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FALL 2024

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HOSPICE AND PALLIATIVE MEDICINE

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## A MESSAGE FROM THE PRESIDENT

# NEW ACADEMY EFFORTS ADVANCE THE INTEGRATION OF SCIENCE IN HOSPICE AND PALLIATIVE CARE

Research is a cornerstone of progress in every medical discipline and is especially vital in the young and evolving field of hospice and palliative care. It drives advancements in quality of care, fosters growth in clinical skills, and translates evidence into practical bedside interventions that profoundly impact patients and families living with serious illness. Recognizing this, the American Academy of Hospice and Palliative Medicine (AAHPM) is taking significant steps to promote research as a key strategic priority. The recent appointment of Stacy Fischer, MD, as the Academy's first science advisor, the creation of the Serious Illness Research Consultant Center (SIRCC), support for early-career investigators to attend the Annual Kathleen Foley Palliative Care Retreat and Research Symposium, and our advocacy for enhanced funding for the field all underscore a commitment to evidence-based care and a brighter future for patients in need of compassionate, high-quality palliative care.

### Impacting Quality and Growing Clinical Skills

Dr. Fischer's research has been focused on pushing the field forward into new areas such as the study of patient navigation approaches that promote equity, understanding decision making at the end of life, and studying the safety and efficacy of psychedelics in palliative care. In addition to being a highly accomplished researcher herself, she is a beloved mentor and practicing clinician. She has also been an active volunteer leader at AAHPM, serving on the research committee, State of the Science planning committee, and recently cochairing the State of the Science in 2024. With her extensive expertise and passion for advancing the field, Dr. Fischer is uniquely positioned to guide AAHPM's research agenda, strengthen key partnerships, and solidify the Academy's role as the professional home for serious illness researchers. We are grateful for the collaboration

with Laura Hanson, MD MPH, and Areej El-Jawahri, MD, who have contributed diverse perspectives toward a vision to support science and researchers within the Academy, enriching this effort to train and support current future scientific leaders in hospice and palliative care.

Complementing Dr. Fischer's appointment is the launch of a 12-month SIRCC pilot program. This initiative pairs early-career investigators with seasoned mentors, providing critical support in research methodology, grant writing, and project development. By fostering the next generation of leaders, AAHPM is creating a robust foundation for the future of palliative care research.

### Evidence-Based Solutions and the Future of Practice

The field of hospice and palliative care is continually evolving, with new evidence shaping clinical practices to ensure patients receive the best possible care. Research directly impacts the quality of care by identifying gaps, testing interventions, and implementing evidence-based practices that can improve outcomes. It equips clinicians with the knowledge and tools to deliver person-centered care tailored to the complex needs of patients with life-limiting illnesses.

AAHPM supported 7 investigators to attend the Annual Kathleen Foley Palliative Care Retreat and Research Symposium. At the retreat, they were able to present their work, be in community with other early career investigators, and learn from experienced researchers in our field. The work of the research scholars is inspiring and has me incredibly excited about the future of our field.

Supporting the dissemination of findings generated through rigorous studies can innovate and improve practice, ultimately transforming care delivery for people with serious illness. Our 2025 Annual Assembly will feature two important plenaries



that I encourage you to attend. On Friday, February 7, we have invited Dr. Jennifer Temel and Dr. Joseph Greer, who served as co-principal investigators for two practice-changing clinical trials. Joining them will be a panel that includes a patient who participated in one of the trials, a nurse investigator, and a physician who ran one of the 22 sites in the REACH trial. The REACH study was a comparative effectiveness trial that demonstrated the efficacy of early palliative care delivered via video vs in-person visits on quality of life in patients with advanced lung cancer. I was fortunate to participate in these trials and am truly amazed by the work of our field. Scores of interdisciplinary clinicians participated in this study from 22 different sites. The REACH trial not only demonstrated the efficacy of video visits but also clearly demonstrated that large-scale practice-changing research can be done in our

field. The State of the Science plenary on Saturday morning, February 8, will feature presentations of the top-rated scientific abstracts, further demonstrating the exciting progress of our field.

By investing in research, AAHPM is fostering an environment where new ideas and innovative practices can emerge, ultimately leading to better symptom management, more effective communication, and enhanced support for patients and families. To learn more about AAHPM's current research programs, visit [aahpm.org/research-qi](http://aahpm.org/research-qi). ●



A handwritten signature in black ink that reads "Vicki Jackson".

*Vicki Jackson, MD  
AAHPM President*

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## CLINICAL PEARLS

# OFF-LABEL USES OF ANESTHETIC AGENTS IN HOSPICE AND PALLIATIVE CARE SETTINGS

Joe Kras, MD

Hospice and palliative care (HPC) clinicians use medications in an off-label manner, including anesthetic agents. Three such sedatives and adjuvant analgesics will be presented since they are increasingly being considered by clinicians.

**Propofol**, a sedative hypnotic, only has bioavailability when given intravenously. Three potential uses are painful dressing changes, intractable nausea and vomiting, and palliative sedation. Nonetheless, common side effects include hypotension and apnea. Dosing of propofol for dressing changes may consist of boluses of 10 to 30 mg every 2 to 5 minutes until an appropriate level of sedation is obtained. As propofol has no activity at opioid receptors, it serves a beneficial role, in conjunction with an opioid, for painful procedures. Infusions for either nausea and vomiting or palliative sedation may be initiated at rates of 0.5 to 1.0 mg/kg/hr and increased by the same amount every 5 minutes until sedation starts to occur or symptoms subside. Smaller incremental adjustments may then be used to fine-tune dosing. It can be infused for several days if necessary. If desired, propofol can offer the advantage of predictably causing unconsciousness that other sedatives (such as benzodiazepines and opioids) cannot. The narrow difference between a dose resulting in sedation vs respiratory depression includes factors such as frailty, low body fat, and decreased plasma proteins and requires caution and careful titration. The cost of propofol is approximately \$71/400 mg. Although not a federally controlled substance, propofol has been diverted and abused, and thus care must be taken in storage and dispensing it.

**Ketamine** produces surgical anesthesia while preserving respiratory drive and reflexes without lowering blood pressure like most anesthetics do, due to its prevention of reuptake of endogenous catecholamines. It is approved for intravenous (IV), intramuscular, and intranasal use but is used subcutaneously, by rectum, and by mouth in HPC. The indications for use in HPC include sedation for painful dressing changes, acute and chronic pain analgesia (especially neurogenic or neuropathic pain), opioid-induced hyperalgesia,

and depression or anxiety. Side effects occur with moderate to high doses, including hallucinations, paranoia, nystagmus, and excessive salivation. If being used as a continuous infusion, one must remember to decrease the dose after about 1 hour, as its metabolite, norketamine, can accumulate and increase unwanted psychomimetic effects. Daily rotation of subcutaneous (SC) injection sites is usually required secondary to otherwise painful induration. Infusion doses for severe pain range from 0.1 to 0.3 mg/kg/hr typically, but higher doses have been used. When initiating and titrating ketamine, the clinician should consider the following: 1) the patient may experience an elevated blood pressure and should be monitored; 2) doses exceeding 0.3 mg/kg/hr have been used, and side effects such as bronchospasm and secretion production could happen; and 3) the patient may experience disassociation, requiring treatment with lorazepam. Doses by mouth may start at 10 to 25 mg three times a day and may range as high as 100 mg twice a day or higher. Ketamine costs approximately \$250/500 mg. It has high abuse potential (street names Special K, Vitamin K, ket, etc).

**Dexmedetomidine** (an alpha-2 agonist) is a sedative that may produce brief hypertension followed by hypotension, bradycardia, nausea and dry mouth. Dexmedetomidine has been shown to decrease delirium, augment opioid analgesia, and provide adequate sedation for both short procedures and long periods of time. One property of dexmedetomidine that is potentially very advantageous is that it appears to restore a person's normal sleep pattern while allowing the patient to be awakened.

Dexmedetomidine is used intravenously but also intramuscularly, subcutaneously, intranasally, and buccally, making it advantageous in HPC applications. Nasal bioavailability is approximately 40% to 50% of IV and levels take about 45 minutes to peak, such that nasal dosing for procedural sedation should start in the range of 1 to 2 mcg/kg. Doses used intravenously and subcutaneously in HPC are usually in the 0.2 to 1.0 mcg/kg/hr range, though some higher doses are reported. Although

often administered via a loading dose followed by a continuous infusion, caution is advised to decrease or eliminate the loading dose in the frail or when other sedative agents are being coadministered. Dexmedetomidine is also supplied in a sublingual (SL) film in 120 and 180 mcg doses. The films may be cut in half. Initial SL or buccal film dosing for agitation is 120 to 180 mcg, with subsequent doses being half that much spaced 2 hours apart. In all routes of administration, dosing should be reduced in the face of decreased liver function. Dexmedetomidine costs approximately \$230/400 mcg. It has low abuse potential.

Anesthetic agents can be prohibitively expensive or require hurdles for HPC providers. There are advantages, and they may help patients with refractory symptoms. ●

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*Joe Kras has been a practicing anesthesiologist for 29 years and is also board-certified in hospice and palliative care.*

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ART OF CARING

## THE GRACE AND CHALLENGE OF PALLIATIVE CARE ADVOCACY

Katherine Pettus

Priorities of the global health narrative are saving and prolonging lives, preventing premature or avoidable death from epidemics and infectious and noncommunicable diseases and promoting maternal and child health, healthy aging, and so on. The World Health Organization (WHO) and most health-focused nongovernmental organizations absorb and promote this narrative unquestioningly. Successful global health interventions that increase life expectancy and decrease premature mortality are funded and implemented. According to health economists, these provide the “best buy”—the biggest bang for the global health investment buck.

Global health champions rarely discuss the fact that the increased life expectancy achieved does not translate into better quality of life for many beneficiaries of these policies, especially those who are older and poorer, and that no matter how advanced, the health sciences have yet to put an end to dying itself.

It is not news to public health scholars and geriatricians that increased life expectancy results in more disease, disability, dementia, and accelerated aging. The acute suffering these conditions produce in increasing numbers of individuals and families, and the costly burdens of this “success” on health and social budgets, which public health experts now have the tools to measure, expose the shortcomings of any global health narrative that excludes palliative care. The global health king parades with no clothes when public health systems lack universal access to quality palliative care.

### Kairos and Chronos

Palliative care gently extends global health’s mortality prevention *telos* into new waters. The definition of palliative cares stipulates that it neither postpones nor hastens death. This positions palliative care at the nexus of chronological and deep time—*chronos* and *kairos*, the life course and the mystery. The latter, a thin place that makes space for grace, gives practitioners and patients access to epistemological and spiritual resources

to transform and integrate serious health-related suffering. It reaches in where scientific knowledge accumulated over the life course cannot tread.

Palliative care’s acceptance of the chronology of a modern human life while simultaneously entering open-heartedly into the mysteries of living and dying, completes and strengthens the currently foreshortened global health narrative that is powerless in the face of nonpreventable death.

### Advocacy’s Kairos Deficit

An existential challenge of global palliative care advocacy—a challenge similar to the one faced by advocates for climate health, also a newbie in the global health agenda—is that it requires policymakers to project into the future, to an experience few have ever encountered up close and personal. Palliative care’s practitioners, supporters, and advocates tend to be called through a personal encounter with death, usually of a loved one. The quality of that experience, or lack thereof, more often than not confers the *palliateur* vocation. In the absence of such a personal experience, it is difficult for the “death naïve,” including key policymakers, to imagine or understand the urgent need for public health, rather than simply philanthropic or private provision of palliative care.

That peculiarly personal *kairos* deficit in global health epistemology has exponentially dangerous public policy consequences, as the “dying badly” and climate crises are both already upon us. Soon everyone will be affected personally, but the question is, will policymakers be prepared to meet the acute population level health needs associated with both? The answer is clearly no, unless policymakers and voters are prepared to think long term about caring for aging populations (themselves) with chronic diseases, as well as attending to short term epidemics and health security. The rational alternatives for those whose deaths can no longer be prevented are abandonment, euthanasia, and overtreatment, whose costs have both direct and knock-on effects on household wealth and development.

Palliative care is the ethical fourth way between abandonment, overtreatment, and euthanasia. It is an interdisciplinary response to nonpreventable death that reduces suffering in both quantifiable and nonquantifiable ways. Palliative care practitioners can relieve severe pain and symptoms and support “good,” as opposed to “bad,” dying in the ICU, at home in the center of a stressed-out family, in a prison, or in a refugee camp. Rather than the death sentence it is usually portrayed as, palliative care

is a way to make life, and nonpreventable death, as untraumatic as possible by reducing suffering wherever possible. Publicly provided palliative care can help in the effort to build civic trust and resilient communities, the foundation of the United Nation’s 2030 Agenda for Sustainable Development. ●

*Katherine Pettus is the senior advocacy and partnerships director for the International Association for Hospice and Palliative Care.*

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# HOW CAN HOSPICE AND PALLIATIVE CARE PROVIDERS ADDRESS ELDER ABUSE?

## LARRY BERESFORD

In June of this year, the National Partnership for Healthcare and Hospice Innovation (NPHI), a professional member organization representing established nonprofit hospice and palliative care providers, issued a white paper and resource guide called “[Breaking the Silence: Addressing Domestic Violence, Elder Abuse and Neglect.](#)” This release launched a campaign aimed at bringing greater attention to the widespread, underappreciated, and underreported epidemic of elder abuse—in all of its forms but for hospice and palliative care patients in particular.

The launch was held in conjunction with World Elder Abuse Awareness Day, June 15, created at the United Nations and observed around the world. Collaborating on NPHI’s project is the [NO MORE Foundation](#), which is dedicated to ending domestic and sexual violence through allied organizations, international chapters, and grassroots activities.

“Breaking the Silence” includes resources on elder abuse and insights into its prevalence and the various forms it takes while encouraging providers to screen for and respond to suspected abuse.

Elder abuse is defined as an intentional act or failure to act that causes or creates a risk of harm to an older adult. It can take many forms, according to the [Centers for Disease Control and Prevention](#), including physical, sexual, emotional/psychological, and financial abuse, along with neglect. A sixth category includes fraud and abuse perpetrated by the healthcare provider. Abuse is a trigger for mandated reporting by hospice and palliative care providers, among other health professionals, typically to the local Adult Protective Services (APS) agency.

What do hospices see regarding this kind of abuse? Several hospice administrators and clinicians

contacted for this article say actual out-and-out elder abuse as it is traditionally understood is less common than the range of challenging, chaotic, dysfunctional, difficult situations in the lives of their patients, in their chosen care setting, and with their designated care provider.

“If people think of elder abuse as an older person getting beat up or slapped or hit, we’re not seeing a lot of that,” said Tasha Walsh, LCSW PCC, CEO of ConnectionsPlus Healthcare + Hospice in Lexington, VA. “We’re seeing more elder neglect. And we’re often on the front lines dealing with such neglect and with dysfunctional family situations that are just not working.”

These dysfunctional situations could be triggered by poverty, substandard housing, drug use, mental illness, posttraumatic stress disorder and other traumas, prior abuse or other long-standing family conflicts, or a host of other challenges, even when the patient and caregiver are doing the best that they can to manage. But the dysfunction makes it hard for the team to deliver on its mission of facilitating a safe, peaceful final chapter of life for the enrolled patient and their family.

Abuse is often done by people who may mean well, but just lose it. “But it’s still abuse, and I think a lot of it could be prevented,” said Laura Mosqueda, MD AGSF FAAFP, professor of medicine at the University of Southern California Keck School of Medicine, advisor to the National Center on Elder Abuse, and an authority on elder abuse and care of older adults.

For hospices, abuse and dysfunction can present similar challenges in trying to serve patients safely and manage their terminal illness. And the typical response to these situations—which is to call APS—is also the same. But some experts wonder if elder abuse is getting the full attention it deserves from hospice and palliative care providers.

## A SILENT EPIDEMIC

“Our white paper calls this a silent epidemic,” said Cameron Muir, MD, a palliative care physician and consultant and lead author of NPHI’s report. It is known that between 2002 and 2016, more than 643,000 older adults were treated in an emergency department for nonfatal assaults, and more than 19,000 homicides occurred in this population.<sup>1</sup> Obviously, Dr. Muir said, the problem is more widespread than many realize. “We don’t know what we don’t know, and it’s a silent epidemic until we take it seriously and acknowledge that it is highly prevalent.”

Past abuse in the lives of hospice and palliative care patients and/or their family caregivers is also relevant but not much talked about. A history of trauma in many patients may call for a trauma-informed therapeutic response. And what if it’s the hospice worker who brings a history of abuse—such as experiencing domestic violence in their own lives?

Taking elder abuse, domestic violence, and neglect seriously means appreciating that we can put our colleagues and ourselves, along with our patients and families, at risk “if we don’t acknowledge that domestic abuse and violence may have been happening in this home 20 minutes before we got there,” Dr. Muir said. “If the hospices you are talking to say they don’t think actual elder abuse is as much of a problem for their patients, they are not acknowledging the data that exist or the safety needs of patients, families, and their own staff.”

***“WE DON’T KNOW WHAT WE DON’T KNOW, AND IT’S A SILENT EPIDEMIC UNTIL WE TAKE IT SERIOUSLY AND ACKNOWLEDGE THAT IT IS HIGHLY PREVALENT.”***

## REPORTING IS MANDATED

Just about everyone who provides health care for older adults is a mandated reporter of suspected abuse, Dr. Mosqueda noted. Making a report to APS rarely fixes the problem. “Still, for the person lying in feces or urine or being yelled at, we forget that any real solution involves getting more resources, talking to the patient and family, talking to other people.” And the way to initiate all of that is to make a report to APS.

Health providers can be trying so hard to understand the challenges the family is going through that they fail to act on suspected abuse, Dr. Mosqueda said. They can miss that something bad might be going on in the home because they are so busy trying to build a working rapport with the patient and family.

Sometimes team members are discouraged from making a report to APS because their employer doesn’t want to get a reputation among referral sources for making these reports or to jeopardize, for example, a relationship with a long-term care facility where abuse might be suspected. “We need to be reminded of our ethical and moral duty to the patient,” Dr. Mosqueda said.

“APS won’t pull patients out of their home against their will, if they have the capacity to make decisions,” Dr. Mosqueda explained. “But making a report is still mandated. You don’t ask for their permission.” She said she emphasizes to patients and families that making a report doesn’t mean there’s any plan to remove the patient from the home, but it’s legally required and an opportunity to try to get more help involved.

According to Dr. Mosqueda, “Sometimes you see a situation coming that you can anticipate. Pay attention to your Spidey-sense. If something starts to seem like it’s going off the rails, don’t wait for the abuse to happen.” Maybe call a family conference or invite someone from APS to meet with the team. It’s also important to talk to the patient without family present.

***“I THINK IT’S WORTH REMINDING OURSELVES THAT AS HOSPICE PHYSICIANS WE ARE IN A VERY SPECIAL TIME IN PEOPLE’S LIVES WHERE THEY TRUST US, AND WE WITNESS THINGS THAT OTHER PEOPLE DON’T WITNESS. AND THAT MAKES THE STAKES VERY HIGH.”***

## **IS REPORTING TO APS BEST?**

Dr. Muir said he is not comfortable viewing APS as the automatic answer to suspected abuse. “What we recommend is a referral to the National Domestic Violence Hotline or similar organization [see resource list at the end of this article]. My own experience is that APS often has limited options available to them and isn’t always helpful. They see the situation, and they say, ‘Sorry, this person seems to accept living in this situation. That’s just the way it is. Nothing is going to change.’”

Providers can make a lot of excuses for not reporting, even though it’s mandated for them, said Carla Perissinotto, MD MHS, a professor in the division of geriatrics at University of California San Francisco (UCSF). “I say that pretty firmly because it astounds me how much elder abuse is actually underreported. There is a hesitancy often with the elderly that you would not find with at-risk children. And I saw that directly in my work as a hospice medical director for different agencies. I think what this partially stems from is a lack of understanding of what elder abuse is,” she said.

“We’re talking about a dependent older adult, someone with a disability, someone who is dependent on others for their care. And all kinds of abuse go on out there. There’s also self-neglect, which we see a lot. And it can be really hard to tease out. But I think the average clinician needs to remember that it’s not our job as hospice professionals or other clinicians to determine whether there’s abuse or not. It is our job to report when something looks off and we don’t know what’s going on.”

That doesn’t require assigning blame, Dr. Perissinotto said. But who else is going to speak out about the problems? “What we are trying to say is that this patient looks like they’re being harmed or potentially harmed, and we need a second set of eyes to look into this. Whether it’s not turning the patient, whether it’s not treating their pain, whether it’s ignoring their physical complaints, whether it’s restraining someone against their will, intent is not part of the definition of elder abuse. So lack of intent should not be the reason why you don’t report,” she said. “Trust your gut. When something doesn’t feel right, it’s usually not right.”

Dr. Perissinotto has been active on the California Elder and Disability Justice Coordinating Council Steering Committee for the State of California and has worked with APS a lot. She said it’s important to appreciate that reporting requirements vary state to state. With cognitively impaired people, it can be hard to know what’s true. The patient might not be a reliable narrator. “But that’s what makes people more vulnerable and easier for others to prey on.”

Ultimately, she said, it’s about the basic principles and oaths taken by physicians, including first do no harm. “I think it’s worth reminding ourselves that as hospice physicians we are in a very special time in people’s lives where they trust us, and we witness things that other people don’t witness. And that makes the stakes very high.”

Dr. Perissinotto posed: What keeps you up at night? “Have you really exhausted all options? How can we think outside the box? Is this family truly acting in the patient’s best interest? These are questions we all should be asking.”

## **IS THE PATIENT TRULY INFORMED?**

The patient’s right to informed consent if they say they want to stay in problematic circumstances takes providers back to the basics of medical ethics, Dr. Perissinotto said. “Does the person truly understand the risks and benefits of their



living situation? And if the answer is yes, then you become a harm reductionist. But there is still a question of whether they have the capacity to understand. I would say to your readers that we often skip true capacity assessments because we assume that someone understands the risks and benefits of their living situation.”

For Ashwin Kotwal, MD, assistant professor of medicine in the division of geriatrics and coleader of the Social Connections and Aging Lab at UCSF, questions about abuse and neglect are complicated, distressing, and lacking easy answers. “But that’s one reason why palliative care has a big role in this issue, because we can draw on expertise from multiple disciplines. We actually get into people’s homes, while most of health care doesn’t have any idea what’s going on in the home.”

Dr. Kotwal said earlier referrals to hospice care can help, because it’s harder to get things done when the length of stay is short. “I tend to err on the side of earlier referral to hospice for socially complicated situations.” He also suggests that a concurrent model of conventional care and hospice, as is offered in the VA where he practices, can help encourage earlier referrals.

***THERE ARE 1- AND 2-HOUR TRAININGS FOR MEDICAL PROFESSIONALS ON DOMESTIC ABUSE SCREENING, ASSESSMENT, AND REFERRAL. WE RECOMMEND THAT ALL HOSPICE PROVIDERS GET THIS EDUCATION.”***

## **WHO ARE THE EXPERTS?**

How can this subject get the attention it deserves from hospice and palliative care teams? Dr. Muir said his experience as past president of AAHPM suggests to him that many of his colleagues don’t realize that elder abuse is as significant of a problem as it actually is—“truly a ‘silent epidemic.’”

In his work on the Innovation Lab at NPHI, whatever is the clinical topic at hand, Dr. Muir tries to pull in internal subject matter experts from the coalition’s member organizations. And usually at least five or 10 experts come forward. “In this case, no one emerged with any practice of any sort in this area, let alone best practices. Once I reviewed the literature, I wrote NPHI’s white paper because it became essential to share the significance of what I was learning.”

How can hospice and palliative care organizations address these complex issues? Start with educational materials and resources, Dr. Muir said. “There are 1- and 2-hour trainings for medical professionals on domestic abuse screening, assessment, and referral. We recommend that all hospice providers get this education.” There is also clear data to support that routine screening for domestic violence and elder abuse is both safe and useful.

“Next, know your local resources. APS obviously is one,” he said. Perhaps meet with APS staff at a time that doesn’t involve an active case so you can talk about how to work more closely together. Also, know your community’s crisis intervention resources, including safe houses for women who are victims of abuse, and be an activist for such services if they don’t currently exist. “If you are screening and identify abuse, you’ve got to be able to help people leave their current environment and get into a safe space,” Dr. Muir said, adding that advocacy is important. That could mean asking for more resources, even for the treatment of domestic violence and elder abuse as the “sixth vital sign.”

Gerontologist Jason Burnett, PhD, who directs the Texas Elder Abuse and Mistreatment (TEAM) Collaboratory at the University of Texas Health Science Center at Houston McGovern Medical School, is now doing research on elder mistreatment and neglect, including evaluating interventions. He recommends a new evidence-based approach called the [RISE](#) (Repair Harm, Inspire Change, Support Connection, Empower Choice) model for prevention of elder abuse and self-neglect. The RISE Foundation recently expanded its outreach into several locations across North America that are in various stages of implementation of this model.

## **ABUSE AT THE GRASSROOTS LEVEL**

Tasha Walsh said the clinical staff at ConnectionsPlus, based in rural Appalachian Virginia, are required to have abuse-and-neglect training upon hire and once a year thereafter. “The training we use for abuse and neglect is good. And we have APS come and do a presentation for our staff every year. We’ll also do updates that we weave into our interdisciplinary team meetings when these cases come up,” she said.

“In terms of the assessments we do, I’m not sure that we need a separate risk-of-abuse assessment process. But I do feel it is something that should be incorporated into basic safety assessments that all hospice providers should do. You know,



are there guns in the home? Is there a history of domestic violence?” she said.

“I’m taking a deep breath as I talk to you because I just came from a conversation with one of our social workers about a patient we’re currently seeing whose daughter isn’t providing him with the care that he needs,” Walsh said. “It’s a very sad situation. We have made an APS referral, and we are trying to find a placement for this gentleman so that he can get the care he needs.”

But this patient is not eligible for Medicaid—due to a technicality about property he owned. “He’s incapacitated and can’t make decisions for himself. His daughter is the only one around. There’s a question of whether she’s unwilling or unable—which may not be a helpful distinction. But it’s absolutely neglect,” Walsh explained.

“We’re going to refer to APS, and they are a resource, and they might be helpful. But it’s just part of the mix of complexities in this case. And honestly, the kind of help that they’re able to provide in this situation may not really help.” In another recent case, the hospice referred a patient to APS, which declined to get involved because the patient was under 65 years of age and thus ineligible.

For hospices, when you’re aware of a difficult situation and you’re doing everything you can, everything you can sometimes still isn’t enough, Walsh said. “There are no resources in this community for individuals like these to get help. And that’s where I get concerned for my staff, just the moral distress they feel from this situation. They’re doing everything they can and it’s still not enough to make the situation better—for the patient to get the care that’s going to keep them safe and comfortable.” ●

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*Larry Beresford is a medical journalist in Oakland, CA, with a strong interest in hospice and palliative care.*

## Resources

- [National Domestic Violence Hotline](#)
  - Call: 800.799.7233
  - Text: Text “START” to 88788
  - Chat: [thehotline.org](https://thehotline.org)
- [National Center on Elder Abuse](#)  
(managed by the University of Southern California Keck School of Medicine)
  - Call: 855.500.3537
  - Email: [ncea-info@aoa.hhs.gov](mailto:ncea-info@aoa.hhs.gov)
- [Institute for Trauma and Resilience Studies](#)  
(formerly the Institute for Family Violence Studies; Florida State University College of Social Work)
- [Center of Excellence on Elder Abuse and Neglect](#) (University of California, Irvine)
- [CDC Intimate Partner Violence Prevention](#)
- [Eldercare Locator](#)
  - Call: 800.766.1116
- [The National Clearinghouse on Abuse in Later Life](#) (a national project of [End Domestic Abuse Wisconsin: The Wisconsin Coalition Against Domestic Violence](#))
- [National Adult Protective Services Association](#)
  - Call: 202.370.6292
- [National Adult Protective Services Training Center](#)
- [The National Elder Fraud Hotline](#)  
(Office for Victims of Crime)
  - Call: 833.372.8311
- [The National Long-Term Care Ombudsman Resource Center](#)
  - Call: 202.333.2275



# THE STATE OF DIVERSITY, EQUITY, AND INCLUSION IN MEDICINE

*Arshia Madni, MD FAAP, Corey Tapper, MD MS, Noelle Marie Javier, MD, Shellie N. Williams, MD FAAHPM, Jon P. Furuno, PhD FAAHPM*

Diversity, equity, and inclusion (DEI) in medicine was born out of the attempt to protect diverse and marginalized patient populations and clinicians from the impacts of bias and racism they face in healthcare spaces. As a result, DEI initiatives intend to equalize the starting point and resources for populations with historically limited access to ensure equitable opportunities. Multiple studies in the fields of hospice and palliative medicine have revealed that Black, Indigenous, and people of color (BIPOC; inclusive of Latinx, Hispanic, Asian American, and Pacific Islander) as well as lesbian, gay, bisexual, transgender, queer, intersex plus (LGBTQI+) patient populations have been on the receiving end of ineffective symptom management, poor communication, and unfulfilled end-of-life wishes compared to their White, cisgender, straight counterparts. Similarly, BIPOC and LGBTQI+ clinicians have felt unseen, unheard, and continue to experience bias and racism by patients and colleagues alike. This type of negative work environment is demoralizing and can lead to qualified individuals not receiving promotions and not having mentorship and allyship opportunities for career development.

Anti-DEI bills have been passed in multiple states across the country, which are undoing the progress made over the last several years. Benefits and services that have grown from DEI programs charged with protecting underrepresented populations to promote equitable care and equal access to academic opportunities are being abolished.

Dismantling DEI initiatives in medicine and in academic medicine curricula presents devastating consequences of access to care, quality of care, and associated patient outcomes. This would further expand disparities between marginalized and majority populations in medicine. Studies strongly support the association between patients'

experiences with their medical care and race, ethnicity, and gender concordance with their healthcare providers. Furthermore, a less diverse provider population will result in reduced provider knowledge and ability to provide patient-centered care to an increasingly diverse patient population.

## Impact of Anti-DEI Efforts: Voices from the Frontlines

The following is a collection of voices from the AAHPM community impacted by anti-DEI legislation. They preferred to remain anonymous.

"I am worried about the future of care for my pediatric palliative care patients. My state has been very vocal about removing any DEI education for our students, which can impact how they view the

importance of giving equitable care."

"I was at a conference where board members were very loudly and proudly sharing their

views on supporting anti-DEI bills. I was taken aback at how they felt so comfortable, if not entitled, to proclaim these views, and now I, being someone who stands for justice, is expected to bite my tongue".

"With more than 500 bills being introduced in congress impacting the LGBTQI+ community, I am worried about further oppression and disenfranchisement regarding basic human rights to high-quality health care, education, and policies that are supposed to be protective for the community."

"The backlash by some in society towards DEI initiatives has led some academic institutions—including mine—to both backstep from these activities and withhold support from leaders in this field. As a member of the LGBTQI+ community who promotes DEI initiatives, it makes me wonder if my institution will continue to have my back."



LEARNING • ACHIEVING • BELONGING

"I practice in a state that is a DEI champion; however, I fear the impact on recruitment and retention of talented clinicians of BIPOC identification in anti-DEI states. We have the privilege of career to geographically be selective; however, no one is considering the impact on loss of race concordance in care in these states when we further limit access to medical training for marginalized communities!"

## What Are the Next Steps?

Though anti-DEI legislation impacts the landscape of DEI presence in institutions, it does not impact the vision, especially from those who are passionate. AAHPM remains committed to diversity, equity, inclusion, and justice. Those of us caring for patients who are marginalized and from underrepresented communities are still responsible for providing high-quality, inclusive, affirming, and equitable care. Furthermore, and addressing a common misperception, implementing DEI initiatives does not threaten majority access, but rather seeks to limit disparities in opportunities resulting from environmental and socioeconomic disadvantages. It is critical to dispel this misconception and continue to vocalize the needs and goals of DEI and how a more equitable healthcare environment will benefit us all. ●

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*Arshia Madni, MD FAAP, is an assistant professor of pediatrics and associate program director of the hospice and palliative medicine fellowship at the University of Tennessee Health Sciences Center/Le Bonheur Children's Hospital. She also is chair of AAHPM's DEI Committee.*

*Corey Tapper, MD MS, is an assistant professor of medicine at Johns Hopkins University School of Medicine.*

*Noelle Marie Javier, MD, is an associate professor in the Brookdale Department of Geriatrics and Palliative Medicine at the Icahn School of Medicine at Mount Sinai in New York. She also is chair-elect of AAHPM's DEI Committee and past-chair of AAHPM's LGBTQI+ special interest group.*

*Shellie N. Williams, MD FAAHPM, is an associate professor of medicine in the section of geriatrics and palliative medicine at The University of Chicago.*

*Jon P. Furuno, PhD FSHEA FAAHPM, is a professor in the department of pharmacy practice at Oregon State University College of Pharmacy.*



## AAHPM POINTS OF PROGRESS

### Advance the Field

#### Faculty Development Tool Kit

The Assessment Work Group is collaborating with the Accreditation Council for Graduate Medical Education (ACGME; by invitation) to develop a faculty best in practice resource tool kit. They are creating a specialized “train the trainer” course for faculty development, which is tentatively scheduled for release in spring 2025. They are also working on producing two videos for the tool kit, centered on delivering serious news. The group convenes virtually once a month, with asynchronous tasks between sessions. The project is slated for completion in 2025.

#### Fellowship Training

The Fellowship Training Committee has been developing a best practices repository that program directors and associate program directors can use when they identify an area for improvement. This repository will be a way to generate ideas, see what other work people have done, and contact programs to learn about their best practices.

#### Palliative Care Quality Measures Project

Two new patient-reported experience measures are available for palliative care and other healthcare clinicians to implement in their practice. Specifically, the measures assess the quality of care provided by asking how much patients felt heard and understood, and if patients got the help they wanted for their pain.

As of January 2024, one measure (Feeling Heard and Understood) is available for any clinician to report on within the Merit-Based Incentive Payment System (MIPS).

To maintain this measure in the program, AAHPM is now participating in the Quality Measures Management and Support measure stewards meetings. These monthly calls are hosted by the Centers for Medicare and Medicaid Services (CMS) to keep track of how measures are performing in CMS quality reporting programs.

In addition, Katherine Ast, director of quality and research at AAHPM, will serve on the advisory

board of RAND’s new study on patient-reported outcome measures, including “Feeling Heard and Understood” and “Help Wanted for Pain,” in palliative care telehealth.

For implementation and quality improvement support, please see AAHPM’s free [Implementation Guide](#).

The *Journal of Pain and Symptom Management* published [Patient-Reported Quality Measures for Palliative Care: The Time Is Now](#), which places the new measures in the overall context of quality measurement for the field.

### Support Professional Success



#### Annual Assembly 2025: AAHPM-Hosted Preconference Workshops

Announcing AAHPM’s slate of preconference workshops for 2025 Annual Assembly:

- HMD Certification Review Course and Update Full-Day Workshop  
*Presented by Bethany Snider, MD HMDC FAAHPM, Balakrishnan (Balu) Natarajan, MD HMDC, and Bethany Calkins, MD MM HMDC FAAHPM*
- Striking a Balance: Understanding Pain Management and Opioids—A Case-Based Curriculum
  - This half-day Medication Access and Training Expansion Act- and Opioid Analgesic REMS-compliant preconference workshop is offered at no charge to preregistered attendees through an independent educational grant from the Opioid Analgesics REMS Program Companies.





- Outpatient Palliative Care: Clinical and Program Management  
*Presented by Christian Sinclair, MD, Eric Goodlev, MD, Kira Skavinski, DO, and Esme Finlay, MD*
- Reconstructing Palliative Care Clinical Practice: Interrogating and Innovating  
*Presented by Vickie Leff, MSW LCSW APHSW-C, and Terry Altilio, MSW ACSW LCSW*
- The Symptomatic Estuary, Where Palliative and Hospice Meet: Advanced Complex Symptom Management in the Terminally Ill Patient (AAHPM and SPPCP Collaborative)  
*Presented by Samuel Perna III, DO, Michelle Krichbaum, PharmD BCPP, and Laura Meyer-Junco, PharmD BCPS CPE FASCP*
- Pharmacotherapy Considerations for Challenging Symptoms in Serious Illness: The Goldilocks Guide  
*Presented by Mary Lynn McPherson, PharmD PhD BCPS FAAHPM, Eric Widera, MD, Jeremy Hirsch, MD, Max Stevenson, PharmD MA BCPS, and Alex McPherson, PharmD MPH*
- Empower: Elevating Personal Leadership through Self-Discovery and Strategic Business Planning (AAHPM and CAPC Collaborative)  
*Presented by Rodney Tucker, MD, Perihan El Shanawany, MD HEC-C, Tom Gualtieri-Reed, MBA, and Donna Stevens*
- Best Practices and Beyond: Updates in Fellowship Education  
*Presented by Stephen Berns, MD FAAHPM, and Laura Dingfield, MD MSED FAAHPM*
- Using Art to Build Connection and Find Meaning: An Experience at the Denver Art Museum  
*Led by Laura Morrison, MD FAAHPM, and Gordon J Wood, MD FAAHPM*

## 2024 Intensive Review Course

AAHPM hosted its biennial Intensive Review Course and Update in Louisville, KY, in August, bringing together over 200 MDs, DOs, physician assistants, and nurses to prepare for the HPM board examination and learn the latest updates in hospice and palliative practice. Here's what learners had to say:



- “[This course] was an excellent prep with [an] exceptional faculty team and not only validated my knowledge and my practice [but also] gave me important updates on advances in the field.”
- “I learned more about what I don’t know and how much I need to update my knowledge. By doing so, I will become a better physician to my patients.”
- “I came away with so many pearls to directly improve my work in palliative [care] and feel more confident about taking the boards exam this fall.”
- “This course has greatly improved my practice.”

2024 Intensive Review Course recordings are now available.

## Learn

Check out the Academy's new CME/MOC activities available on Learn.



- On-demand self-study [2024 Intensive Review Course](#) recordings offer 24.5 CME/MOC credit awards.
- On-demand self-study [Essential Psychiatric Skills for the Palliative Care Practitioner](#) offers 5.0 CME/MOC credit awards.
- Quarterly Grand Rounds Lecture Series: “The Importance of Being Human: Reflections of an Aspiring Medical Humanist” with Joe Rotella, MD MBA HMDc FAAHPM (Recording will be made available.)

## Leadership Scholarship

Congratulations to AAHPM's Leadership Scholarship recipients:

- **Ashley Autrey**, MD, Children's Hospital New Orleans (South, pediatrician)
- **Andrea Cuvillo**, MD FAAP, Phoenix Children's Hospital (pediatrician)
- **Harry Han**, MD, Beth Israel Deaconess Medical Center of Harvard Medical School
- **Lindsay Marszal**, MD, University of North Carolina (pediatrician)
- **Allison Silverstein**, MD, University of Colorado School of Medicine (South, pediatrician)

## Advocacy Update

AAHPM was invited by Rep Earl Blumenauer's (D-OR) office to provide comments on a legislative discussion draft on hospice integrity and payment. The legislation is entitled “Hospice Care Accountability, Reform and Enforcement

(Hospice CARE) Act” and covers multiple areas related to hospice policy. A copy of AAHPM’s [comment letter is here](#). This legislation has now been introduced as [HR 9803](#) and the Academy’s Hospice Policy Ad Hoc Work Group will continue to address policies that will impact hospice integrity.

AAHPM [submitted comments](#) on the Medicare Physician Fee Schedule proposed rule. Comments were drafted with input from both the Public Policy and Quality Committees. The Academy’s comments addressed issues related to the proposed physician pay cuts that would result from the proposed rule, discussed issues related to telehealth and MIPS, and responded to a request for information on building the MIPS value pathways (MVP) framework to improve ambulatory specialty care.

AAHPM [submitted comments](#) to CMS in response to the Fiscal Year 2025 Hospice Wage Index and Payment Rate Update [proposed rule](#). The letter focuses on proposals related to the Hospice Quality Reporting Program as well as a request for information related to payment for high-intensity palliative care services. The letter also urges CMS to pursue higher-impact strategies to address program integrity under the Medicare hospice benefit.

AAHPM [submitted comments](#) to the House Energy and Commerce Committee on a [proposal to reform](#) the National Institutes of Health ([summary document](#)).

AAHPM participated in a meeting with the Office of Management and Budget to discuss the existing proposed rule regarding the use of telehealth to prescribe controlled substances, which was originally issued in 2023. AAHPM reiterated its position that the Drug Enforcement Administration (DEA) account for the unique needs of seriously ill patients—including those near the end of life—when finalizing policies related to the prescribing of controlled substances via telemedicine. The Academy had previously submitted comments on this proposed rule, and Joe Rotella, MD, [provided testimony](#) to the DEA on this proposed rule.

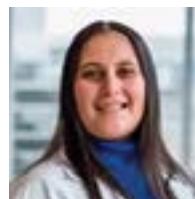
## Build a Vibrant Community

### Research

AAHPM Science Advisor Stacy Fischer with support from Areej El-Jawahri and Laura Hanson have been working diligently on operationalizing AAHPM’s vision to grow and sustain a home for an interdisciplinary community of palliative



*Stacy Fischer*



*Areej El-Jawahri*



*Laura Hanson*

care scientists. To this end, the science advisors are meeting with internal stakeholders like the Research and Quality Committees, staff, and board members to share the vision and solicit feedback. Outreach to external stakeholders, such as the American Geriatrics Society, American Society for Clinical Oncology, and the National Coalition for Hospice and Palliative Care, among others, has also kicked off, to learn from other organizations’ efforts with their research communities.

In the U54 grant application, “Advancing the Science of Palliative Care Research Across the Lifespan (ASCENT) Consortium,” AAHPM pledged support through their science advisors to prioritize and implement new and ongoing research initiatives in alignment with the ASCENT Consortium, ensuring synergy, cooperation, and collaboration.

Former Palliative Care Research Collaborative Special Interest Group members were able to join “Research Collaboratives” on AAHPM’s Connect platform and received complimentary AAHPM membership for 1 year.

### Quality

AAHPM was represented on a task force of the National Coalition for Hospice and Palliative Care to discuss updating the Clinical Practice Guidelines for Quality Palliative Care, currently in its fourth edition. The task force’s efforts focused on scoping the work required to update the guidelines, with the goal being to develop a budget to inform funding requests. One important focus of the group was to identify key conditions to warrant updates to the guidelines, such as innovations in clinical practice, advancements in technology, emergence of new evidence, shifts in health policy, uptake of telehealth, and the need to address equity.

As part of the American Board of Medical Specialties (ABMS) certification standards, ABMS member boards were asked to undertake a process, in collaboration with stakeholder organizations, for supporting an agenda to improve the quality of care in their specialties, with one area of emphasis involving eliminating health care disparities. AAHPM shared its top issues, including

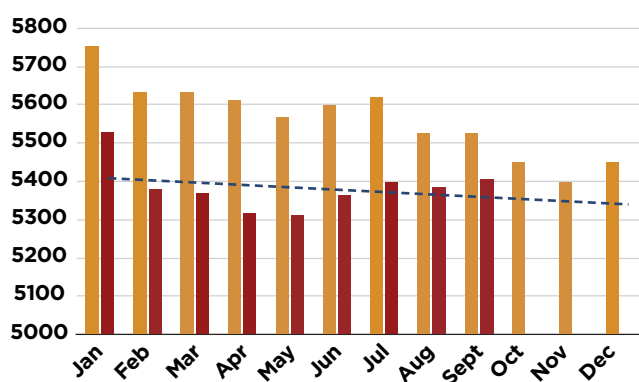
1. goals of care and shared decision making
2. relief and prioritization of symptoms.

The “Feeling Heard and Understood” measure could act as a surrogate for patient-reported perception of having whole-person care, regardless of who is providing that care, while the “Help Wanted for Pain” measure could fall under the “relief and prioritization of symptoms” bucket.

## Membership

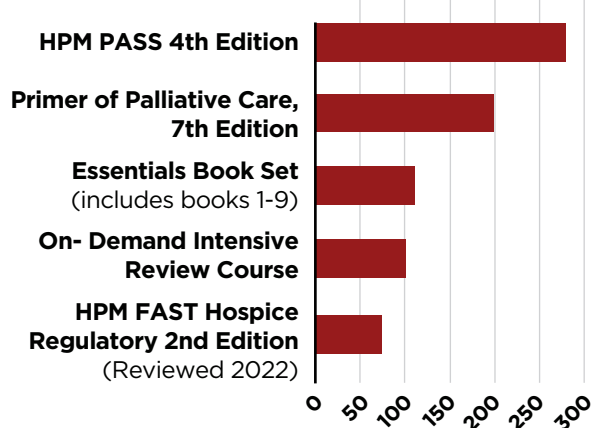
Currently, AAHPM has 5,405 total members. Membership numbers remain consistent with prepandemic levels as the Academy conducts a survey to gauge current membership.

### Total Membership; Trends 2023/2024



The best-selling products from AAHPM between July 1 and October 1, 2024, include the HPM PASS 4th Edition, *Primer of Palliative Care* 7th Edition, *Essentials* Book Set, and the HPM FAST 2nd Edition. The fourth edition of the *Hospice Physician and Medical Director Manual* is coming in the spring.

### Q3 2024 Top 5 Product Sales By Quantity



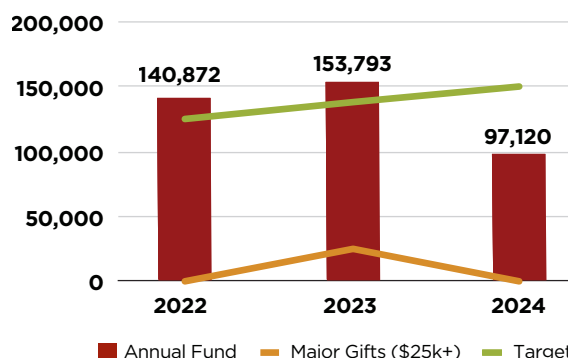
## Ensure a Strong Organization

### Development Update

With \$98,813, development has reached 65% of its total revenue goal. Revenue is expected to pick up significantly with Q4 campaigns, including mentors of excellence, #GivingTuesday, and the year-end appeal.

Typically, 60% or more of AAHPM’s annual revenue is received in the last 2 months of the calendar year. ●

### Total Giving by Year



## HMDCB UPDATE



### Presidential Transition

HMDCB wants to thank **Dr. David Wensel** for serving as the board president for the past 2 years. Dr. Wensel was instrumental in overseeing the development of the new Continuing Certification Program, helping the organization

grow partnerships with external organizations, and expanding HMDCB's educational offerings to best meet the needs of certificants. Dr. Wensel is a selfless leader, and HMDCB is incredibly thankful for his time as president.



HMDCB also wants to welcome **Dr. Todd Cote** as our next board president. Dr. Cote joined the board in 2020 and has served as director at large, treasurer/secretary, and president elect. Dr. Cote brings a wealth of hospice knowledge and years of experience

into the president's role. HMDCB looks forward to his leadership and all he will accomplish throughout his term.

### Hospice Super Forum

HMDCB partnered with AAHPM to host the Hospice Super Forum on **November 14, 2024**. The three-session virtual event covered trending topics in hospice care, including complex symptom management, hospice deprescribing, and hospice ethical challenges. The 2024 recording will be available in early 2025, and the next Hospice Super Forum is being planned for Q4 2025. Visit [www.HMDCB.org/events](http://www.HMDCB.org/events) for updates.

### HMDCB Community Events

HMDCB invites all certified physicians to attend its 2025 community events! Most events are free for certificants and provide an opportunity to expand your hospice knowledge and connect with your peers.

The next event is a webinar focused on medical aid in dying. This session will take place on January 21, 2025, at 1:30 pm CT.

To learn more and register for all upcoming events, visit [www.HMDCB.org/community](http://www.HMDCB.org/community).

### Become Certified in 2025

Do you want to highlight your knowledge as a hospice physician? Would you like to join the HMDCB community and gain access to exclusive educational and networking events? Then we encourage you to become HMDCB-certified. The next opportunity to take the HMDCB initial examination is in 2025, and the application will open on Monday, **January 27**. Start preparing now by reviewing the eligibility requirements and exam prep resources available at [www.HMDCB.org/exam](http://www.HMDCB.org/exam).

### Advertise with HMDCB

Attention hospice employers! HMDCB invites you to promote your organization, educational activities, and/or jobs to more than 1,200 dedicated hospice physicians and medical directors through its advertisement program. Popular options include webinar sponsorship, sponsored emails, and newsletter ads. Visit [www.HMDCB.org/advertising](http://www.HMDCB.org/advertising) to learn more.

### Contact HMDCB

HMDCB staff are happy to answer your questions or assist you. Contact HMDCB staff at [info@hmdcb.org](mailto:info@hmdcb.org) or call 847.375.6740 ●





## AAHPM PARTNER UPDATE

# PALLIATIVE CARE QUALITY COLLABORATIVE HOSTS THIRD ANNUAL VIRTUAL QUALITY MATTERS CONFERENCE

The Palliative Care Quality Collaborative (PCQC) hosted its third annual virtual Quality Matters Conference (QMC) November 20-22, 2024. QMC is a 3-day virtual event that brings together thought leaders to share best practices, opportunities, and innovations that promote high-quality palliative care.

Each year, PCQC designates a new theme for the conference that is imperative to quality. The theme for this year's conference was *Identifying Various Perspectives of Quality*, with the goal of bringing interprofessional subject matter experts together to have conversations where we recognize that quality looks different depending on where a person may sit in the health system.

### **The objectives of the discussions during QMC 2024 included**

1. what quality means at each level of an organization
2. what differences exist in enacting quality between these levels
3. how we can come together to synthesize these perspectives to create unity throughout organizations.

New this year, PCQC offered a 2-hour Quality Improvement Basics Workshop as part of registration. During this session, participants learned fundamental quality improvement skills to improve upon their operational and care processes.

Regardless of experience in quality, participants received actionable skills to promote a culture of quality within their program. The jointly accredited conference welcomed all members of the field to learn about quality standards and improvement skills through expert presentations, peer networking, and participatory workshop formats. Conference details for QMC are available on PCQC's website at [www.palliativequality.org](http://www.palliativequality.org). ●



## AAHPM NEWS

# CONGRATULATIONS, 2024 AAHPM RESEARCH SCHOLARS

AAHPM's Research Scholars Program aims to advance the scientific endeavors of new or early-career investigators whose goal is to become independent scientists actively involved in palliative care research. Seven professionals were selected for the program this year and attended the annual Kathleen M. Foley Palliative Care Retreat and Research Symposium September 25-27, 2024, in Cape Neddick, ME, alongside AAHPM President Vicki Jackson, Science Advisor Stacy Fischer, Quality and Research SCC Chair Rebecca Aslakson, Quality and Research staff Katherine Ast, and many others.

- **Bethany-Rose Daubman**, MD FAAHPM, Massachusetts General Physicians Organization
- **Carine Davila, MD MPH**, Massachusetts General Hospital
- **Lyndsay DeGroot**, PhD RN CNE, University of Colorado School of Medicine
- **Tessa Jones**, PhD LMSW, Icahn School of Medicine at Mount Sinai
- **Lingsheng Li**, MD MHS, University of California, San Francisco
- **Lauren Pollack**, MD MS, University of Washington
- **Casey Walsh**, PhD MSW, Fred Hutchinson Cancer Center

For 17 years, AAHPM has been cosponsoring this retreat and sending six new early-career researchers, expenses paid, to benefit. In 2024, AAHPM received 28 applications and chose seven scholars. The scholars represent research excellence and diversity of discipline and population studied. ●



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