Coalition for Supportive Care of Kidney Patients



Annual Report 2024

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Annual Report 2024

1. Message from the Executive Director

Invigorating the Coalition

As I reflect on my first full year as Executive Director of the Coalition for Supportive Care of Kidney Patients, I am deeply inspired by our vast, global network of clinicians, advocates, and patients who share our commitment to advancing kidney supportive care. I began my tenure with an extensive listening tour, making it a top priority to hear directly from our network about their needs and aspirations. My goal was to understand their vision for the field and identify concrete steps we could take to expand access to kidney supportive care, both immediately and in the years to come.

We spoke directly with our network to hear about their needs and aspirations.

In the latter half of the year, I worked closely with our Program Manager, Matthew Ryan, to transform these insights into action. Together, we focused on building a strong foundation for the Coalition's continued growth and impact, particularly in policy advocacy, research initiatives, and resource development to enhance the experience of patients and caregivers. We've made significant strides in disseminating crucial insights and research through presentations and publications at national and international forums. A particular highlight was our participation in an International Delphi Study, where we collaborated with global experts to establish consensus on best practices and future directions in kidney supportive care.

Working alongside the Coalition's Executive Committee member Dr. Alvin "Woody" Moss, we contributed to the American Nephrology Nurses Association (ANNA) Position Statement on Kidney Supportive Care, emphasizing the crucial role of nephrology nurses in providing compassionate, patient-centered care. We've also strengthened our relationships with organizations like the Center to Advance Palliative Care, the American Nephrology Nurses Association, the National Hospice and Palliative Care Organization, and the National Kidney Foundation, advancing our mission to integrate palliative care principles into nephrology practice.

These achievements have established a robust foundation for our future work, and I look forward to continuing our efforts to improve outcomes for patients with kidney disease.

Dr. Christine Corbett Executive Director Coalition for Supportive Care of Kidney Patients



2. Listening to our Members

In Spring 2024, the Coalition conducted comprehensive stakeholder engagement through two listening tours and a Pathways Project reconvening session, bringing together diverse interprofessional clinicians. These sessions yielded valuable insights and identified strategic priorities for advancing kidney supportive care. The engagements revealed four core areas for development:

Educational Resources

Accessible article repository, specialized podcasts and webinars covering topics from acute care challenges to conservative care options, and targeted continuing education opportunities.

Community Engagement

Regular networking opportunities and narrative medicine initiatives

Provider and Patient Support

Provider wellness programs and patient/family-centered resources

Advocacy and Awareness

Promoting value-based care models and home therapies, particularly addressing gaps in supportive care across hemodialysis, transplant, and clinic-based services

This input established a clear roadmap for the Coalition's efforts to enhance kidney supportive care delivery and education across all stakeholder groups. **Our work** since these listening tours has been directly informed by the feedback and suggestions we heard from participants.



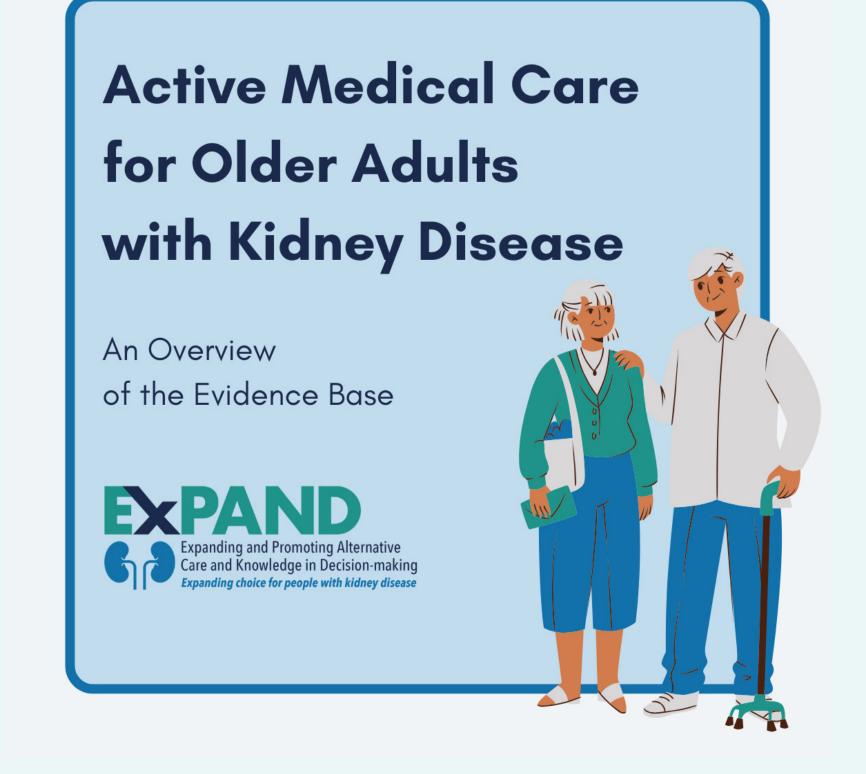
3. Strengthening our Foundation

Building on insights from our listening tours, the Coalition evolved its communications strategy in 2024. We enhanced our platforms to not only address immediate stakeholder needs but also provide a scalable base for future growth.

Rebuilt web presence at kidneysupportivecare.org

In addition to simpler navigation and cleaner graphics, we've introduced a **Resource Library**. Visitors can quickly search and filter through handouts, toolkits, presentations and more from the Coalition and its network of world-renowned experts. Highlights in the resource library include:

- An overview of the evidence base for Active
 - Medical Care in older adults, created by our George Washington University and West Virginia University team members
- Conservative Kidney Management (CKM) patient decision aid by the Mass General Brigham KidneyPal team.
- Implementation toolkits from the Pathways project (Lupu, Moss) and Conservative Kidney Management pathway (University of Alberta).



In its first month, the website has already received hundreds of visitors from across the globe, which speaks to the universal need for kidney supportive care programming.

Refreshed newsletter

Our refreshed monthly newsletter delivers key information to our readers in a branded format.

This year, we've highlighted the latest research in kidney supportive care, new resources for patients and caregivers, and the bios of our patient advisors. As of December 2024, our newsletter audience has grown to 400 engaged contacts. Our November 2024 newsletter achieved a click rate over 4x higher than the industry average! *

Realigned sponsorship strategy

In addition to making sponsorship simpler through our digital presence, we have developed a **<u>tiered giving model</u>** that aligns with the Coalition's future projects. The Pine, Maple and Oak levels help sponsors understand the direct impact their giving will have on the Coalition's efforts.

*Based on Intuit Mailchimp's benchmarks for the Health and Fitness Industry. The Coalition's November 2024 newsletter had an open rate of 51% (industry average: 37%) and click rate of 9% (industry average: 2%).

4. Engaging the Community

Fostering the network and presenting at top-tier conferences

It has been a big year for our network. Online, our LinkedIn page continues to be a central tool for sharing the latest research and news from the kidney supportive care field. **In 2024, our follower count increased 400%!** And in person, we have presented at key conferences including:

- American Society of Nephrology Kidney Week
- Annual Assembly of Hospice and Palliative Care
- American Nephrology Nurses Association National Symposium
- American Nephrology Nurses Association Fall Nephrology Nursing Summit
- National Kidney Foundation Spring Clinical Meeting
- Renal Physicians Association Annual Meeting
- Supportive Care for the Renal Patient Meeting
- Renal Healthcare Association Annual Conference

Convening world experts in kidney supportive care

The Coalition is fortunate to have an executive committee of diverse voices, from world-renowned clinical researchers to extraordinary patient advocates. In 2024 we strengthened the Coalition's committee by welcoming Charlonda Thaxton, MSW and Melissa Sanchez, patient advocate.
At the American Society of Nephrology's Kidney Week 2024, the Coalition team connected with some of the leading voices in kidney supportive care (pictured

right).





International kidney supportive care specialists gathered for lunch at ASN Kidney Week 2024, exchanging ideas to advance patient-centered care worldwide. Participants included Drs. Edwina Brown, Annie Liu, Mark Brown, Jennifer Scherer, Jane Schell, Kate Butler, Sara Davison, Alvin (Woody) Moss, Josh Mannix, Ann O'Hare, and Christine Corbett.

5. Conducting Research

The Coalition is proud to support pioneering studies in kidney supportive care. In 2024, we wrapped our work with the <u>HIGHway Project</u>, which empowered nurse case managers and social workers in dialysis centers to incorporate advance care planning (ACP) into their workflow.

HIGHWAY ROADMAP

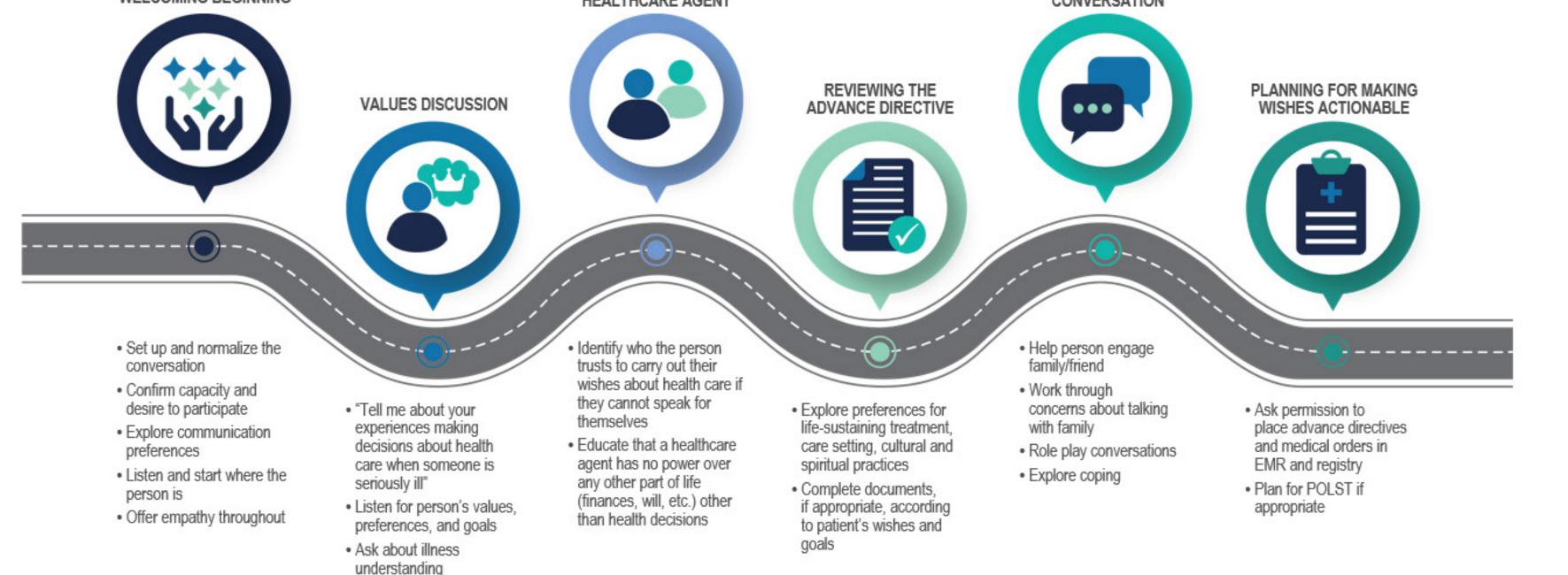
• Listen, reflect and offer empathy throughout.



"Empathy is the gas that fuels the conversation"

WELCOMING BEGINNING

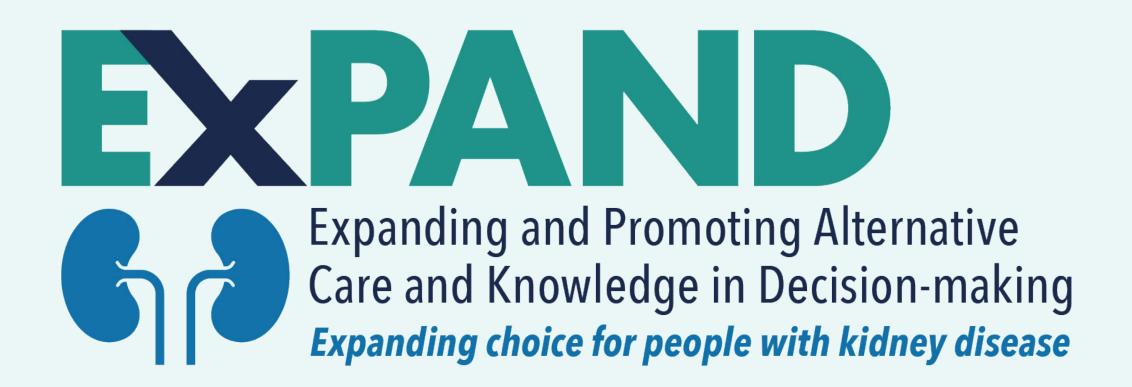
CHOOSING THE HEALTHCARE AGENT EXPANDING THE CONVERSATION



For the next few years, the Coalition is proudly supporting the <u>ExPAND Project</u>, a 5-year study sponsored by the Patient-Centerd Outcomes Research Institute (PCORI).

Advisory Group, design and consult on educational materials to ensure they are culturally sensitive through a trauma-informed lens, and coach physicians on empathetic listening skills and treatment option discussions.

The project's core themes of shared decision-making and continuous support of patients across kidney treatment options are deeply aligned with the Coalition's mission. We are proud to coordinate the ExPAND Project's Patient



We'll be presenting on our research at various conferences in 2025, including the National Kidney Foundation Spring Clinical Meeting, the Annual Assembly of Hospice and Palliative Care, and the American Nephrology Nurses Association National Symposium. If you're also attending, we would love to connect!

(6. Looking Ahead

With a strong communications platform, an enthusiastic and engaged network, and a core team of world-leading experts, the Coalition is poised for significant growth in the coming years. As we look ahead, we are excited to explore several major projects, including:

Rural Innovation Center for Kidney Supportive Care

As a practicing clinician, Dr. Corbett splits her time between leading the Coalition and caring for patients in a rural clinic in Las Cruces, New Mexico. The clinic offers a window into the challenges and opportunities for patients seeking kidney supportive care in resource-limited, rural settings.

We are looking to fund a range of research centered on rural health to better understand barriers to care, social determinants of health, and methods for ensuring

continuous supportive care in geographically dispersed regions.

Global Kidney Supportive Care Directory

The Coalition is fortunate to collaborate with pioneers in kidney supportive care across the globe. For our patients and their loved ones, it can be hard to find the clinicians and practices that are leading kidney supportive care efforts. We aim to make this easier by creating the first global directory for kidney supportive care - a dynamic list of clinical settings that regularly include key aspects of supportive care, including primary palliative care and active medical care without dialysis, into their workflows.

Kidney Supportive Care Training

The Coalition is aiming to enhance its programming for clinicians by offering a tiered approach: education for those interested in kidney supportive care core principles, and an implementation course for experienced learners who are operationalizing kidney supportive care programming at the organization level.

How can you help?

Sponsor | With your support, we can accomplish these projects and many more. **Collaborate** | Researcher? Advocate? Student? Let's work together! **Connect** Join our newsletter and follow us on LinkedIn to share the messge about kidney supportive care.

kidneycoalition@gwu.edu

kidneysupportivecare.org

