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[Letter from Executive Director Sara Dado](#)

Welcome to the launch of IL-HPCO's new and improved 2024 Newsletter! I am so honored to be serving as your new Executive Director. For those who don't know me, I have a long and rich history with IL-HPCO, serving as chair of the Government Affairs Committee for 7 years, Vice Chair and Chair of the Board of Directors before taking on this current role. In addition, I have had the privilege to work for two community-based hospice provider organizations, serve as an Illinois State Delegate on Capitol Hill, and lead several advocacy trips to Springfield. Improving access to high quality care at the end of life for all individuals has been my passion for over 20 years and will continue to lead me in my work with IL-HPCO.

In this first issue, we will have transparent communication in terms of where we have been, where we are now and where we hope to go in the days, weeks and months ahead. Doug Irvin, IL-HPCO Board Chair, has courageously navigated some challenging waters over the past 18 months with strong and focused leadership. In his Letter from the President, he shares candidly about the process that the Board of

Directors followed in coming to this place where we are today. He also shares his hopes and goals for IL-HPCO moving forward.

Merilee Smith, IL-HPCO Vice Chair and Education Committee Chair, has some exciting updates to share in her column. Planning is underway for IL-HPCO's 2024 Annual Meeting and Conference in May. I can't wait for us all to gather once again for a day of learning and networking. That will be happening on May 14th so mark your calendars now.

Ellen Byrne, IL-HPCO Director of Policy and Government Affairs, has continued to diligently work on behalf of all of us in both Springfield and Washington DC to ensure that our voices are always present at the table with policy makers when important conversations are being held that affect our work and the care we provide. She has some important legislative updates to share as well.

Lastly, we take a moment to honor and thank Mary Kay Sheehan, Lightways CEO, as she steps off the IL-HPCO board of directors after nearly a decade, several of which she served as Board chair. Mary Kay is a true hospice advocate, an agent of change and an inspiring leader. Take the time to read more about her journey and what continues to motivate her every day.

We have been through a lot these past few years. But we are still standing strong and growing together. I invite you to join in our efforts this year- participate in a committee, attend a webinar, come to a conference, or become an advocate. It is only together that we will continue to serve the mission that has been IL-HPCO since its founding in 1980. I can't wait to see you soon,

“Alone we can do so little; together we can do so much” – Helen Keller

Letter from Chairman Doug Irvin

As many of you likely know, the last few years have been different – and not just for IL-HPCO. The global pandemic compelled us to live outside comfort zones and forced us to take on challenges we never dreamed we would face. IL-HPCO found itself facing its own host of challenges, some imposed by the pandemic while others were a byproduct of changes with our management organization. Through the steadfast commitment of our board and countless others interested in seeing IL-HPCO succeed and thrive into the future, we have arrived at a new place – a new chapter.

After careful consideration, thoughtful reflection, and sincere excitement about the future, the IL-HPCO board has engaged The HAP Foundation to serve as our new association management entity. The HAP Foundation, with its passionate staff and supporters, brings a unique commitment to this field of work. Additionally, the IL-HPCO board is excited about the rich industry experience Sara Dado brings as our Executive Director.

Over the last year, IL-HPCO's board, to no fault, found itself doing what many of us did each day during the pandemic – surviving while planning for the future. Unfortunately, without an association management relationship, the board's work was disproportionately dedicated to the everyday demands of maintaining IL-HPCO's existence. We are all excited to announce that with The HAP Foundation's relationship in place, the work of the board can return to a singular focus on driving our mission.

Under the direction and diligent efforts of Ellen Byrne the amazing work on the legislative and government affairs front has never slowed. Our relationship and influence with the Medicaid MCOs and state Medicaid partners has continued and improved. The impact our

reimbursement work group has for all hospices persisted.

Additionally, we are excited to resume the valuable offerings that our members enjoy. These include educational opportunities and more regional based meetings with impactful peer group connection.

More than anything, I personally look forward to resuming an unfettered focus on why I volunteer for IL-HPCO. I do this to expand access to high-quality hospice and palliative care and to engage in learning from, and sharing with, this committed community of caring professionals. I look forward to interacting with all of you - whether that be one-on-one or in future group settings. Thank you for all that you do in the service of your organizations, the communities they serve, and most importantly for the impact you have on patients and families.

[Education Update from Merilee Smith](#)

We were so happy to be a part of HAP's Fall Education Conference on October 17th, 2023. It was wonderful to be in person for the first time in so long. The Northern Illinois University's (NIU) Naperville campus has been the site of IL-HPCO's past Education Conferences. The October conference gave us an idea of what in person conferences look like post pandemic.

We have reserved NIU for IL-HPCO for Tuesday, May 14th for our full day Education Conference. We are calling for proposals for presentations. This is very exciting to be planning this important event.

IL-HPCO has partnered with the Wisconsin Hospice and Palliative Care, (WHPC) organization for shared educational opportunities. Both organizations will host 2 quarterly sessions for a total of 4

webinars. The first session will be by WHPC, Husch Blackwell Attorneys, will host a webinar on Tuesday, February 20th, 11am–12PM CST.

IL-HPCO will likely present on Emergency Preparedness for our first webinar. More to come soon on this session.

Government Affairs Update from Ellen Byrne

The IL-HPCO Government Affairs Committee works hard to support advocacy for health policies that benefit all Illinois licensed community-based hospices and palliative care programs as well as Illinois citizens impacted by a serious or life-limiting illness. As the Director of Public Policy and Government Affairs, I am very grateful for each member of the committee for their thoughtful input and diligent efforts in 2023. Over the past couple of years, IL-HPCO's advocacy efforts have helped achieve:

- Redesign of the Illinois Department of Public Health Uniform POLST form
- State funding to support family caregivers
- Passage of legislation expanding the scope of practice of advance practice registered nurses and physician assistants in their roles as hospice and palliative care providers
- Passage of legislation increasing the capacity of in-patient hospice care in Illinois
- Passage of legislation establishing professional licensure for music therapists

IL-HPCO Executive Director, Sara Dado, members of the GA Committee and I have had the privilege of meeting with eight state and nine federal lawmakers in 2023, and I am happy to report that thoughtful policies targeted at improving equitable access to high quality hospice care are strongly supported on a bipartisan basis.

Additionally, we continue to work with agency staff at the Illinois Department of Health Care and Family Services (HFS) to finalize a state plan amendment establishing Pediatric Palliative Care as a benefit in the Illinois Medicaid program and assist health insurance plans regulated by the Illinois Department of Insurance to implement mandated coverage for Pediatric Palliative Care. Finally, with leadership from Carrie Bill and Kelly Schnetzer from IL-HPCO member Accent Care, nearly 40 members of the Reimbursement Workgroup met throughout 2023 to share information and strategies for optimizing payment from the state of Illinois, Medicaid MCOs and Medicare. Carrie and Kelly continue to meet monthly with representatives of Medicaid and the Illinois Association for Medicaid Health Plans to discuss global hospice reimbursement concerns and review open claims issues impacting IL-HPCO members.

Advocacy is a TEAM activity, and IL-HPCO is proud to participate in several stakeholder coalitions representing the voice of our community and families facing a serious illness. These include:

- Illinois Aging Together – a coalition of stakeholders working to develop a state master plan on equitable aging in Illinois
- The Illinois Family Caregivers Coalition – a coalition of organizations that seeks to support those caring for a close friend or family member
- The Illinois Telehealth Coalition – a group for healthcare provider organizations promoting access and reimbursement for medical services delivered through telehealth when appropriate
- The Illinois State Hospice & Palliative Care Advisory Committee – a legislatively mandated panel of individuals providing expertise to state agency leaders regarding hospice and palliative care issues, rules, and regulations

Our Policy Priorities for 2024 are focused on practical changes that will help our member hospice programs succeed in delivering high quality and high value care for their patients and families. Workforce enhancement and flexibility is top of mind. IL-HPCO is working closely with Senator Lakesia Collins of Chicago to pass legislation

creating a Community Hospice & Palliative Care Professional Loan Repayment Program Administered by the Illinois Student Assistance Commission. We are also pursuing regulatory changes allowing LPNs, hospice aides and CNAs to leverage and utilize the full extent of their training and education reducing the burden on RNs and other hospice clinicians. IL-HPCO will continue to encourage IL lawmakers to have Illinois join the Nurse Licensure Compact. And finally, we hope to engage HFS in planning to eliminate the Hospice-Nursing Facility Room & Board Passthrough.

I am very pleased to be serving on the State of Illinois Hospice & Palliative Care Advisory Committee along with IL-HPCO Chair, Doug Irvin and board member, Kristin James. Together we have spearheaded a new palliative care subcommittee which will convene stakeholders and experts to make recommendations to the full committee about how to establish state standards for community-based, adult palliative care that is consistent with data demonstrating a positive impact on patient outcomes and experience. We believe this effort will improve equitable delivery of hospice & palliative care services to disproportionately under resourced communities who experience great challenges in the face of serious illness.

I encourage you to check out the full list of 2024 Policy Priorities on the IL-HPCO website. Please join our advocacy efforts by becoming a member of the Government Affairs Committee or working with us to meet with state and federal policy makers that represent you or your organization. Contact Ellen Byrne, Director of Policy & Government Affairs to find out more (ebyrne@il-hpc.org). You don't need experience, just a great story to tell about the importance of providing seriously ill patients and their families with an extra layer of support from an interdisciplinary team of caring providers.

Special Announcements



Recognizing Mary Kay Sheehan for Years of Service to IL - HPCO

In this edition, we recognize Mary Kay Sheehan for nine years of continuous service to the Illinois Hospice and Palliative Care Organization (IL-HPCO). Through her commitment as Board Chair as well as serving on various committees, she has led with compassion and support of providing patients with quality end-of-life care.

As an oncology nurse, Mary Kay experienced many people suffering during the dying process. She found that many died in pain or suddenly, resulting in their families' receiving calls of their loved one's death in the middle of the night leaving them grief-stricken and in shock because they weren't properly informed of the reality of their loved one's prognosis. She recalls the difference in young patients versus older patients. Older patients at the end of life had a sense of closure for themselves and their families while young patient's families were puzzled with the unknown of death as imminent and the profound impact of their grief manifested on the care teams. She thought "there has to be a better way to take care of patients at the end of life."

During this time, in the early stages of the hospice movement in the United States, Mary Kay accepted a position as one of the first nurses at the newly established in-patient hospice unit at Northwestern Hospital. Her experiences at the bedside of dying patients, especially during the peak of the AIDS crisis, taught her how to be with families to talk about the end of life earlier, and how to manage pain and symptoms better. Later, she conducted home visits for patients at St. Thomas Hospice and felt the strong privilege it is to be with patients and families in their home, where they are most comfortable. From there, she worked under Dr. Martha Twaddle at the Hospice of the North Shore in quality and education research. "I caught the bug that this is the best type of nursing. Hospice is whole person care in a way that *really* takes care of people. Right then, I made it my mission to improve hospice care in Illinois, make it more accessible for everyone and dispel the myths and misconceptions." Today, she is the CEO of Lightways Hospice and Serious Illness Care, for the past 8 years.

Since 2016, Mary Kay has served in many capacities with IL-HPCO, most notably as the Chair from 2018-2022. Through her deep commitment to her personal mission, she has led efforts to increase the in-patient bed count, most recently up to 24 beds, fostering and

strengthening the relationship between nursing homes and Medicaid, and continuing to provide education throughout the state, such as when she and Pam Cramer traveled downstate to meet with executive directors of hospices, allowing them to feel heard and build a relationship of understanding and reassurance.

“Mary Kay has been a leader and advocate in this space for decades,” said Douglas Irvin, Chairman of the Board of Directors. “Her work with IL-HPCO has extended the impact of her commitment and passion to the entire industry. The selflessness of her contributions have benefited many organizations, and by extension countless patients and families. This alone is truly a remarkable impact and says nothing of the amazing influence her professionalism and leadership has had on the careers of many.”

IL-HPCO continues to work hard to support providers in creating a community of collaboration and support for patients. Mary Kay strives to provide everyone with a choice by providing options for their care. Hospice should serve as a transitional care for patients to work with interdisciplinary teams as they decide when the risks and burden outweigh the benefits. Then, the hospice care team is already part of their journey through it all.

For 2024 and beyond, as Mary Kay transitions off the IL-HPCO Board of Directors, she aims to continue to teach people about the benefits of hospice and palliative care while sharing her gratitude for those who work in end-of-life care. “It is hard work and important to set boundaries and practice self-care.” Additionally, her message of working together is important as IL-HPCO moves forward.

“Stay focused on quality of care and taking care of staff. Always do the right thing, and if we do that, we will come together for patients and families.”







[Save the Date](#)

We are excited to announce that on Tuesday, May 14, we will be hosting the **Annual Meeting and Educational Conference** at NIU Naperville. Stay tuned for more details!



Our mailing address is:
The HAP Foundation

c/o IL-HPCO Executive Director
18W140 Butterfield Road, Suite 1120
Oakbrook Terrace, IL 60181-4848

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