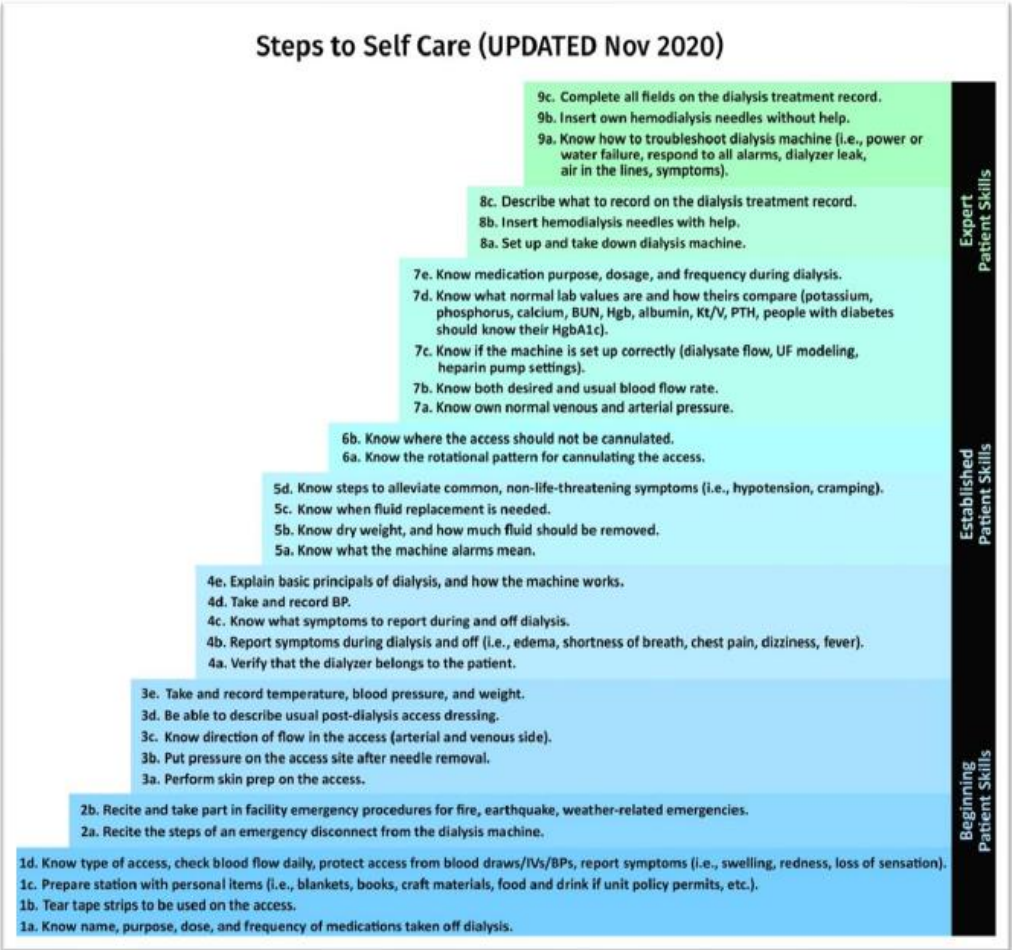
Our dialysis organization, Southeastern Renal Dialysis, is located in southeast Iowa, and there are five clinics, each approximately 30 miles apart. The central location is the small town of Mount Pleasant (population 9000, 2020 data), and is located 50 miles from Iowa City, IA, 85 miles from Davenport, IA, 135 miles from Des Moines, IA, 210 miles from St. Louis, MO, and 260 miles from Chicago, IL. Our other clinics are located in Fairfield, West Burlington, Fort Madison, and Keokuk, IA and cover seven counties, with a total population of approximately 150,000 individuals covering nearly 3,300 square miles. Our organization offered peritoneal dialysis (PD) for many years, but due to interest voiced by patients, our organization began a HHD program in 2022.

Following are some steps that our organization took to build and sustain a successful dialysis program. We recognize that not every point will be applicable to all readers, but nevertheless, we felt these to be the most important takeaways from our experience.

Steps in Starting a Rural Home Hemodialysis Program

Home Dialysis Toolkit Update

Figure 7: Recommended Steps to Achieve Patient Proficiency in Dialysis Self-care



Chapter 7: Transitional Dialysis Care Units

Chapter Synopsis

- Transitional dialysis care (TDC) is a term more recently used to describe the provision of hemodialysis to dialysis patients using home equipment in an in-center setting, supplemented with thorough patient education on the psychosocial issues associated with dialysis, as well as nutrition and vascular access.
- TDC units provide education over several weeks to patients and caregivers regarding dialysis modality options as well as transplant referral during a critical transition period from chronic kidney disease to end-stage renal disease. Such units can either intermingle with the dialysis unit's in-center hemodialysis program or be physically separated.
- A key aspect to a successful TDC program is a robust educational curriculum that offers dialysis patients all dialysis modality opportunities through a shared decision-making process.

What is Transitional Dialysis Care?

Forum MAC Health Equity Toolkit



Most recent Health Equity Toolkit Meeting 11/27/2023

Members: Dan Landry DO, Kam KalantarZadeh MD, Debra Hain APRN, Elizabeth Witten (Social Worker), John Wagner MD, Kelly Mayo (NCC), Don Molony MD, Chaio Wen Lan PhD (NCC), Keith Norris MD, Barbara Dommert-Breckler RN, Dawn Edwards (KPAC), Amaka Eneanya MD (FKC), Lilia Cervantes MD (Univ Colorado), and Sarah Hendry

Forum MAC Health Equity Toolkit TOC



Glossary of Terms: We discussed tonight consideration for a glossary of important terms in beginning of toolkit followed by use of “key terms” that are more chapter specific in place at beginning of each chapter (please see Chiao’s chapter work for examples of the latter)

Chapter 1: Defining the Problem: Discussing the Many Forms of Healthcare Inequity

K. Norris, KKZ

Chapter 2: Social Drivers of Health in Kidney Care

D. Landry, Chaio Wen Lan

Chapter 3: Detecting Disparities in Kidney Care

Barbara Dommert-Breckler, Chaio Wen Lan

Chapter 4: The Challenges Faced by Immigrants with ESKD in the U.S.

D. Molony and ASN/Dr. Cervantes

Chapter 5: Promoting Patient Engagement and Health Literacy in Kidney Care

D. Forfang and D. Landry

Chapter 6: Causes and Consequences of Involuntary Discharges from Dialysis Clinics

D. Molony, D. Hain, B. Witten

Chapter 7: Creating a Safe Environment for Patient-Provider Collaboration and Seeking Solutions during Patient-Provider Disagreement

KPAC using examples of lived experiences; Kelly Mayo

Chapter 8: Implementing and Practicing Health Equity

Chaio Wen Lan, Nephrology Social Workers who meet with Kelly

Chapter 9: Making Best Use of Resources and Sharing Highly Effective Practices: Suggested Approaches and Solutions

Dawn/Rogosin will describe how their “home ambassador” program

CMS Proposed Rule CY 2024



FORUM OF END STAGE RENAL DISEASE NETWORKS

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Dawn Edwards
Jamaica, NY

August 23, 2023

The Honorable Chiquita Brooks-LaSure
Administrator
Centers for Medicare & Medicaid Services
Department of Health and Human Services
Attention: CMS-1768-P
Mail Stop C4-26-05
7500 Security Boulevard
Baltimore, MD 21244-1850

Re: CMS-1782-P: Medicare Program; End-Stage Renal Disease Prospective Payment System, Payment for Renal Dialysis Services Furnished to Individuals with Acute Kidney Injury, End-Stage Renal Disease Quality Incentive Program, and End-Stage Renal Disease Treatment Choices Model

Dear Administrator Brooks-LaSure:

The National Forum of ESRD Networks appreciates the opportunity to comment on the changes proposed in CMS-1782-P. We are aware of the continued importance of the QIP and ETC model in the Advancing American Kidney Health (AAKH) initiative and recognize the intent of the proposed rule to promote excellence. We have primarily limited our comments to those sections of the proposed rule that specifically relate to renal dialysis services insofar as they

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Forum Position Papers, Press Releases & Public Comments

[Forum Comments to CMS Re: CMS-1782-P Medicare ESRD PPS \(August 2023\)](#)

[Forum Comments to PQM Re: Spring 2023 Quality Measures \(June 2023\)](#)

[Forum Comments to NQF Re: Renal Measures \(September 2022\)](#)

Sharing Highly Effective Practices (SHEP)

- Five submissions approved to-date
 - Monthly Chairside IDT Meetings
 - COVID-19 Communication Between SNF/PCH & Dialysis Facilities
 - Second Chance: A 90-Day Trial Basis Program
 - Transplant Patient Checklist
 - ***NEW*** Emergency Preparedness Community Drill

<https://esrdnetworks.org/education/sharing-highly-effective-practices-in-the-kidney-community/approved-highly-effective-practices/>

Approved Highly Effective Practices

Monthly Chairside IDT Meetings - Patient Engagement [01/16/2020]

[Monthly Chairside IDT Meetings.pdf](#)

COVID-19 Communication Between SNF/PCH & Dialysis Facilities - Communication [06/19/2020, Updated 07/30/2020]

**** Update 03/22/2021 **** Version 2.0.3 below has been updated to include COVID-19 Vaccination Status and to new CDC guidelines regarding when to discontinue transmission-based isolation.

[Update 07/30/2020] *The 3 original forms referenced in this project have been replaced with an updated version which has been endorsed by several Nursing Home organizations.*

[COVID-19 Communication Between SNF-PCH & Dialysis Facilities V2.pdf](#)

[LTCF-Dialysis COVID-19 Communication Form v2.0.9.pdf](#)

Second Chance: A 90-Day Trial Basis Program - Involuntary Discharge Access to Care [06/16/2020]

[Second Chance - A 90-Day Trial Basis Program.pdf](#)

[No Fault Letter Trial Basis Generic.pdf](#)

[Expectations of Treatment Agreement.docx](#)

[Policy - Trial Basis Placement for IVD Patients FINAL.pdf](#)

Kidney Transplant Checklist [06/02/2023]

[Kidney Transplant Checklist Overview](#)

[Kidney Transplant Checklist \(English\)](#)

[Kidney Transplant Checklist \(Spanish\)](#)

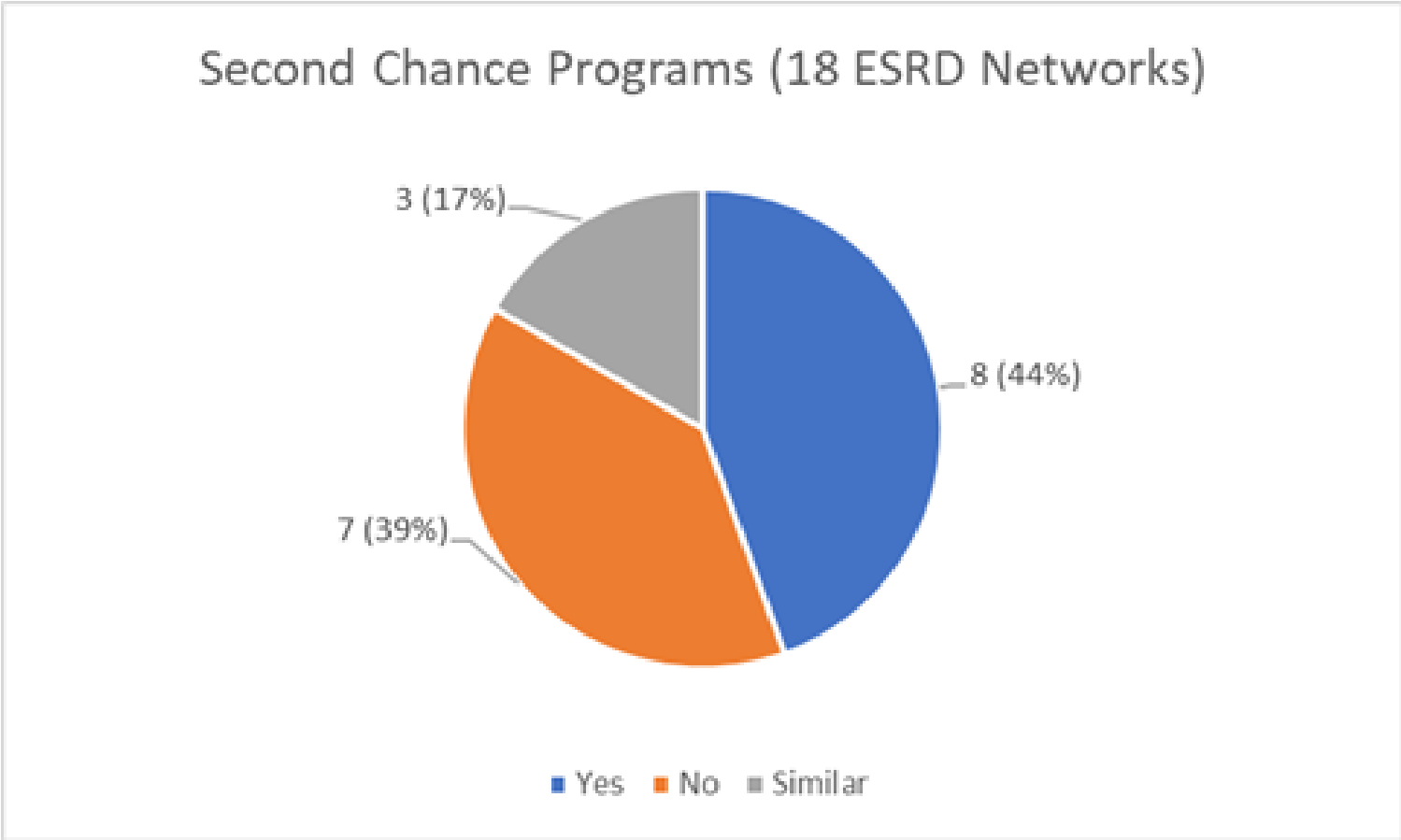
Congratulations!

Latest SHEP Submission Approved!

Emergency Preparedness Community Drill

- Conducted full-scale emergency preparedness drills including dialysis staff, volunteer mock patients from the community, hospital emergency department, and local EMS, police, and fire department.
- Helped to educate the fire department, ambulances, and police about the unique needs and circumstances of dialysis patients and the dialysis facility.
- The volunteer mock patients each had mock accesses including catheters or AV accesses, and the staff had to practice quickly getting patients disconnected from dialysis and evacuating patients in their dialysis chairs.
- Each mock volunteer patient had a unique situation that they were given ahead of time and played to help drill the dialysis staff.

Second Chance Program Participation



MAC Vision & Goals for 2023-24

- Communication: with CMS, Networks
- Education: Toolkits – Health Equity, ? APP
- Delivery: Reaching our Network audience and other organizations
- Ensure the growth and vitality of the Forum
 - Share your accomplishments with the Forum
 - Outreach and education to early-career nephrology providers
 - Take back what we are doing to the Network level

Questions?

Dan Landry, DO, FASN
daniel.landry@baystatehealth.org



Treasurer's Report

Stephanie Counter, MBA

Treasurer

ESRD Network 16

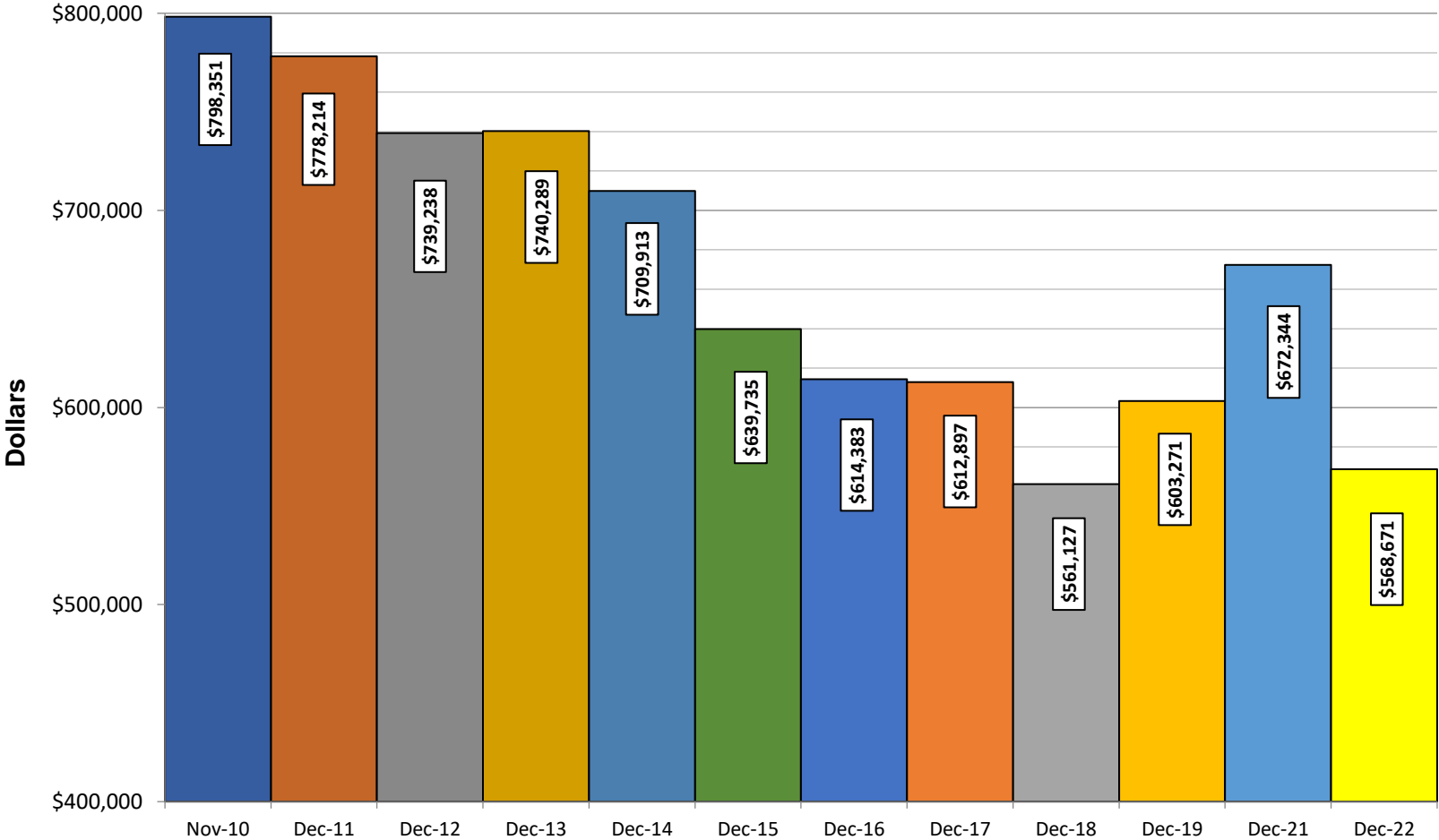
Balance Sheet



	(as of 11/30/2023)	(as of 11/30/2022)
Chase Bank Checking	\$8,207.09	\$ 3,161.28
Chase Bank Savings	10,124.43	6,123.45
PayPal	6,244.71	532.05
Investments	<u>556,606.24</u>	<u>563,714.76</u>
Total Assets	\$581,182.47	\$ 572,999.49

Forum Finances over Time (November 2010–December 2022)

**Forum Finances Over Time
November 2010 – December 2022**



Finance Committee Update

- 990 filed and accepted by the IRS
- 2024 budget being drafted
- Resource Development

“The Forum will diversify its revenue sources and increase over asset base by 10% in the next 2 years in order to sustain Forum activities and reduce deficit budgeting.”

- Semi-annual appeal
- Marketing Donate button (recognition, memorials)
- Derek Forfang Memorial Fund (<https://esrdnetworks.org/donate/>)
- Grants
- Include patient stories and utilize social media marketing

Questions?

Stephanie Counter, MBA
shutchinson@comagine.org



Final Thoughts

Q&A

On the Horizon in 2024

- Advancing American Kidney Health
- Focus on enhancing social media presence
- Updates to MAC Toolkits and development of 3 new MAC Toolkits
- New KPAC Toolkits
- Actively pursuing additional financial resources to support Forum/Network activities
- Sharing Highly Effective Practices in the Kidney Community: consider submitting a best practice to the Forum's new community education resource

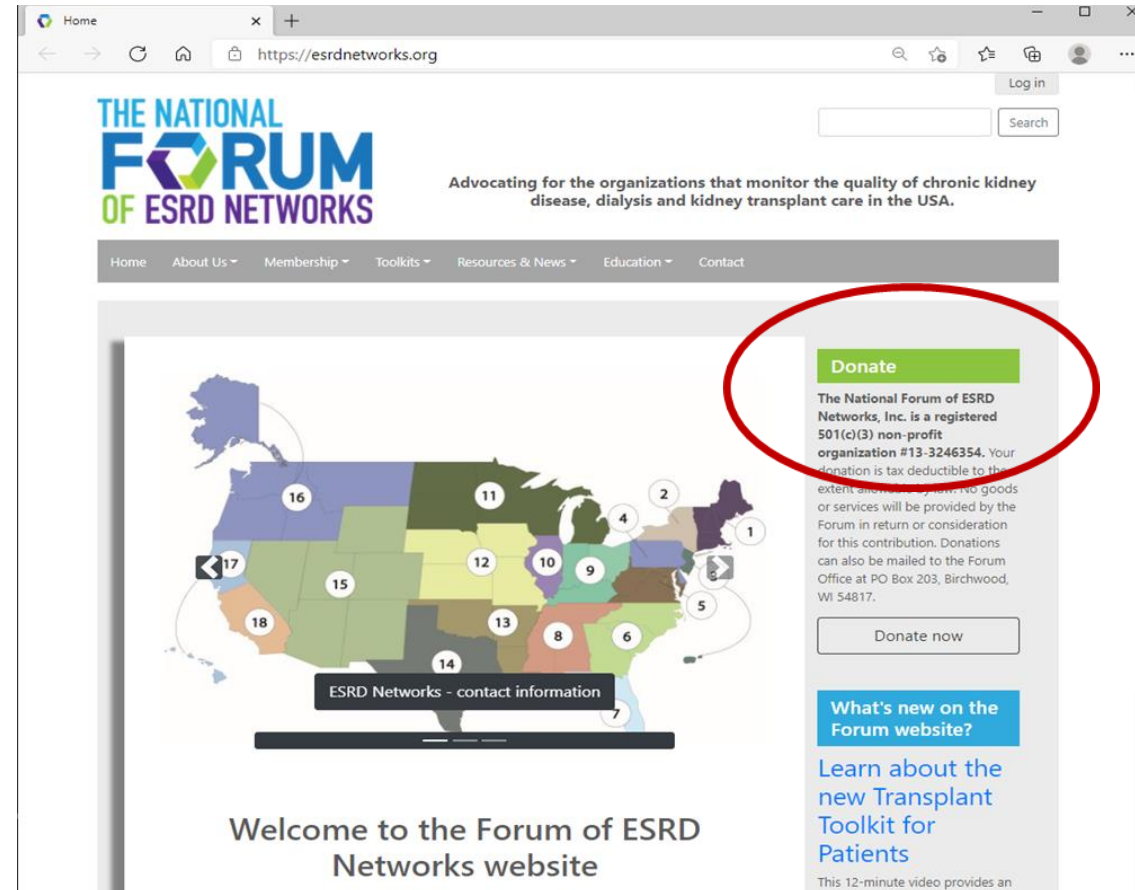
<https://esrdnetworks.org/education/sharing-best-practices-in-the-kidney-community>

Derek Forfang Memorial Fund

The Forum has established the Derek Forfang Memorial Fund to honor Derek's legacy. The Fund will support the work of the Forum's KPAC. Make your tax-deductible donation today at <https://esrdnetworks.org/donate/>.



Donate Online!



<https://esrdnetworks.org/donate/>



Advocating for the organizations that monitor the quality of chronic kidney disease, dialysis and kidney transplant care in the USA.

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Donor Wall

A gracious "Thank you" to all of our donors, big and small, who are making a difference in the life of a kidney patient!

With more than 75 engaged volunteers actively involved in identifying gaps in care and filling those gaps, the Forum has developed both patient and provider centered resources. Through the generous donations from the community, we will continue this work. What is the community saying about these resources?

- "Good info graphics and something for every staff member in the dialysis clinic." ~Corporate VP in Dialysis, about the Kidney Transplant Toolkit
- "The information is geared to improving the health and safety of patients with ESRD." ~Dialysis Social Worker, about the Kidney Transplant Toolkit
- "It gives a new way to look at things. We need to make sure we continue to meet patient needs." ~Dialysis Nurse, about the Transitions of Care Toolkit

Thank You to all of our Generous Donors in 2021
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esrdnetworks.org/donor-wall/

Donate

The National Forum of ESRD Networks, Inc. is a registered 501(c)(3) non-profit organization #13-3246354. Your donation is tax deductible to the extent allowable by law. No goods or services will be provided by the Forum in return or consideration for this contribution. Donations can also be mailed to the Forum Office at PO Box 203, Birchwood, WI 54817.

[Donate now](#)

What's new on the Forum website?

[Learn about the new Transplant Toolkit for Patients](#)

This 12-minute video provides an overview of the Toolkit

[Is A Kidney Transplant Right for Me?](#)

[COVID-19 vaccination flyer for Dialysis patients](#)

Please share this flyer with your dialysis patients

[Resources & Links for Kidney Patients](#)

Questions?

**Use the Chat feature
on your Zoom panel
to submit your questions.**

All unanswered questions will be reviewed by our speakers;
they will be summarized in a Q&A document
which will be posted to the Forum website.



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<https://www.linkedin.com/company/national-forum-of-esrd-networks-inc>



<https://www.youtube.com/channel/UC9Vp4Hfu7VmSTbSwG7-6e2g>

Sharing something about the KPAC? Use #KPACPatientVoice

Questions / Comments:
Kelly Brooks, Forum Coordinator
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