

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.

Forum Matters

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Forum Coordinator

Dee LeDuc
PO Box 203

Birchwood, WI 54817
(715) 354-3735

forumcoord@centurytel.net

www.esrdnetworks.org

Since the last issue:

- During the Winter Board of Directors meeting, members recognized the dedicated volunteer service of the following current and past members:
 - ◇ Maggie Carey: stepped down as KPAC Chair after 4 years of leadership, we are happy to report Ms. Carey continues to serve as Network 11 representative to the KPAC
 - ◇ Jay Ginsberg, MD, MMM, Cindy Kristensen, MD, and Jenny Kitsen BA, have stepped down as co-chairs of the Quality Conference Planning Committee after a combined 19 years of leadership service as co-chairs, committee members and presenters.
 - ◇ Judith Kari and William McClellan recently retired and were also recognized for their many years of service to the Forum and ESRD Network program.

The Forum wishes to acknowledge Ms. Carey, Dr. Ginsberg, Dr. Kristensen and Ms. Kitsen for their dedicated service to the Forum. Thank you!

- Call for Board Members! **Elections** of the Board of Directors will take place this spring. Forum members will be formally contacted in May to solicit nominations for the President-Elect, Treasurer, and two (2) Member-At-Large positions. Please contact [Dee at the Forum Office](#) if you are interested in serving on the Forum Board.
- Members of the Forum's Board of Directors met in Atlanta on February 24-25, 2017, for the **Winter Board Meeting**. A 1-page bulleted summary highlighting the discussion topics and the President's Message slide set are available for your review. Please contact the [Forum Office](#) for more information.
- The Forum's **Medical Advisory Council** will convene their annual meeting on November 1, 2017, in New Orleans immediately prior to the ASN Kidney Week Conference. More information will be available at the Forum website this summer.
- **Dialysis Patient Grievance Toolkit Recognized by CMS Leadership:** Derek Forfang, KPAC Chair, was invited to present the new Dialysis Patient Grievance Toolkit during the February monthly AIM 1 Community of Practice call with ESRD Networks. The goal of the toolkit goes beyond grievances, the primary goal of the toolkit is to promote and improve communication. CMS leaders expressed a desire to have the toolkit in the hands of all kidney patients. [Please share the toolkit](#) with your colleagues and patients.
- **Dialysis Patient Grievance Toolkit** is now available in **Spanish** and can be downloaded from the [Forum website](#).

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- **Forum's Quality Conference Webinar Series:** Plans are underway for the 2017 webinar, check the Forum website this summer for more information. Volunteers are always welcome on the planning committee; contact [Dee at the Forum Office](#) if you'd like to learn more.
- **During recent calls between Forum and CMS leadership** the following topics were discussed:
 - ◇ CMS leaders reported that as part of the usual transition of new White House Administration, a "policy team" has been established and a number of meetings have taken place between leaders of CMS and DHHS.
 - ◇ Tom Duvall, MBA, CMMI, presented an update on the [ESCO Project](#) noting a detailed evaluation report will be produced and made available this summer.
 - ◇ The QIO 12th SOW is under development. CMS has convened calls/meetings with federal partners to gather comments. Opportunities for public comment are anticipated to begin later this year. ESRD Networks and the Forum were encouraged to offer input related to CKD and AKI.
 - ◇ Discussions continue around the issue of AKI patients dialyzing in outpatient ESRD facilities. In particular, concerns regarding the receipt of grievances from AKI patients and AKI data inadvertently included in NHSN data received by Networks from facilities.
 - ◇ Forum leaders also continue to engage CMS leaders in discussions regarding the ESRD Network AIM 2 Projects (the definition and 75% threshold for home and transplant referral).

Forum Members In The Community

- **Network 5 Receives Grant:** "The Gordon and Betty Moore Foundation has awarded Mid-Atlantic Renal Coalition (MARC) a 15-month grant to support the development of evidence-based best practices for delivering person-centered palliative care to patients with chronic kidney disease. The program, named the Pathways Project, will develop tools to establish pathways to conservative non-dialytic management, palliative care throughout the continuum of kidney disease, and dialysis withdrawal for those patients who choose to stop dialysis."
- **Derek Forfang** received the [National Kidney Foundation's](#) Celeste Castillo Lee Patient Engagement Award. This new award is given to a distinguished kidney patient who exemplifies NKF and Celeste's mission of putting patients at the center of all aspects of healthcare through their involvement with NKF and community partners.

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Forum Members In The Community, Cont'd

- **KPAC Members Attend CMS Quality Conference:** Stephanie Dixon (Nw 2), Allen Nelson (Nw 4), and Maggie Carey (Nw 11), Forum KPAC members, were invited to attend the CMS Quality Conference in Baltimore, MD, in December 2016. These KPAC members were also presenters during plenary and breakout sessions at the conference.



CMS Quality Conference, Baltimore, MD, December 2016

Press Release : MARC, Richmond, VA, March 20, 2017

The **Coalition for Supportive Care of Kidney Patients (CCKP)** is pleased to announce the release of two new tools to assist patients and their kidney care teams in advance care planning. The brochure, *Planning Today for Tomorrow's Healthcare: A Guide for People with Chronic Kidney Disease*, introduces patients and their kidney care teams to the process of advance care planning. It details the five steps of planning that allow patients to have control over their healthcare in the event that they cannot speak for themselves. The companion *Curriculum Guide for Advance Care Planning* is designed to assist facility staff in having advance care planning discussions with patients.

These tools were developed as part of the MY WAY Project, which seeks to test the impact of advance care planning coaching on outcomes and health service utilization of patients with chronic kidney disease. Although advance care planning discussions are associated with improved care, only a small percentage of dialysis patients have an advance care plan, according to the project's principal investigator Dale Lupu, PhD. The project, which is funded by The Patrick and Catherine Weldon Donaghue Medical Research Foundation, is being conducted by The George Washington University Center for Aging, Health & Humanities, with CCKP serving as a sub-awardee.

To learn more about CCKP, visit <http://kidneysupportivecare.org>.