Coalition for Supportive Care of Kidney Patients

www.kidneysupportivecare.org
About the Coalition

The Coalition for Supportive Care of Kidney Patients (CSCKP) brings together like-minded people who care deeply about the quality of compassionate, supportive care for kidney patients. We are professionals from many disciplines and laypersons who are working for true patient-centered care that values quality of life.

Mission

Promote effective interchange among patients, families, healthcare professionals, and payers to ensure the provision of patient-centered supportive care for patients with kidney disease.

Vision

Offer palliative care to everyone with chronic and end-stage kidney disease, from the time of diagnosis through the end of life and bereavement. Informed, supported patients and families receive the care they want.
Priority Areas

Goal
Create culture change that transforms the treatment of persons with kidney disease, putting every patient at the center and integrating palliative principles and practices throughout the care continuum.

Priority Areas

- **Education**: Pursue development and deployment of educational offerings for healthcare professional team members and patients/families
- **Quality, Advocacy, and Policy**: Improve quality of care under the umbrella of the 3 Aims and the National Quality Strategy
- **Research**: Foster conditions for conducting research that meets supportive kidney care research agenda
Membership

- Almost 500 US and international members

<table>
<thead>
<tr>
<th>Countries Represented</th>
<th>Stakeholders Represented</th>
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<tbody>
<tr>
<td>United States</td>
<td>Kidney and palliative care professional societies</td>
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<tr>
<td>Canada</td>
<td>Organizations of kidney patients and advocates</td>
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<td>Australia</td>
<td>ESRD Networks</td>
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<td>Taiwan</td>
<td>Dialysis provider organizations</td>
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<tr>
<td>India</td>
<td>Hospitals and universities</td>
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<td>Saudi Arabia</td>
<td>National Institutes of Health</td>
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<td>United Kingdom</td>
<td>National hospice and palliative care organizations</td>
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<td>Germany</td>
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<td>Colombia</td>
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Education

Resources

- **Medicare Hospice Benefit & ESRD Patients** flowchart for professionals


- **Planning Today for Tomorrow’s Healthcare: A Guide for People with Chronic Kidney Disease** brochure for patients

- American Nephrology Nurses Association (ANNA) **Palliative Care Module** for nurses caring for dialysis patients
Education

Resources

- *Treating Pain in Late CKD & Dialysis Patients: Clinical Algorithm & Preferred Medications* brochure for professionals (revised 11/2016)
Education and Research

Publications in the Field


Education and Research
Publications in the Field


Education and Research

Pending Publications in the Field

- **NIH Funding for Palliative Care Kidney Research** article by Dale Lupu and Jacob Bernhardt for *Journal of Palliative Medicine*


- Arnella C, Von Roenn, J, Lupu, D. **Lessons learned from oncology: A template for incorporation of palliative care into core clinical concepts of other medical specialties.**
Education

In 2017...

- Coalition leadership/membership to present *Supportive Care in Nephrology: Teaching the Clinician, Treating the Patient* pre-conference course at NKF Spring Clinical Meetings (April 2017)
Quality, Advocacy, & Policy

- Coalition Steering Committee members Nancy Armistead, MPA, and Louis Diamond, MB, ChB attended the NHPCO’s Congressional screening of the PBS/Frontline documentary, *Being Mortal*, based on Dr. Atul Gawande's best-selling book of the same name.

- Ms. Armistead and Dr. Diamond met with Senator Mark Warner's (D-VA) office to express the Coalition's support for *The Care Planning Act*, Senator Warner's and Senator Johnny Isakson's (R-GA) bipartisan legislation designed to provide people with serious illness the freedom to make more informed decisions about their care and the power to have those decisions honored.

- Dale Lupu attended the National Academy of Medicine’s private workgroup meeting on *Assessing Progress in End-of-Life and Serious Illness Care*
Research

Grants

- Funding from the **Patrick and Catherine Weldon Donaghue Medical Research Foundation** awarded to George Washington University with the Coalition serving as a sub-awardee.

- The **MY WAY (Make Your Wishes About You) Project** will test advance care planning with patients with advanced kidney disease.

- Three clinical sites are also serving as sub-awardees:
  - Jane Schell, MD-University of Pittsburgh Medical Center Kidney Clinic
  - Jennifer S. Scherer, MD-New York University Nephrology Faculty Group Practice
  - Michael Germain, MD- Baystate Medical Center
Research

Grants

- Funding from the **Gordon and Betty Moore Foundation** awarded to the Coalition
- 15-month grant to support the development of the **Pathways Project**
- Focus on evidence-based best practices for delivering person-centered palliative care to patients with CKD
- The 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.
Research

- The Coalition reached out to Sean Morrison, MD, Director of the National Palliative Care Research Center (NPCRC), asking for CKD to be among those chronic diseases for which the NPCRC would develop research priorities.

- Consequently, Alvin Moss, MD, Ann O’Hare, Mi-Kyung Song, PhD, RN, and Manjula Kurella Tamura, MD, were invited to participate in a NPCRC-NIH Research Priorities for Geriatric Palliative Care in Surgery and Select Medical Sub-Specialties workshop to develop research priorities for supportive care for patients with chronic disease, including CKD.

- Manuscript on CKD palliative care research priorities is in press in the Journal of Palliative Medicine.
Research

Sojourns Scholar Leadership Program Grant Awardees

- Coalition member Jennifer Scherer, MD, NYU School of Medicine, was awarded a Sojourns Scholar grant to develop her renal palliative care program, Kidney CARES (Comprehensive Advanced Renal and End Stage Renal Disease Support).

- Coalition member Daniel Lam, MD, the University of Washington School of Medicine, was awarded a Sojourns Scholar grant to systematically integrate palliative care and advance care planning into the routine care delivery of ESRD patients across an entire dialysis provider system.
ASN Supportive Care Community Forum

- Most commented ASN online Community

- Ambassadors
  - Mike Germain, MD
  - Jane Schell, MD
  - Jennifer Scherer, MD
# Supportive Care Community Initiatives

## How Are YOU Advancing Supportive Care?

<table>
<thead>
<tr>
<th>Topic</th>
<th>Contact</th>
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<tbody>
<tr>
<td>• Renal supportive care in Taiwan</td>
<td>Chia-Ter Chao, MD National Taiwan University Hospital <a href="mailto:b88401084@gmail.com">b88401084@gmail.com</a></td>
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<tr>
<td>• Communication skills training programs for renal fellows, nurses</td>
<td>Katharine Cheung, MD University of Vermont <a href="mailto:klcheung@med.uvm.edu">klcheung@med.uvm.edu</a> 650-644-5994</td>
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<td>• Assessing distress level in patients to inform clinic visits</td>
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<td>• Conducting ACP conversations with patients/families</td>
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<tr>
<td>• <em>Advance Care Planning: Let's All Talk</em></td>
<td>Denise Eilers, BSN, RN Davenport, IA <a href="mailto:GeneDeEi@aol.com">GeneDeEi@aol.com</a> 563-888-5463 or 563-508-4883</td>
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<tr>
<td>• Care partner and patient perspectives on ACP</td>
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<tr>
<td>• Timing of Hospice Enrollment and End-of-Life Utilization and Spending among Patients with ESRD</td>
<td>Melissa Wachterman, MD, MPH, MSc Boston VA Healthcare System &amp; Brigham and Women's Hospital <a href="mailto:melissa.wachterman@alumni.tufts.edu">melissa.wachterman@alumni.tufts.edu</a> 617-821-5110</td>
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For additional information, including resources for patients and families,

visit: www.kidneysupportivecare.org
or
email: csckp@nw5.esrd.net