Chair Message
Mary Sheehan, IL-HPCO Chair, CEO Joliet Area Community Hospice

IL-HPCO “Advocacy” Is Taking Off!

Last year, the IL-HPCO board of directors identified advocacy as one of its primary objectives. Over the past several months, many members have spent a significant amount of time in both Springfield and local district offices, meeting with legislators, building coalitions, educating and working on several important pieces of legislation that will impact all hospice providers in the state of Illinois. IL-HPCO has identified the following as legislative priorities:

- Elimination of the Medicaid Room and Board Pass Through for Hospice;
- Align Illinois with federal law on disposal of medications;
- Align Illinois with Federal law, allowing patients to choose Physician Assistants as Attending Physicians when electing the Hospice Benefit;
- Passage of the Pediatric Palliative Care Act;
- Elimination of the Double Dosage Mandate (Varcan).

In addition to these important issues, we continue to raise awareness via education and outreach to all legislative contacts regarding the importance of hospice and palliative care in our communities. Specific legislation that IL-HPCO is currently supporting:

SB 1105 - Pediatric Palliative Care Act. This bill will be voted on in late April by the House. It passed last month in the Senate 53-0! House Sponsors are identified. We hope to have it on Governor’s desk for signature by summer!

HB2638-Naloxone Prescribing. IL-HPCO is currently working on draft language for this bill.

Room and Board Elimination HB3037. Currently in the Human Services Medicaid Subcommittee, IL-HPCO has worked tirelessly advocating and gathering legislative support for this bill.

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Legislative Update – Betsy D. Mitchell, IL-HPCO Legislative Consultant

Only five more weeks of session are left before the May 31 adjournment deadline. Many issues remain on the docket to be discussed. Revenue issues and the budget will be the main statewide concern. For IL-HPCO, we remain hopeful that our key legislative issues will be resolved including the room and board pass through, pediatric palliative care, and a feasibility study for an advanced public directive.

**SB1105/Righter (R-Mattoon) and Durkin (R, Western Springs)** — Ten years ago, legislation was passed at the suggestion of ILHPCO and GIPPCC to provide for pediatric palliative care. This year, IL-HPCO Board member, Senator Dale Righter, worked with GIPPCC to introduce HB1105 to develop collaboration between healthcare providers and families in securing the appropriate care and resources for seriously ill children and their families. In partnership with the Department of Healthcare and Family Services and Illinois’s Medicaid managed care organizations, the bill will develop a program to help control the cost of care while improving the health and quality of care for children and their families. Our goal is to work together to assure the State’s most medically fragile children have the quality care they deserve. In early April, the Senate passed SB1105. The bill is now in the House before the Appropriations Committee for Human Services. IL-HPCO and GIPPCC continue to work with HFS to strengthen the bill’s language. IL-HPCO and GIPPCC are working diligently to pass this bill.

**HB 3037/Rep. Unes (R, Pekin) and Rep. Manley (D, Romeoville)** — Requires HFS to make all room & board payments directly to long-term care providers instead of hospice providers whenever recipients of medical assistance opt to receive hospice care at long-term facilities. The bill has been referred to the House Rules Committee which means it is no longer moving in the process, but it does not mean the issue is dead. IL-HPCO remains hopeful this issue will be made part of a more comprehensive bill moving in the Illinois General Assembly. IL-HPCO strongly supports this issue.

**SB 182/Morrison (D, Northbrook) and (Moeller, Elgin)** — Directs IDPH to study feasibility of creating a statewide registry of advance directives and POLST. An amendment will ensure POLST is part of this study. This bill is on 2nd Reading in the Senate. The bill was amended in the Senate and passed. It is now in the House for consideration.

**SAVE THE DATE**

**CREATING CONNECTIONS**  
building for the future  
IL-HPCO ANNUAL CONFERENCE  
OCTOBER 16-17  
Northern Illinois University, Naperville, IL 60563

**2019 FEATURED SPEAKERS**

Martha Twaddle, MD, FACP, FAAHMP, HMDC  
Medical Director-Palliative Medicine & Supportive Care-NMLF

Mary Mihalyo, PharmD, BCPS  
Delta Care Rx CEO/Pharmacotherapy Specialist

Jennifer Kennedy, EdD, MA, BSN, RN, CHC  
Sr. Director Regulatory and Quality-NHPCO
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We recently met with HFS Director Theresa Eagleson and her colleagues to address the issue. We have also reached out to other states who have passed similar legislation for guidance.

We continue to work diligently to explore paths that will work within our state and federal guidelines. Our hope is to move this bill out of committee by fall or early 2020.

IL-HPCO leaders have spent countless hours traveling to visit Legislators in their home districts and Springfield offices to lobby these issues on our members behalf. Later in this newsletter, you will see photos and captions of these important visits.

Advocacy Day

IL-HPCO held an Advocacy Day in early April and had success meeting with several legislators at the Capitol.

At the IL-HPCO Annual Educational Conference in October, the Legislative Committee will be hosting a session dedicated to lobbying, teaching and educating members about how to schedule, visit and speak with legislators in their home districts. This is a very effective way to establish relationships and gain support for important hospice and palliative care issues. IL-HPCO members are becoming the primary resources to legislative leaders on our industry. We thank you all for this!

During the training, Betsy Mitchell, IL-HPCO Legislative Consultant, spoke to attendees on the issues and talking points with legislators. Several IL-HPCO attendees enjoyed connecting with their district legislature representatives and staff and sharing the IL-HPCO message.

Welcome New Member

We are pleased to welcome Heartland Hospice Rockford

HFS- Healthcare and Family Services Meeting in Springfield

IL-HPCO leaders met with HFS newly appointed Director, Theresa Eagleson, Kelly Cunningham-Deputy Administrator for Programs Division of Medical Programs, and Doug Elwell-Medicaid Administrator Division of Medical Programs to discuss Elimination of Room and Board, what it would mean to HFS, and how other states have handled this. The Pediatric Palliative At Home Bill was discussed.

This was the beginning of quarterly meetings with HFS leaders to discuss common issues.
IL-HPCO Leaders Legislative Visits

Rep. Fran Hurley (D) represents the 35th district, and is chair of the Subcommittee on Medicaid, where SB3037 on Elimination of Room and Board was referred. As usual, IL-HPCO leaders offered to be Rep. Hurley’s main resources on hospice and palliative care as well as speaking to her constituents at any time about our industry. Pictured: Ellen Byrne, Sara Dado, Rep. Hurley, Kristin James, and Jim Dale.

Sen. Laura Fine represents the 17th District, and her interests are higher education and environment. She is a supporter of hospice and palliative care and has attended our events. Pictured: Pam Cramer, Carrie Bill, Sen. Laura Fine, and Ellen Byrne.

Rep. Mike Unes, (R) had represented the 91st district since 2011. IL-HPCO Leaders Sara Dado and Trish Benson have visited him in his home district and in Springfield. He is a good friend to hospice, and will help navigate the elimination of the Room and Board issue. Pictured: Sara Dado, Lisa Encarnacion, and Rep. Mike Unes.

Rep. Michelle Mussman (D) represents the 56th district which includes parts of Schaumburg, Elk Grove Village, Roselle, Hoffman Estates, Hanover Park, Rolling Meadows and Bloomingdale. She will support IL-HPCO efforts with eliminating Room and Board and also Pediatric Palliative Care at Home. We were happy to begin a relationship with her, and she knows that IL-HPCO leaders can be her resource in all matters hospice and palliative.
Visit with Senator Julie Morrison

Sen. Julie Morrison (D) represents the 29th district, northern suburbs and in Lake and Cook Counties. She was most interested in Pediatric Palliative Care at Home, and agreed to co-sponsor the bill which is being sponsored by Sen. Dale Righter. She has been a good friend to hospice, and our visit was beneficial to all.

The quarterly meeting hosted at Seasons and sponsored by IL-HPCO and IAMHP (Illinois Association of Managed Health Plans) was held the last week in April. All “plans” except Aetna were in attendance and more than 25 Provider IL-HPCO Members

Member News

Joliet Area Community Hospice held a ground breaking ceremony April 24, 2019 for the renovations and addition to the Hospice Home Inpatient Unit. Since opening as Illinois’ first freestanding hospice home in 2004, community need for compassionate end-of-life care has outgrown the Joliet (JACH) facility’s capacity.

The hospice home’s $7 million dollar expansion will improve the patient and family experience by creating an enlarged, brighter and more efficient refreshed environment. The guiding philosophy focuses on creating as many of the comforts of home as possible in an atmosphere where patient symptoms are controlled and can be surrounded by loved ones.

Greater Illinois Pediatric Palliative Care Coalition (GIPCC) Success

Kristin James, Executive Director (GIPPC) says “Thanks to you, our testimony, and nearly 100 online supporters who acted within that hour, the bill successfully passed out of the Human Services Committee and this afternoon, April 9, passed the Senate 53-0.”

Next step: The House. In a few weeks, IL-HCPO leaders will also be asked to testify before a House committee before it goes to a full House vote. There will be one hour again to solicit online witness slips. By submitting these slips, you can help support improving the care for seriously ill children and their families in Illinois!