STATE SENATOR ESSE

January 10th, 2024

Representative Moses, Chair Members of the Assembly Committee on Health, Aging, and Long Term Care

#### Testimony on 2023 Assembly Bill 736

AMES 23RD DISTRICT

Relating to: establishing a Palliative Care Council.

Thank you, Chairman Moses and other members of the committee, for hearing my testimony on Assembly Bill 736 today. Health care is a complex world; different people have different conditions that require different levels of care. Palliative care is not limited to any age or prognosis, but instead focuses on helping anyone with a serious or chronic illness with tailored support to improve the quality of life.

Palliative care treatments range from person to person, but in general, palliative care often includes: medication, nutritional help, emotional and spiritual support, relaxation techniques, and support for the patient's family. The treatment timeline also varies depending on if a patient is able to make a full recovery, it's a lifelong chronic condition, or it eventually evolves into a terminal illness. This differs from hospice care, which is end-of-life care for those with life-threatening illnesses with an expectancy of six months left to live. Palliative care teams also work with social workers and chaplains to provide a comprehensive treatment approach. This type of treatment should be available to any patient or family that wishes to utilizes it, but unfortunately, lack of access and education on palliative care prevents people from utilizing it.

That is what is legislation aims to address. This bill would establish a Palliative Care Council through the Department of Health Services, with a goal of trying to promote the education and awareness of palliative care. This 22 person council would be comprised of medical and clinical professionals, as well as actual patients and families from all over the state to work with DHS on the following palliative care issues: evaluating established palliative care programs, the effectiveness of palliative care that is provided along with treatment, the reimbursement for palliative care services, and any other issues relating to palliative care the council finds appropriate. This bill also requires DHS and the council to establish educational and informational programs for patients and professionals about palliative care services.

Living with a chronic or serious illness takes a toll on the patient, family, friends, and other caregivers. Palliative care aims to help everyone involved with the healing and treatment process. This tailored care helps improve the quality of life for these patients and is worth investing in. Thank you, and I will take any questions at this time.

Respectfully,

Senator Jesse James 23<sup>rd</sup> Senate District <u>Sen.James@legis.wisconsin.gov</u>



State of Wisconsin Department of Health Services

Tony Evers, Governor Kirsten L. Johnson, Secretary

TO: Members of the Assembly Committee on Health, Aging, and Long-Term Care

FROM: HJ Waukau, Legislative Director

DATE: January 10, 2024

**RE:** AB 736 relating to: Establishing a Palliative Care Council

The Wisconsin Department of Health Services (DHS) would like to submit written testimony for information only for Assembly Bill 736 (AB 736), relating to the creation of a Palliative Care Council (Council) within DHS. AB 736 specifies the size, member requirements, and responsibilities for the Council. It also requires the Council to consult and advise DHS on the evaluation of established palliative care programs, the economic and quality of life efficacy of palliative care, mechanisms for reimbursement of palliative care, best practices, and any other palliative care issues the Council would determine as appropriate; and submit reports to the legislature. DHS would also be required to establish and make publicly available a statewide palliative care consumer and professional information and education program. Additionally, AB 736 prohibits the Council from consulting with or advising DHS on physician-assisted suicide, euthanasia, medical aid in dying, or any other act that would condone, authorize, approve, or permit any act to end life other than the withholding or withdrawing of health care under an advance directive or power of attorney for health care.

It is well documented Wisconsin has an increasingly aging population with those who are age 60-plus growing 38 percent since 2010.<sup>1</sup> As Wisconsin's population continues to age palliative care is likely to play an increasing role in how people receive care and treatment. Palliative care as a treatment modality has been shown to improve quality-of-life outcomes for patients,<sup>2</sup> lower costs and hospital visits,<sup>3</sup> and improve both patient and family experiences.<sup>4</sup> It has been shown to be an effective method of treatment for a wide range of illnesses<sup>5</sup> including but not limited to cancer,<sup>6</sup> pediatric care,<sup>7</sup> and dementia.<sup>8</sup>

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Protecting and promoting the health and safety of the people of Wisconsin

<sup>&</sup>lt;sup>1</sup> "Vintage 2022 Estimates of National, State, and County Population by Age, Sex, Race, and Hispanic Origin; and Estimates of Puerto Rico Commonwealth and Municipios Population by Age and Sex," United State Census Bureau, last accessed January 8, 2024, <u>https://www.census.gov/newsroom/press-kits/2023/population-estimates-characteristics.html</u>.

<sup>&</sup>lt;sup>2</sup> S Milazzo et al. "How Effective is Palliative Care in Improving Patient Outcomes," *Current Treatment Options in Oncology* 21, no. 12 (2020) doi: <u>10.1007/s11864-020-0702-x</u>.

<sup>&</sup>lt;sup>3</sup> KL Quinn et al. "Association between palliative care and healthcare outcomes among adults with terminal noncancer illness: population based matched cohort study," *BMJ* 370 (2020) doi: <u>10.1136/bmj.m2257</u>.

<sup>&</sup>lt;sup>4</sup> M Glajchen et al. "Family Meetings in Palliative Care: Benefits and Barriers," *Current Treatment Options in Oncology* 23, no 5 (2022) doi: <u>10.1007/s11864-022-00957-1</u>.

<sup>&</sup>lt;sup>5</sup> AE Singer et al. "Populations and Interventions for Palliative and End-of-Life Care: A Systematic Review," *Journal of Palliative Medicine* 19, no. 9 (2016) doi: <u>10.1089/jpm.2015.0367</u>.

<sup>&</sup>lt;sup>6</sup> J Mathews et al. "Models of Integration of Specialized Palliative Care with Oncology," *Current Treatment Options* in Oncology 22, no. 5 (2021) doi: <u>10.1007/s11864-021-00836-1</u>.

<sup>&</sup>lt;sup>7</sup> MS Weaver et al. "Palliative Care as a Standard of Care in Pediatric Oncology," *Pediatric Blood & Cancer* Suppl 5, (2015) doi: <u>10.1002/pbc.25695</u>.

<sup>&</sup>lt;sup>8</sup> N Weisbrod, "Primary Palliative Care in Dementia," *Neurotherapeutics* 19, no. 1 (2022) doi: <u>10.1007/s13311-021-</u><u>01171-x</u>.

The Council created under AB 736 could help in promoting awareness and best practices for palliative care in Wisconsin. Neighboring states Minnesota and Illinois have also created palliative care councils with similar requirements and structures as AB 736. Under AB 736, DHS would be responsible for developing consumer and professional education materials, external communications such as a website, coordinating between council members and the legislature, and assisting with meeting logistics. 1.0 FTE would be needed for the communication and education activities and a 0.5 FTE would be needed for coordination between council members, the legislature, and meeting logistics. The Council will also incur operational costs for materials, equipment, lodging, meeting space, and other related costs. DHS estimates the staffing needs will cost \$117,200 GPR annually and the operational costs will be \$23,766 GPR, for a total estimated cost of 1.5 FTEs and \$158,216 annually. AB 736 as currently drafted does not provide funding for DHS to administer and oversee the functions of the Council. By comparison Minnesota provides for administrative services for its council, and Illinois provides for reimbursement of council member expenses.

Additionally, DHS does not oversee the scope of practice for the professions that would be on the Council, nor does it have expertise in the area of palliative care. As such this would be a new program area for DHS to develop. While evaluating and promoting best practices for palliative care may be worthwhile endeavor, DHS does not currently have the capacity or expertise to sufficiently run a Council. Without sufficient funding for operations DHS would not be able absorb the costs of a Palliative Care Council as defined by AB 736 at this time.

DHS thanks the Committee for the opportunity to provide written testimony for information only and offers itself as a resource for the Committee.

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Moving Wisconsin Hospice & Palliative Care Forward

| то:   | Honorable Members of the Assembly Committee on Health, Aging and Long-Term Care   |
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| FROM: | Danielle DiGennaro<br>Director of Supportive Care, Agrace<br>on behalf of the Wisconsin Hospice & Palliative Care Association (WiHPCA)                        |
| DATE: | January 10, 2024  |
| RE:   | Assembly Bill 736, related to creation of a Palliative Care Council to advise the Wisconsin Department of Health Services and provide reports to Legislature. |

Good morning, Chair Moses, Vice Chair Rozar, Ranking Member Subeck, and members of the Assembly Committee on Health, Aging and Long-Term Care.

My name is Danielle DiGennaro, and I am the Director of Palliative Care at Agrace, which is a nonprofit, community-based health care agency; I have been a palliative care nurse practitioner for nine years. Agrace provides hospice and supportive/palliative care services in private homes, and in skilled nursing, assisted living and other community based residential facilities across southern Wisconsin. Agrace is a member of WiHPCA – the Wisconsin Hospice and Palliative Care Association.

I have worked in four states and at multiple institutions including private, non-profit, and academic health centers. While each state's scope of practice, licensing and regional practice patterns vary, one consistent element has been the lack of understanding of palliative care. According to the Center to Advance Palliative Care (CAPC) "Palliative care is specialized medical care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of the illness. The goal is to improve the quality of life for both the patient and the family. Palliative care is provided by a specially trained team...to provide an extra layer of support. Palliative care is based on the needs of the patient, not on the patient's prognosis...and it can be provided along with curative treatment."

Throughout my practice, I have expected to educate patients and families on the nuances of palliative care services, however, I am routinely surprised by the lack of understanding among the public and medical professionals. I was fortunate to start an inpatient palliative care service at a 550-bed hospital and during my seven years there, I interviewed physicians on how they utilize palliative care and where they see added benefit to their practice and patients. The most frequent, and honest, answer was "I don't know exactly what palliative care is, but I know when I need help on a case". While it is fortunate that those providers recognized when extra support provided superior care, it is disappointing to hear the continued lack of understanding around palliative care - even within the field of medicine.

Palliative care continues to be considered a relatively new medical field and was born out of hospice care. It wasn't until 2006 that the American Board of Medical Specialties recognized hospice and palliative care as separate specialties. There are multiple studies that show disease directed therapy, concurrent with

palliative care, reveals patient-centered benefits such as increased quality of life and in some cases, increased survival.

The proposed legislation will help combat misunderstandings regarding this important medical specialty, which focuses on improving quality of life. The multidisciplinary council proposed will have a breadth of experience, including medical professionals, a health insurance representative, members of the Legislature and importantly, patients and families. I'll end with a story, and while the details have been slightly changed to protect patient privacy, it exemplifies common themes throughout palliative care.

Fatima is a palliative care patient suffering from chronic obstructive pulmonary disease (COPD). She lives with her adult son and is on home oxygen. She is not fluent in English. She gets overwhelmed easily by clinic appointments, including the quick questions in English and the walk through the facilities. She finds herself anxious and increasingly short of breath as the visit unfolds. As a result of her increasing anxiety and resulting shortness of breath, she has frequent emergency room visits, rarely resulting in hospitalization and instead providing reassurance and discharge. Palliative care was involved at the request of her pulmonologist, who struggled to be as responsive and available as Fatima and her family needed to keep her out of the emergency room. A palliative care team worked closely with Fatima's primary care provider, pulmonologist, and family, coordinating care, and providing visits at her home. Her palliative care team included providers who helped prescribe medications to ease her symptoms, but also provided education about her prognosis and what to expect in the future. The palliative care social worker was available to provide options such as in-home care and placement should her care become overwhelming for her family. Ultimately, she was able to significantly reduce her emergency room utilization and spend more time at home, with an improved quality of life.

For Fatima, palliative care could have been integrated into her care sooner to help avoid emergency room visits related to uncontrolled symptoms. By eliciting goals of care from individual patients and families, palliative care can help align stated goals with what medical care is reasonable. It would have been expected for a palliative care team to partner with Fatima earlier in her illness trajectory and describe what to expect, such as worsening symptoms with exertion, like walking into a clinic. Earlier intervention may have also collaborated with physical therapy to build strength or request an assist device such as walker or wheelchair or help obtain a handicapped parking permit.

The creation of a Wisconsin Palliative Care Council could help elevate awareness of palliative care among providers – thereby helping more patients like Fatima, and their families.

Thank you for your time and consideration of my testimony in support of Assembly Bill 736. Please contact WiHPCA's government relations representatives, Tim Hoven (at 414.305.2011 or tim@hovenconsulting.com) or Nathan Butzlaff (at 608.310.8833 or nathan@hovenconsulting.com) if you have any questions or need additional information.

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| TO:   | Members of the Assembly Committee on Health, Aging and Long-Term        | Care |
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| FROM: | Najmus Sehar Liang, MD<br>Medical Director, Wisconsin, VITAS Healthcare |      |
| DATE: | January 10, 2024  |      |
| RE:   | Assembly Bill 736 – a bill establishing a state palliative care council |      |
|       |   |      |

Good morning- Chair Moses, Vice Chair Rozar, Ranking Democratic Member Subeck - and committee members.

I thank the committee chair for scheduling a hearing on this bill today and I am humbled and privileged to testify in support of Assembly Bill 736. I am a dual Board-Certified Family Medicine & Palliative and Hospice Care Physician. I have been practicing Palliative & Hospice Medicine for the last 6 years and have been graced by the utmost heartwarming and bittersweet encounters.

My training in Palliative & Hospice care was at a well-established hospital network in Bethlehem, Pennsylvania. As a full-fledged Palliative Physician, I moved to Wisconsin to lead an established Palliative Care Practice consisting of a Social Worker, Licensed nurse, Chaplain, and two advanced practitioners. We as a team had the opportunity of establishing a Palliative consulting service for patients suffering from life limiting diseases in the hospital and offer these individuals individualized care plans including understanding values, goals, and addressing symptoms including pain, anxiety, hunger for air, depression, loneliness and much more.

It took over a year to have other consultants including hospital-based doctors who regularly perform rounds in a hospital, cardiologists, pulmonologists, interventional radiologists, intensive care unit clinicians, emergency department clinicians, physical/speech/occupation/respiratory therapists and many more to understand the true value of Palliative Care Services when it is offered and practiced by compassionate, highly trained, and dedicated staff.

Within two years in my first role as a Palliative Care Physician, we were able to reduce rehospitalization rates, have the quickest palliative care referrals out of all the other hospitals in the network, and have our emergency department geriatric-palliative certified. Not only was our work recognized at the local level, but we also received grants and donations from patients/families/community members as they understood the value of patient-oriented care with an entire team dedicated to their advocacy.

Palliative care is a service like any other specialty, such as a heart or lung specialist that you see, except the individual is not looked at as a single failing organ system. This type of care can be provided at any age and any stage in someone's disease trajectory with a focus on excellent symptom management and support for any individual and their loved ones.

The most regretful aspect of my career as a Palliative Care physician is the question that I have been asked over a thousand times by patients and families – a question that I am still not able to answer – "Why didn't we meet you sooner?" Indeed, there are studies that prove that when palliative care is involved at the time of a cancer diagnosis, those patients live longer and have a better quality of life. We know from experience that navigating the healthcare system is exquisitely challenging and to have access to a team dedicated to your loved one's dignity, quality of life, and values whilst they are battling with a life-threatening illness can only ameliorate their situation and give their loved one peace of mind.

In writing this testimony, so many individuals and their loved ones came to mind, but I wanted to share a story of a 48-year-old husband and father of two young adult women. Both daughters are highly involved in sports and require their father to accompany them to competitions. Unfortunately, the father has a rare genetic disease that only a few people have in the entire world. This disease is so debilitating and rare that it usually is not diagnosed.

This spouse and father, who is also a hospital executive who enjoys hiking, fishing, and family time, spent the majority of his adulthood with debilitating bone pain, kidney stones, fractures, and strains/sprains of his muscles without any known cause. When this individual finally did get diagnosed and was under the care of an endocrinologist, he was able to self-advocate for a referral to palliative care services.

From the time of referral to palliative services and within a few months of the palliative team's involvement, he had over fifteen encounters with the palliative care team involving the different disciplines to address his care as a whole. Various members of this team contributed to his care, including a palliative social worker, who worked on insurance approval for his multimillion-dollar treatment; a chaplain, who provided psychosocial support not only for him but his family; and a registered nurse, who had discussions about medication education with the patient.

In addition, his palliative clinician collaborated with an endocrinologist, an orthopedic surgeon (bone surgeon), the hospital team, and a pharmacist to put in place a concise plan of care, including advance care planning, to address his significant pain. (As he had a horrible bone disease, chest compressions would be harmful but other resuscitative measures would be accepted like a breathing tube, medications to resuscitate his heart, etc.). This plan required medications that were previously only allowed to be administered in a hospital setting – either in the emergency department or requiring hospitalization with heart monitoring. After his palliative care team advocated for him by educating the hospital's medical committee, the hospital approved a ketamine protocol in which the pain medicine could be administered orally, instead of via injection. In fact, his palliative care team convinced the hospital to make this change not only for him, but for others in similar situations.

It's quite a process for someone to be admitted to the hospital and get pain medications, even for somebody in his role. I am proud to share this successful story of how palliative care services can benefit not only the person dealing with life-limiting disease, but also their loved ones, as well as removing additional burdens to the healthcare system.

Assembly Bill 736 would help improve awareness of palliative care in Wisconsin among the general public, health care providers and health care facilities. There is a dire need for more trained professionals that choose palliative care as their calling. Ultimately, the creation of a palliative care council would help more patients access this type of valuable care.

Again, thank you for holding a hearing on Assembly Bill 736. I am happy to answer any questions you may have.

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American Cancer Society Cancer Action Network Sara Sahli, WI Government Relations Director 608.215.7535 sara.sahli@cancer.org fightcancer.org/wisconsin

January 10th, 2024

Chairman Clint Moses Assembly Committee on Health, Aging and Long-Term Care Public Hearing, Assembly Bill 736

Good morning, Chairman Moses and members of the committee, my name is Sara Sahli, I'm the Government Relations Director for the American Cancer Society Cancer Action Network (ACS CAN) in Wisconsin. ACS CAN, our board members, our volunteers, and our staff advocate for public policies that reduce death and suffering from cancer.

I am here today to testify in favor of Assembly Bill 736 which seeks to improve health care quality and outcomes, through the delivery of patient-centered and family-focused care by establishing a state advisory council on palliative care. I would like to recognize and thank Representative Snyder as the lead sponsors as well as members on this committee who are among the bi-partisan cosponsors.

Palliative care is a type of coordinated care that is designed to work alongside curative care by treating the whole patient, not just the disease. It is appropriate at any age and any stage – whether the diagnosis is chronic or terminal - and is designed to improve the quality of life for a cancer patient, and by extension, their family, and caregivers by providing an extra layer of support. A patient's palliative care team focuses on things such as relieving pain and managing treatment-related physical, emotional, social, financial, and spiritual needs. The team itself might include a social worker, an occupational therapist, a physical therapist, a mental health professional, a dietician, and if appropriate, a chaplain. Each team is designed to treat a specific patient, but whatever the case, the goal is to improve quality of life and help reduce health care costs.

Improving the quality of life for cancer patients during and after treatment is one of the American Cancer Society, and the American Cancer Society Cancer Action Network's main goals. Studies have shown that when palliative care teams work together with oncologists, patients are able to remain at home – they don't end up in the ER and hospital with pain and symptom crises. As a result, they go through fewer unnecessary tests and procedures, which in turn leads to lower costs. In short, palliative care programs provide higher-quality care for patients and a better bottom line.

While palliative care is a rapidly growing specialty, it is still not found in all areas of the state, which is why it's important to identify existing barriers to this care and ensure that accurate, comprehensive information and education about it is made available to the public, health care providers and health care facilities. ACS CAN contends that AB 736 is key to doing this, and in fact 35 other states have passed similar legislation.

Establishing a committee that can evaluate the palliative care system in Wisconsin and make policy recommendations to the legislature on how to improve it will help all patients with serious or chronic conditions and their families get the care and support that they need. Palliative care, especially the parts of palliative care that do NOT address end-of-life care, have received little attention at the state level, and with Wisconsin's coming age wave, now is the time to talk about how patients can have the highest quality of life for as long as possible.

Thank you for the opportunity to testify, and I urge you to vote yes on Assembly Bill 736.

Page 1 of 1

To: Members of the Assembly Committee on Health, Aging and Long-Term Care

From: Chad William Spitz

Date: 10 January 2024, 10:00AM

RE: Assembly Bill 736 - A bill establishing a state palliative care council

Good morning committee leadership- Chair Moses, Vice Chair Rozar, Ranking Democratic Member Subeck and members of this committee.

My name is Chad William Spitz, son of the late Mark William Spitz for whom I am speaking. My father was a soldier and a great, patriotic man. Thank you for holding this hearing, as well as the invitation to allow my father's voice to be heard through me.

It was the statement from my father to his Palliative Care Physician Dr Liang; "You must do the same for others as you have done for me" that would ultimately place me before this committee today. It was just before Christmas of 2021 when we found ourselves comforting my father during his battle with both cancer and COVID. My father would endure a 17-day battle fighting the symptoms of both. While he was admitted to the hospital, the physician that was there that day would come in and perform his checks and tests and come to the same conclusion – they would tell my mother and father that the inevitable was near and to start planning for end-of-life measures. However, for my father, giving up was not an option. He did not give up on anything or anyone he believed in.

My father was able to summon the courage to convince himself that, or at least portray to others, that he would beat this. In a way, he did. My father would eventually be discharged from the hospital with will and courage and smiling ear to ear because he had in fact, in his mind, played that he beat both cancer and COVID and was walking out. It, however, was not his sheer will alone that gave him this. It was the care of a young and determined Palliative Care Physician who did exactly what Palliative care is supposed to do, but also went above and beyond with creative treatments, out of the box thinking, compassion, the ability to listen, and most importantly, an ability to understand and apply what Palliative Care is.

Palliative Care is not Hospice Care. This has been a misunderstanding for many years. Hospice and palliative care are two essential branches of healthcare that focus on improving the quality of life for individuals facing serious illnesses. While they share common goals, there are crucial distinctions between the two. Hospice care is typically provided to individuals in the final stages of a terminal illness, emphasizing comfort and support for both the patient and their family. Palliative care, on the other hand, can be initiated at any stage of a serious illness and is aimed at alleviating symptoms, managing pain, and enhancing overall well-being.

It was because of the Palliative Care approach executed by his physician, Dr. Liang, which gave my father strength, will, determination, and desire on top of his already fierce determination to live and fight on for another 5 months. While 5 months may not seem like a long time for some, it was a lifetime for us. During this period, we still had a family Christmas, he was able to spend more time at his favorite place, the cabin, he was able to stand up in my wedding, celebrate my birthday, have everyone over for Easter, celebrate another birthday with my mother and celebrate Mother's Day. During this time period as

January 10, 2024

Representative Clint P. Moses, Chair and Members of the Assembly Committee on Health, Aging and Long-Term Care

RE: Opposition to AB 736 creating a Palliative Care Council within DHS

Dear Representative Moses and Committee Members:

Thank you for the opportunity to explain why I oppose AB 736.

I am a retired attorney and CPA who has worked on health care issues for 40+ years. I ran employee benefit programs at the Department of Employee Trust Funds and at the University of Wisconsin. I served on Governor Thompson's task force on health care costs. As an elder law attorney, I advocate for the elderly and disabled and wrote health care decision making articles for a State Bar publication. I currently serve on the board of the Euthanasia Prevention Coalition USA as immediate past chair and their resource person for palliative care. Palliative care is an extension of hospice and a pathway to hospice.

I am not against good palliative care for those who choose it. I appreciate your desire to help folks. Sadly, dangerous palliative care is often identified too late; distinguishing it from safe palliative care is difficult. I have seen many cases where people who were not terminal were tricked into hospice (comfort care) which then went on autopilot with strong drugs followed shortly by death. Many palliative care programs are owned by hospices and used as "loss leaders" <sup>1</sup> to enroll people sooner and sometimes inappropriately in hospice. Palliative care programs are financially unstable, leading to cost saving<sup>2</sup> justifications and the resulting pressure for inappropriate clinical decisions. This is why protective language in the Bill is important. The Bill's sponsors recognize this need and have included protective language at s.146.695 (2)(b).

The proposed protective language in AB 736 at s.146.695 (2)(b) is unenforceable because it violates the Free Speech protections of the U.S. Constitution. It also allows euthanasia by omission as it is limited to acts. Section146.695 (2)(b) says:

<sup>&</sup>lt;sup>1</sup> Palliative Care Needs a Defined Scope to Expand Access, Reimbursement, Hospice News Oct. 2022 at <u>https://hospicenews.com/2022/10/20/palliative-care-needs-a-defined-scope-to-expand-access-</u>reimbursement/

<sup>&</sup>lt;sup>2</sup> Savings typically accrue to providers not the State because Medicaid pays flat fixed rates for hospitalizations and many other services. So, if Medicaid pays \$20,000 per case and the provider spends \$13,000, thereby saving \$7,000, the State pays the provider \$20,000 and the provider keeps the \$7,000.

The council may not consult with or advise the department on physicianassisted suicide, euthanasia, medical aid in dying, or any other act that would condone, authorize, approve, or permit any affirmative or deliberate act to end life other than the withholding or withdrawing of health care under an advance directive or power of attorney for health care so as to permit the natural process of dying.

Consultation and advice to the Department of Health Services by a government entity such as the Palliative Care Council is protected speech under the First Amendment which AB 736 cannot restrict. Even speech directed at people encouraging or advising them to commit suicide is protected as long as it does not explain how to commit suicide. There are two cases on point from Minnesota, one decided by the state's Supreme Court and another by the state's Court of Appeals.

Melchert-Dinkel posed as a depressed and suicidal nurse online who encouraged others to commit suicide by hanging themselves while he watched online. In <u>State v.</u> <u>Melchert-Dinkel</u>, 844 NW2d 15 (MN 2014) the Supreme Court of Minnesota held the State, consistent with the First Amendment, can prosecute a person for assisting another in committing suicide but not for encouraging or advising another to commit suicide. Assisting means "...speech or conduct that provides another person with what is needed for the person to commit suicide... [such as] instructing another on suicide methods..."

A subsequent case, <u>State v. Final Exit, Inc.</u>, 889 NW2d 296 (MN App 2016), applied the Supreme Court's holding to an organization, Final Exit, Inc. which advocates for assisted suicide and also provides "exit services" to individuals. The advocacy is protected speech, but the "exit services" which instruct the individuals about how to commit suicide using a helium filled hood and provide addresses of companies that supply the materials are not protected speech. Exit guides attend the death and then remove the hood and helium tank.

The language I have recommended in the past would chill dangerous palliative care practices. It would amend s.50.90(3) by excluding "the intentional hastening, assisting or causing of deaths" from the definition of palliative care for the licensing of medical and care organizations.

I will be happy to answer any questions or provide additional information. If AB 736 were amended to exclude hastened death from the statutory definition of palliative care, I would reconsider my opposition to the legislation.

Sincerely,

/s/ Attorney Sara Buscher



#### Testimony in Opposition to Assembly Bill 736: establishing a Palliative Care Council Assembly Committee on Health, Aging and Long-Term Care By Matt Sande, Director of Legislation / January 10, 2024

Good morning, Chairman Moses and Committee members. My name is Matt Sande and I serve as director of legislation for Pro-Life Wisconsin. Thank you for this opportunity to express our opposition to Assembly Bill (AB) 736, legislation that would establish a Palliative Care Council within the Department of Health Services.

Pro-Life Wisconsin has had serious concerns with legislation establishing a state Palliative Care Council since it was first introduced in 2017. The past several sessions we remained confident that, working with the bill authors, our concerns could be alleviated. Some changes have been made to the legislation that have been beneficial, such as adding primary care physicians along with patients and family members who have received palliative care services to the council membership. Other changes have been detrimental, such as removing anesthesiologists, pharmacists, and patient advocates from the council membership. **Our most critical concern, amending the statutory definition of "palliative care" to specifically exclude intentionally ending life, has gone unheeded.** To be sure, we do not question the intentions of the authors in forwarding this legislation - we know they are good and noble.

Pro-Life Wisconsin continues to believe that it is not the place of government to create such a council. We prefer to let the medical community create their own, private palliative care council and educate the public and legislature on best practices. Beyond that, we would prefer to have the legislature first create a balanced study committee to assess the need for appropriate palliative care and its safety.

It is critical that palliative medicine be understood and defined as managing pain, not hastening death – or rather, helping dying patients live well, not helping patients die. According to hospice physician and Duke University professor Farr Curlin, many families have said that when "hospice and palliative medicine (HPM) professionals became involved in their care, their loved ones were put on powerful drugs, became unconscious and unresponsive, and were soon dead. These stories are clearly shared within communities and powerfully shape people's perceptions of HPM, which many see as a sophisticated and seductive way of getting people to die." (*Excerpts from Farr A. Curlin, MD Hospice and Palliative Medicine's Attempt at an Art of Dying, ch 4 in Dying in the Twenty-First Century, edited by Lydia Dugdale, MD, MIT Press 2015*)

Dr. Curlin further explains that "(w)hen the goal of HPM shifts from helping patients who are dying to helping patients die, practices that render patients unconscious or hasten their death no longer seem to be last-resort options." The heavy opioids/sedatives that are a part of current palliative care drug protocols can easily cause overdoses that result in respiratory failure. Accountability measures for patient safety are of the utmost importance. As you will hear from

PRO-LIFE WISCONSIN, INC PROLIFEWI.ORG INFO@PROLIFEWI.ORG P.O. BOX 221 BROOKFIELD, WI 53008 262.796.1111 FACEBOOK.COM/PROLIFEWI TWITTER.COM/PROLIFEWI YOUTUBE.COM/PROLIFEWI physicians testifying today, the practice of palliative medicine in the field is quite controversial. How medicine is practiced and with what intention can make it salutary or deadly.

**Pro-Life Wisconsin opposes sedating people to death in the name of palliative medicine. We support reducing pain, fatigue and other symptoms thus allowing patients to actively participate in dying well. That is true palliative medicine**. Accordingly, we support amending the current law definition of "palliative care" found in Wis. Stat. 50.90(3) to specifically exclude intentionally hastening, assisting in, or causing death. Regrettably, the palliative care community has continually and steadfastly resisted amending the statutory definition of palliative care to exclude hastened death, and without any satisfactory explanation. This is deeply troubling, and I urge Committee members to press them for an answer.

Another critical reason it is imperative to place safeguards directly in the definition of palliative care is that the proposed protections included in AB 736 on page 4, lines 15-20, creating s.146.695(2)(b), violate First Amendment free speech protections. **Wisconsin elder law attorney Sara Buscher, the immediate past chairperson of the Euthanasia Prevention Coalition USA, provides written testimony today stating**,

"Consultation and advice to the Department of Health Services by a government entity such as the Palliative Care Council is protected speech under the First Amendment which AB 736 cannot restrict. Even speech directed at people encouraging or advising them to commit suicide is protected as long as it does not explain how to commit suicide. There are two cases on point from Minnesota, one decided by the state's Supreme Court and another by the state's Court of Appeals."

Attorney Buscher then summarizes the two Minnesota cases which clearly demonstrate that the protective language in AB 736 would not withstand a challenge on free speech grounds. I encourage Committee members to read it closely. To resolve this dilemma, the definition of palliative care in s.50.90(3) needs to be amended to exclude hastened death. This would not violate free speech because s.50.90(3) does not concern speech. Rather, it lays out conditions of being licensed and of qualifying for reimbursements for providing palliative care services. This is the proper statute to add any protective language around the practice of palliative medicine.

It is imperative that palliative care be collaborative and integrated. Palliative care physicians and practitioners must work with primary care doctors to ensure full knowledge of patient medical history and patient end-of-life wishes so as to provide the most appropriate type and level of care. We believe the current makeup of the council as proposed in AB 736 is too heavily weighted toward palliative care doctors and specialists. We support amending the bill to include anesthesiologists, pharmacists, patient advocates (especially those for disabled people), health care professionals that have pain relief and symptom management work experience, more primary care doctors, and more patients.

In sum, if our shared goal is to promote safe and responsible palliative care, we must understand and employ it as pain management promoting activity and interaction, not sedation inducing premature death. We believe this goal can be achieved by properly amending AB 736, and if that can happen, Pro-Life Wisconsin would strongly consider removing our opposition to the legislation and even supporting it. Thank you for your consideration, and I am happy to answer any questions from Committee members.



### WISCONSIN CATHOLIC MEDICAL GUILDS

Upholding the Principles of the Catholic Faith in the Science and Practice of Medicine

January 10, 2024

| То:   | Members, Assembly Committee on Health, Aging, and Long-Term Care  |
|-------|---|
| FROM: | Robin Goldsmith, MD, State Director, Wisconsin Catholic Medical Guilds<br>Elizabeth Anderson, MD, Assistant State Director; President - Madison Catholic<br>Medical Guild |
| RE:   | Assembly Bill 736 – to establish a Palliative Care Council under Department of Health Services  |

Good morning Chairman Moses and members of the Assembly Health Committee.

My name is Elizabeth Anderson. I am an emergency medicine physician here in Madison. I graduated from the Medical College of Wisconsin in 2005 and completed my residency at Froedtert Hospital in Milwaukee in 2008. I have been an ER physician here in Madison since then. I am also the current president of the Catholic Medical Guild of the Diocese of Madison and the Assistant Director of the Wisconsin Catholic Medical Guilds. I am here today on behalf of the Wisconsin Catholic Medical Guilds which represents the six guilds of the Catholic Medical Association throughout Wisconsin, with more than 100 physician and healthcare provider members.

I am here today on behalf of the Wisconsin Catholic Medical Guild to speak in opposition to Assembly Bill 736.

The World Health Organization states that palliative care: "provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patients illness and in their own bereavement; uses a team approach to address the needs of patients and their families."

I include this definition because it is important to distinguish palliative care from hospice care. Unfortunately, these are often used interchangeably and even practitioners generally consider these a continuum. In fact, at least 50% of home-based palliative care programs are administered by hospice agencies, which helps grow hospice. (https://hospicenews.com/2020/09/25/amedisys-expanding-palliative-care-operations/)

Assembly Bill 736 seeks to establish a state Palliative Care Council. Evaluating the availability and need for Palliative care resources in Wisconsin is important. Palliative care can be a very positive and beneficial addition to a patient's care and to their families. However, the bill as currently written has some very concerning components. The make-up of the committee is heavily weighted to palliative care practitioners. Current protocols in palliative care in Wisconsin contain concerning doses of medications including sedatives (such as Propofol) and opiates

(such as fentanyl) that could in fact hasten death in patients. As such, a broader spectrum of specialties, such as anesthesiologists who are specifically trained in these medications, is needed. We also believe that for the safety of patients, any definition of palliative care needs to include that it does not intentionally hasten, assist in, or cause death. Palliative care and hospice utilize very powerful sedating medicines and high dose opioids that can be helpful to terminal patients who are in severe pain but can also be dangerous, especially when given to people who are not in pain.

Although we appreciate the authors' addition of two primary care physicians to the council membership in AB 736, we would like to see more. These are the physicians who know their patients' medical, emotional, and psychological condition, as well as their end-of-life wishes, the best. Primary physicians have expressed concerns re: palliative and hospice care, including rapid demise of hospice patients, loss of contact with patients after hospital admission, and transfer to hospice without notifying the primary physician.

As physicians, we have taken the Hippocratic oath. Hippocratic principles of medicine may seem old fashioned. However, the point is we treat persons in a most vulnerable state of illness who can be taken advantage of by various parties, some even with good intentions, including insurance companies or health care institutions that have their bottom financial line to worry about; as well as organizations interested in promoting "death with dignity" for those whose lives they deem "not worth living."

Hippocratic medicine means our patients are our solemn charge, and we must not allow their most important decisions to be delegated to others. We have vowed to put our patients first, superseding all other considerations, despite being told this is not "best practice" or "evidence based." Situations, which may include palliative care and hospice, where non-physicians with no previous medical experience are trained to explain to patients the disadvantages of life sustaining treatments are inexcusable. Ideally, palliative care should be managed by, and the community/legislature educated by, the medical community and not a government entity.

As representatives of the Wisconsin Catholic Medical Guilds, we urge you to amend AB 736 to include in the definition of palliative care, as mentioned above, that it does not intentionally hasten death. We also urge you to assess the make-up of the proposed council, so it is more inclusive of multiple specialties that are involved in palliative care and the medications used, including more primary care physicians, anesthesiologists, and pharmacists, as well as more patient care advocates including a disability rights member.

With the changes, we would be able to consider supporting this bill as a means to identify and promote ethical and excellent palliative care.

To: Members, Assembly Committee on Health, Aging and Long-Term Care

Re: Opposition to AB 736, establishing a state Palliative Care Council

Date: Wednesday, January 10, 2024

Good morning, Chairman Moses, and members of the Assembly Health Committee. Thank you for allowing me to speak in opposition to Assembly Bill 736.

My name is Dr. Stephen Pavela. I am a retired Internal Medicine physician from La Crosse, Wisconsin. I am Board Certified in Internal Medicine and practiced in La Crosse for 39 years. I was a Department Chair and a Chief of Staff for my hospital system. I also taught Internal Medicine to Family Practice Residents for 34 years.

My practice included the hospital care of patients, including intensive and acute cardiac care; outpatient clinics, as well attending at local nursing homes. I did the end-of-life care for all my patients throughout my career. I was involved in the beginning of the hospice movement in the 1990s. In the last 5 to 10 years of my practice, the Palliative Care specialty was introduced to my healthcare system. Since I was the long-time physician for my adult patients I took care of them right up to the end of their lives, whether they were in hospital, at home or in a long-term care facility. I took care of my own patients who were on hospice care. I tell you all of this so that you understand that I am thoroughly familiar with palliative and hospice care, both its good points and its failings.

In my opinion, done well and done ethically, palliative care and hospice care can be beneficial to patients. Despite this ideal, I am here to tell you that on the local, practical level this is frequently not the case. Why do I say this? Because I have observed it and have heard it from the families of my patients. For example, the families would be surprised that despite an oncologist's estimate of lifetime in weeks or months, when palliative care transitioned the patient to hospice, their loved ones died so quickly. The main culprit in most of these cases was the inappropriate sedation of their loved ones by excessive dosing of medication to treat pain and perceived shortness of breath. Because of this excessive use, the families felt deprived of their loved one's alertness and their companionship in their last days. Another culprit, I often found, was the aggressive discontinuance of even routine medications for on-going chronic conditions that had nothing to do with the primary terminal illness. Medications for diabetes or cardiac conditions were often prematurely withdrawn. I don't mean to say what I am describing happens in all cases, but it happens enough that family members would call on the phone or come into my office a bit bewildered at the rapid unexpected death of their loved one. A Catholic priest friend of mine observed that he used to go to a deathbed to administer the last rights to a dying person and be able to talk to them. But he notes that in recent years in most cases that person is unarousable due to sedation.

What I am telling you is common knowledge among primary care physicians. And, in recent years, there is another problem. Today, except for rural areas, hospital care is done not by the primary physician but by hospitalists. When a patient with a serious medical condition, possibly terminal, is admitted to the hospital, a palliative care consult is routinely placed by the hospitalist, and upon discharge the patient is either sent home or to a nursing home without any communication to the primary physician. All the counseling is done by physicians unknown to the family. The patient is quickly transitioned to hospice care. The quality of that care highly depends on the physician and nurses directing that care and may not match the values of the family as they only are assigned a team, not the ones they choose.

I have found that the best protection for a patient is an inquisitive family member, or a primary care physician known and trusted by the family who can appropriately assess recommendations being made by Palliative Care or the Hospice team.

Again, I am not testifying that this is a universal occurrence, but it happens often enough to be known by longtime physicians who have observed the evolution in endof-life care in recent years.

When I look over AB 736, I note the make-up of the council is very heavy on those practicing Palliative Care. Only two primary care physicians are included. In my opinion, this is exactly opposite of what it should be. Most of the council should be made up of those skilled in the ongoing long term primary care of patients. Not just those who enter the person's life for only a short time. Also, the council should include pharmacists and anesthesiologists who are medication and pain care specialists who can help supervise proper protocols and the use of medications.

I have second more fundamental objection to AB 736. Why is the state getting involved with this specialty at all? Shouldn't it be done by private healthcare systems who are responsive to the local needs of their patients? Shouldn't the need be started at the grass roots level, rather than directed "top-down" from the governmental level?

We have just been through several years of the Covid pandemic. During that time, a government agency, namely, the Center for Disease Control (CDC), made numerous "recommendations" regarding lock downs, school closures, travel restrictions, and masking. It actively interfered with the medical profession's prescribing of medication. And how did that turn out? The CDC's so-called "recommendations" were taken as necessary mandates by most institutions. But we now have scientific evidence that almost all those recommendations had no effect on Covid disease spread, were unnecessarily mandated, and in some cases caused great harm. This is an example of government attempt to control medicine "top down."

What I am saying is that if something is worth doing and of great value, the private sector will see that it is done; it doesn't need government involvement. So, I am curious as to the origin of this bill? Where is the evidence that a government sponsored palliative care council is needed? There is no similar government sponsored council for any other specialty in medicine such as pediatrics, surgery, or cardiology. Why this one? From my own experience, it is not necessary.

For these reasons I oppose the passage of AB 736. Thank you for listening to my concerns.



#### WISCONSIN CATHOLIC CONFERENCE

TO: Representative Clint Moses, Chair Members, Assembly Committee on Health, Aging and Long-Term Care

FROM: Barbara Sella, Executive Director

DATE: January 10, 2024

RE: Opposition to Assembly Bill 736, Palliative Care Council

On behalf of the Wisconsin Catholic Conference, the public policy voice of the bishops of Wisconsin, thank you for the opportunity to testify in opposition to Assembly Bill 736, which would establish a palliative care council.

The Catholic Church supports the use of quality palliative care for those who are gravely ill and at the end of life. As Pope Francis has stated:

Palliative care is an expression of the truly human attitude of taking care of one another, especially of those who suffer. It is a testimony that the human person is always precious, even if marked by illness and old age. Indeed, the person, under any circumstances, is an asset to him/herself and to others and is loved by God. This is why, when their life becomes very fragile and the end of their earthly existence approaches, we feel the responsibility to assist and accompany them in the best way.<sup>1</sup>

True palliative care, which improves a suffering person's life and that of their loved ones, is the appropriate response to human suffering and disease. Studies show that when patients receive proper physical, psychological, emotional, and spiritual care, they live longer and score substantially higher on quality-of-life measures. In short, true palliative care is meant to help manage pain and care for individuals who are dying, not to hasten their death. We support and encourage efforts to provide more true palliative care options for patients in Wisconsin.

However, any public policy designed to aid those who are vulnerable and facing serious illness cannot include any means of treatment that values expediency over life. Nor can we encourage a system of care that places undue cultural, financial, or other pressures on an individual to hasten the end of his or her life. And while there are many testimonies of true palliative care, unfortunately there are also growing testimonies of palliative care that has hastened death.

In past sessions, the WCC, along with other groups here today, has requested that the authors include clear protection for those at the end of life. The current bill prohibits discussion with the department on "physician-assisted suicide, euthanasia, medical aid in dying, or any other act that would condone, authorize, approve, or permit any affirmative or deliberate act to end life."

Regrettably, however, the bill does nothing to prohibit the actual practice of hastening someone's death, especially via the overuse of sedatives and opiates.

The best way to protect patients is to amend the current definition of palliative care in Wisconsin statute. The definition in Wis. Stat. 50.90(3) should explicitly state that palliative care excludes intentionally hastening, assisting in, or causing someone's death. Until this change is made, either by amending this bill or introducing another one, the WCC cannot support the creation of a state palliative care council.

We are deeply indebted to physicians and other professionals who continually strive to provide compassionate and appropriate care for their patients. As individuals and as a society, we can and must comfort those facing serious illness and reassure them that we cherish their continued presence. We can and must tell them that their need does not diminish their value. We respectfully urge the authors of this bill to make this explicit by amending the bill.

Thank you again for the opportunity to testify today.

<sup>&</sup>lt;sup>1</sup> Address of His Holiness Pope Francis to Participants in the Plenary of the Pontifical Academy for Life (March 5, 2015), <u>http://w2.vatican.va/content/francesco/en/speeches/2015/march/documents/papa-</u>francesco 20150305 pontificia-accademia-vita.html

# L fe WISCONSIN

TO: Members, Assembly Committee on Heath, Aging, and Long-Term Care
FROM: Gracie Skogman, Legislative Director, Wisconsin Right to Life
DATE: Wednesday, January 10th, 2024
RE: AB 736, Relating to: establishing a Palliative Care Council.

Thank you, Chairman Snyder and members of the committee, for your time today. My name is Gracie Skogman, and I am the Legislative Director of Wisconsin Right to Life.

Wisconsin Right to Life fully supports better education on palliative care as a life-affirming alternative to physician assisted suicide. We applaud the efforts of Rep. Patrick Snyder and Senator James for bringing forward this legislation as a good faith effort to improve education in this important area of healthcare.

With that said, at this time Wisconsin Right to Life has a few concerns with the legislation as written. We have sadly seen in too many states great medical organizations and advisory bodies hijacked by the pro-assisted suicide movement. Often, the tactic is to bring up assisted suicide in the conversations of a council or organization that is not actually dedicated to discussing that issue, to push for it to take a position on assisted suicide.

Since conversations about palliative care can be so closely tied to other end-of-life conversations, we believe there may be a chance for assisted suicide advocates to try a similar sort of sabotage for the Council being discussed today, even though the goal of the Palliative Care Council is laudable.

As currently written, the committee's make-up is weighted to palliative care practitioners and does not include medical professionals, such as anesthesiologists, trained in the medications used under palliative care protocols. We support amending the bill to ensure that the voices within the council be further diversified to include patient advocates, non-medical personnel, and primary care physicians who also have a stake in this issue and can offer real-life scenarios that should be addressed for palliative care in this state to improve. We also ask that the definition of palliative care be further clarified to ensure it does not intentionally hasten, assist in, or cause death.

Thank you very much for your time,

Gracie Skogman



Date: January 10, 2024

To: Chairperson Moses and members of the Assembly Committee on Health, Aging and Long-Term Care

From: Janet Zander, Advocacy & Public Policy Coordinator

Re: Support for AB 736 – Establishing a Palliative Care Council

Thank you for this opportunity to share testimony on AB 736. The Greater Wisconsin Agency on Aging Resources, Inc. (GWAAR) is a nonprofit agency committed to supporting the successful delivery of aging programs and services in our service area consisting of 70 counties (all but Dane and Milwaukee) and 11 tribes in Wisconsin. We are one of three area agencies on aging (AAAs) in Wisconsin. We provide lead aging agencies in our service area with training, technical assistance, and advocacy to ensure the availability and quality of programs and services to meet the changing needs of older people in Wisconsin. Our mission is to deliver innovative support to lead aging agencies as we work together to promote, protect, and enhance the well-being of older people in Wisconsin.

Palliative care is specialized care focused on the pain, symptoms and stress of serious illness. Though palliative care is a rapidly growing specialty, this type of care aimed at improving the quality of life for both patients and their families, is not available in all parts of the state or across all settings. Though palliative care can be provided in hospitals, nursing homes, outpatient palliative care clinics and other specialized clinics, or at home, finding providers to provide palliative care in the setting the person desires can be challenging, especially if care is desired in their own home.

GWAAR supports AB 736 establishing a palliative care council to evaluate the palliative care system in Wisconsin and make policy recommendations to the state Department of Health Services and the legislature on how to improve it, so that improved quality of life through palliative care can be available to patients with serious illness and their families no matter where they live in the state. This legislation will also help with the development of a palliative care information and education program focused on the general public and health care providers to help increase the awareness of this essential type of care.

While we are strong supporters of efforts to strengthen Wisconsin's palliative care system, we recognize that improving serious illness care requires integration of timely, person-centered serious illness conversations and care planning across all specialties and care settings, including ambulatory, inpatient, and home and community-based care. To this end, we are advocating for Wisconsin to take a more comprehensive approach by amending this legislation to create a Serious Illness Care Council which broadens the scope and membership of the advisory council to include and represent all specialty areas and interests that serve individuals with serious illness, their families and caregivers (hospital staff, hospice and palliative care program staff, physicians, nurses, social workers, clergy, counselors, advanced care planning, caregiving agencies and individuals, advocacy organizations, community-based service providers, nursing homes, veterans administration and Veteran Service

J. L. Zander – AB 736 Testimony – Assembly Committee on Health, Aging and Long-Term Care\_1/10/24

Officers, health and social service providers, as well as individuals with serious illness and their family members). Improved access and understanding of each of these areas of care and service is needed for people in need of serious illness care; yet it is not feasible for the state to establish numerous councils. A Serious Illness Care Council would provide a more comprehensive and effective means of supporting the seriously ill and their families, while improving care outcomes.

We appreciate the interest in and efforts of policy makers to improve awareness and access to specialty care addressing the needs of individuals with serious illness and their families. We look forward to continuing to work with you on policies that improve the quality of life of older people in Wisconsin.

Thank you for your consideration of these comments and recommendations related to AB 736.

Contact: Janet Zander Advocacy & Public Policy Coordinator, MPA, CSW Greater Wisconsin Agency on Aging Resources janet.zander@gwaar.org (608) 228-7253



| то:   | Members of the Assembly Health Committee                                |
|-------|---|
| FROM: | Wisconsin Hospice and Palliative Care Association                       |
| DATE: | January 9, 2024   |
| RE:   | Assembly Bill 736 – Relating to: establishing a Palliative Care Council |

Wisconsin Hospice and Palliative Care Association is an organization committed to ensuring optimal outcomes and expanding access to high-quality, compassionate care for Wisconsinites facing life-altering illness, we are respectfully requesting your support for legislation – Assembly Bill 736 – authored by Representative Pat Snyder and Senator Jesse James to create a palliative care council to advise the Wisconsin Department of Health Services (DHS) and provide recurring reports to the Legislature.

#### Definition of palliative care

Palliative care is specialized, integrated medical care for people with serious illness, focused on providing patients and families with relief from the symptoms, pain, and stress of a serious illness. Examples of such illness include cancer, congestive heart failure, chronic obstructive pulmonary disease (COPD), kidney failure, Alzheimer's disease, and Parkinson's disease.

- Palliative care is meant for the sickest, most vulnerable, costliest patients and their families. It provides an additional level of support for patients and their caregivers. It is appropriate for children and adults.
- Working with a palliative care provider helps simplify patient transitions across care settings.
- Patients in palliative care receive medical care for their symptoms, along with treatment intended to cure their serious illness.
- Palliative care specialists may include a physician, nurse, social worker, chaplain, and other care specialists who work alongside a patient's doctor to provide an extra layer of support.

#### Why do we want to create a Palliative Care Council?

- Access to palliative care varies widely across our state. Palliative care in Wisconsin is mostly provided during a patient's hospitalization, and this is typically only in the larger hospitals. 52% of rural hospitals do not provide any type of palliative care specialists.
- Home and clinic based palliative care is extremely limited in Wisconsin. There are less than a dozen health care organizations who provide palliative care in patients' homes.
- The purpose of the council will be to study ways to increase awareness and usage of this highly valuable type of care. In addition, there is a shortage of health care providers in Wisconsin who specialize in palliative care, with only 4.0 providers per 100,000 residents.

The following are examples when palliative care has been extremely valuable to patients:

#### Example One

- A 32-year-old female with metastatic cancer was suffering severe pain, which resulted in her inability to function and to be frequently admitted to a hospital. Also, she is a single parent of a 13-year-old daughter. The patient was reluctant to have a palliative care assessment, as she did not understand palliative care and wanted to continue active cancer treatment to prolong her life for the sake of her only child.
- Her oncologist struggled to manage her pain and needed the expertise of palliative care specialists to assist in pain management. This patient was in crisis and needed help now. Fortunately, the oncologist was able to find a community-based palliative care program a type of care that she would be able to receive in her home. Upon receiving the referral, a palliative board-certified physician and a nurse practitioner (NP) were able to work with the patient and her oncologist to develop a regime that would manage her pain and provide her with an improved quality of life. Without palliative care, this patient would have continued to suffer severe pain and would likely have made multiple expensive visits to a hospital's emergency department.

#### Example Two

• Kathy had been struggling to manage her heart disease for some time. It had become clear to her cardiologist that she was not taking her medications. On the palliative care team's initial visit to her home, Kathy was proud to show her a fishbowl full of a colorful array of pills. Kathy explained she was pretty sure she knew which pills to take based on their color. Over a series of visits, the palliative care nurse reconciled Kathy's medications and got them organized in a pill box. Furthermore, the team's social worker was able to steer Kathy's children towards community services to assess her for dementia. If Kathy had not received palliative care, her heart disease would have likely worsened and her mental state may also have gotten worse, as she would have likely not received a dementia assessment. This could also have resulted in multiple expensive visits to a hospital and her loss of independence.

#### **Palliative Care Saves Costs**

Evidence-based research has demonstrated that patients in hospital systems with palliative care programs experienced reduced emergency department visits, fewer days in intensive care and fewer hospital readmissions after discharge.

#### Palliative Care Provides Access to Needed Support for Patients

The provision of palliative care is flexible – it may be provided to patients in various settings. In addition to being provided in some hospital settings, palliative care may be provided in facilities, such as skilled nursing (e.g., "nursing homes"), assisted living, and other community-based facilities. In addition, palliative care teams are also able to travel to patients' homes and provide care in that setting.

The creation of a Palliative Care Council – via Assembly Bill 736 – will help increase awareness of palliative care throughout the state and help Wisconsinites receive needed medical care for their symptoms that will improve the quality of life for them and their families.

If you have any questions, please contact the WiHPCA government affairs team, Tim Hoven and Nathan Butzlaff, at <u>tim@hovenconsulting.com</u> or <u>nathan@hovenconsulting.com</u>.

To: Members, Assembly Committee on Health, Aging and Long-Term Care

Re: Opposition to AB 736, establishing a state Palliative Care Council

Date: Wednesday, January 10, 2024

Good morning, Chairman Moses, and members of the Assembly Health Committee. Thank you for allowing me to speak in opposition to Assembly Bill 736.

My name is Dr. Stephen Pavela. I am a retired Internal Medicine physician from La Crosse, Wisconsin. I am Board Certified in Internal Medicine and practiced in La Crosse for 39 years. I was a Department Chair and a Chief of Staff for my hospital system. I also taught Internal Medicine to Family Practice Residents for 34 years.

My practice included the hospital care of patients, including intensive and acute cardiac care; outpatient clinics, as well attending at local nursing homes. I did the end-of-life care for all my patients throughout my career. I was involved in the beginning of the hospice movement in the 1990s. In the last 5 to 10 years of my practice, the Palliative Care specialty was introduced to my healthcare system. Since I was the long-time physician for my adult patients I took care of them right up to the end of their lives, whether they were in hospital, at home or in a long-term care facility. I took care of my own patients who were on hospice care. I tell you all of this so that you understand that I am thoroughly familiar with palliative and hospice care, both its good points and its failings.

In my opinion, done well and done ethically, palliative care and hospice care can be beneficial to patients. Despite this ideal, I am here to tell you that on the local, practical level this is frequently not the case. Why do I say this? Because I have observed it and have heard it from the families of my patients. For example, the families would be surprised that despite an oncologist's estimate of life time in weeks or months, when palliative care transitioned the patient to hospice, their loved ones died so quickly. The main culprit in most of these cases was the inappropriate sedation of their loved ones by excessive dosing of medication to treat pain and perceived shortness of breath. Because of this excessive use, the families felt deprived of their loved one's alertness and their companionship in their last days. Another culprit, I often found, was the aggressive discontinuance of even routine medications for ongoing chronic conditions that had nothing to do with the primary terminal illness. Medications for diabetes or cardiac conditions were often prematurely withdrawn. I don't mean to say what I am describing happens in all cases, but it happens enough that family members would call on the phone or come into my office a bit bewildered at the rapid unexpected death of their loved one. A Catholic priest friend of mine observed that he used to go to a deathbed to administer the last rights to a dying person and be able to talk to them. But he notes that in recent years in most cases that person is unarousable due to sedation.

What I am telling you is common knowledge among primary care physicians. And, in recent years, there is another problem. Today, except for rural areas, hospital care is done not by the primary physician but by hospitalists. When a patient with a serious medical condition, possibly terminal, is admitted to the hospital, a palliative care consult is routinely placed by the hospitalist, and upon discharge the patient is either sent home or to a nursing home without any communication to the primary physician. All the counseling is done by physicians unknown to the family. The patient is quickly transitioned to hospice care. The quality of that care highly depends on the physician and nurses directing that care and may not match the values of the family as they only are assigned a team, not the ones they choose.

I have found that the best protection for a patient is an inquisitive family member, or a primary care physician known and trusted by the family who can appropriately assess recommendations being made by Palliative Care or the Hospice team.

Again, I am not testifying that this is a universal occurrence, but it happens often enough to be known by long time physicians who have observed the evolution in endof-life care in recent years.

When I look over AB 736, I note the make-up of the council is very heavy on those practicing Palliative Care. Only two primary care physicians are included. In my opinion, this is exactly opposite of what it should be. Most of the council should be made up of those skilled in the ongoing long term primary care of patients. Not just those who enter the person's life for only a short time. Also, the council should include pharmacists and anesthesiologists who are medication and pain care specialists who can help supervise proper protocols and the use of medications.

I have second more fundamental objection to AB 736. Why is the state getting involved with this specialty at all? Shouldn't it be done by private healthcare systems who are responsive to the local needs of their patients? Shouldn't the need be started at the grass roots level, rather than directed "top-down" from the governmental level?

We have just been through several years of the Covid pandemic. During that time, a government agency, namely, the Center for Disease Control (CDC), made numerous "recommendations" regarding lock downs, school closures, travel restrictions, and masking. It actively interfered with the medical profession's prescribing of medication. And how did that turn out? The CDC's so-called "recommendations" were taken as necessary mandates by most institutions. But we now have scientific evidence that almost all those recommendations had no effect on Covid disease spread, were unnecessarily mandated, and in some cases caused great harm. This is an example of government attempt to control medicine "top down".

What I am saying is that if something is worth doing and of great value, the private sector will see that it is done; it doesn't need government involvement. So, I am curious as to the origin of this bill? Where is the evidence that a government sponsored palliative care council is needed? There is no similar government sponsored council for any other specialty in medicine such as pediatrics, surgery, or cardiology. Why this one? From my own experience, it is not necessary.

For these reasons I oppose the passage of AB 736. Thank you for listening to my concerns.

Wisconsin Chapter Offices 620 S. 76<sup>th</sup> St., Ste. 160

Milwaukee, WI 53214

4600 American Parkway, Ste. 103 Madison, WI 53718

2700 Vernon Dr., Ste. 340 Green Bay, WI 54304 505 S. 24th Ave., Ste. 304 Wausau, WI 54401 404 1/2 N. Bridge St. Chippewa Falls, WI 54729 P0 Box 1472 Rhinelander, WI 54501

### ALZHEIMER'S ASSOCIATION

Date: Wednesday, January 10, 2024

**To:** Chairman Moses and Members of the Assembly Committee on Health, Aging, and Long-Term Care **Subject:** 2023 Assembly Bill 736, relating to: establishing a Palliative Care Council

Dear Chairman Moses and Members of the Assembly Committee on Health, Aging, and Long-Term Care,

I am writing on behalf of the Alzheimer's Association Wisconsin Chapter to express our support for Assembly Bill 736, which seeks to establish a Palliative Care Council within the Department of Health Services. Alzheimer's disease is a prevalent neurodegenerative disorder characterized by progressive cognitive decline, memory loss, and impaired daily functioning, making it the most common form of dementia—an umbrella term for conditions marked by memory loss and cognitive impairment. This bill signifies a step forward in recognizing the importance of palliative care for individuals affected by Alzheimer's disease and related dementias, a growing concern in Wisconsin as reflected in the following statistics<sup>1</sup>:

- 120,000 people aged 65 and older are living with Alzheimer's in Wisconsin.
- 10.9% of people aged 45 and older have subjective cognitive decline.
- 191,000 family caregivers bear the burden of the disease in Wisconsin providing 213 million hours of unpaid care.

Palliative care, with its focus on relieving symptoms, managing pain, and addressing the emotional and psychological needs of patients and their families, is particularly relevant in the context of Alzheimer's disease and related dementias. Palliative care provides a framework for addressing these challenges and improving the overall well-being of those affected by Alzheimer's disease and related dementias.

The proposed Palliative Care Council, comprising medical and clinical professionals with expertise in palliative care services, along with individuals who have direct experience as patients or family members, ensures a holistic and nuanced understanding of the unique needs and complexities faced by those with Alzheimer's disease and related dementias. This targeted focus enables the council to address the multifaceted nature of the disease, offering guidance on outcome evaluation, economic and quality of life effectiveness, reimbursement mechanisms, and other pertinent issues related to palliative care. The Council's formation is a crucial step toward enhancing the quality of care and support for the 120,000 individuals aged 65 and older living with Alzheimer's disease and related dementias in Wisconsin, addressing not only their medical needs but also providing compassionate assistance to families navigating the challenges of this devastating condition.

Thank you, Chairman and Committee members, for the opportunity to submit comments and for your consideration of Assembly Bill 736.

Sincerely,

Allison Cramer Director of Public Policy Alzheimer's Association Wisconsin Chapter <u>amcramer@alz.org</u> | (608) 571-3939

<sup>&</sup>lt;sup>1</sup> Wisconsin 2023 Alzheimer's Statistics

January 2, 2024

Representative Clint Moses Chair, Committee on Health, Aging and Long-Term Care Wisconsin State Assembly Room 12 West State Capitol PO Box 8953 Madison, WI 53708

Dear Representative Moses,

Wisconsin would benefit from a Palliative Care Council because palliative care adds so much to patient care and not everyone in the world of health care in Wisconsin is aware of this.

When I joined Mayo Clinic Health System in 2013 as their first palliative care physician, I had already practiced family medicine for 27 years in Tomah. In Eau Claire, I saw first-hand how palliative care was able to facilitate conversations during serious illness and how it helped smooth landings for those who had run out of gas. One senior physician leader commented that in his experience, no other specialty had had as great an impact on patient care as palliative care.

There are many good people delivering health care across Wisconsin who have still not worked directly with a specialist in palliative care. This is where a Palliative Care Council would play a valuable role to assess its availability, identify barriers, and pool wisdom to recommend legislation and policies.

Some worthwhile innovations in medicine catch on immediately. Others, like palliative care, benefit from nurturing. I strongly endorse AB-736 to create a palliative care council in Wisconsin.

Sincerely,

Tames Deming, M.D. Retired palliative care and family physician 4669 N Shore Drive Eau Claire WI 54703 <u>Deming.james@mayo.edu</u>



Representative Clint Moses Chair, Committee on Health, Aging and Long-Term Care Wisconsin State Assembly Room 12 West State Capitol PO Box 8953 Madison, WI 53708

Dear Representative Moses,

Wisconsin would benefit from a Palliative Care Council because palliative care adds so much to patient care and not everyone in the world of health care in Wisconsin is aware of this. As a practicing nurse practitioner, I am writing to respectfully request that you support **Senate Bill 703 & Assembly Bill-736** authored by Representative Pat Snyder and Senator Jesse James to create a palliative care council.

This legislation will create a palliative care council to improve awareness of and access to this specialized type of care that provides patients relief from the symptoms, pain and stress of serious, life-altering illnesses, such as cancer, congestive heart failure, chronic obstructive pulmonary disease, kidney failure, Alzheimer's disease, Parkinson's disease, as well as other serious medical conditions. Palliative care is meant to enhance a person's current care by focusing on quality of life for them and their family.

Many other states have already taken the step of creating a similar advisory group to increase awareness of access to this specialized type of care. In fact, 25 other states from coast to coast have formed such entities. There are many good people delivering health care across Wisconsin who have still not worked directly with a specialist in palliative care. This is where a Palliative Care Council would play a valuable role to assess its availability, identify barriers, and pool wisdom to recommend legislation and policies.

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Sincerely,

Susan Ferguson, MD

Susan Ferguson, MD Home Care Physician Agrace



Representative Clint Moses Chair, Committee on Health, Aging and Long-Term Care Wisconsin State Assembly Room 12 West State Capitol PO Box 8953 Madison, WI 53708

Dear Representative Moses,

Wisconsin would benefit from a Palliative Care Council because palliative care adds so much to patient care and not everyone in the world of health care in Wisconsin is aware of this. As a practicing physician, I am writing to respectfully request that you support Senate Bill 703 & Assembly Bill-736 authored by Representative Pat Snyder and Senator Jesse James to create a palliative care council.

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Sincerely,

Shauna Lambrecht APNP Rainbow Hospice Care

147 W Rockwell Street, Jefferson, Wisconsin 53549



Representative Clint Moses Chair, Committee on Health, Aging and Long-Term Care Wisconsin State Assembly Room 12 West State Capitol PO Box 8953 Madison, WI 53708

Dear Representative Moses,

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Sincerely,

Maureen Leaky

Maureen Leahy RN, BSN, MHA, CHPN Chief Clinical Officer Sharon S Richardson Community Hospice

January 9, 2024

Representative Clint Moses Chair, Committee on Health, Aging and Long-Term Care Wisconsin State Assembly Room 12 West State Capitol PO Box 8953 Madison, WI 53708

Dear Representative Moses,

I am writing to you today to voice my support for a state palliative care council in Wisconsin. As our population ages and the time spent living with chronic illnesses increases, the need for **support as people move through their illnesses also increases. We can greatly improve the quality of life experienced by these patients and their families.** As a practicing Registered Nurse, I am writing to respectfully request that you support **Senate Bill 703 & Assembly Bill-736** authored by Representative Pat Snyder and Senator Jesse James to create a palliative care council.

This legislation will create a palliative care council to improve awareness of and access to this specialized type of care that provides patients relief from the symptoms, pain and stress of serious, life-altering illnesses, such as cancer, congestive heart failure, chronic obstructive pulmonary disease, kidney failure, Alzheimer's disease, Parkinson's disease, as well as other serious medical conditions. Palliative care is meant to enhance a person's current care by focusing on quality of life for them and their family.

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Sincerely,

Michelle Hackett RN Sharon S. Richardson Community Hospice Sheboygan Falls, WI 53081

Representative Clint Moses Chair, Committee on Health, Aging and Long-Term Care Wisconsin State Assembly Room 12 West State Capitol PO Box 8953 Madison, WI 53708

Dear Representative Moses,

Wisconsin would benefit from a Palliative Care Council because palliative care adds so much to patient care and not everyone in the world of health care in Wisconsin is aware of this. As a practicing physician, I am writing to respectfully request that you support Senate Bill 703 & Assembly Bill-736 authored by Representative Pat Snyder and Senator Jesse James to create a palliative care council.

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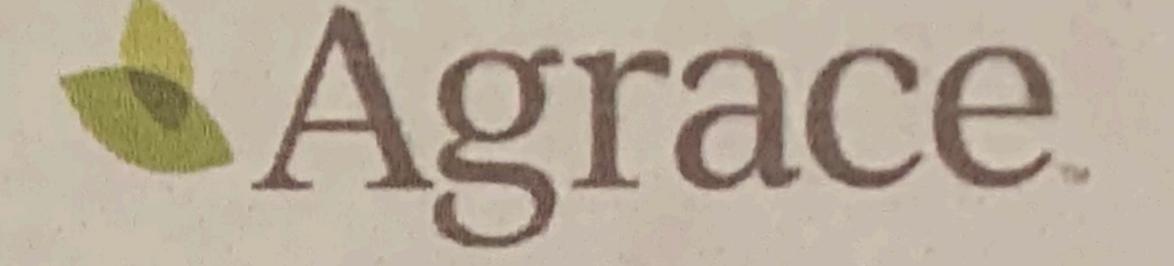
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Sincerely,

Cariann Petri RN BSN

Clinical RN Navigator

Richardson Palliative Care



**Representative Clint Moses** Chair, Committee on Health, Aging and Long-Term Care Wisconsin State Assembly Room 12 West State Capitol PO Box 8953 Madison, WI 53708

Dear Representative Moses,

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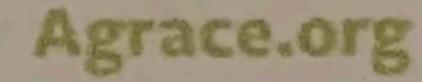
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## Sincerely,

ame Red aPNP

Aimee Reed, APNP, MSN Agrace

Supportive Care • Age at Home • Adult Day Center • Hospice Care • Grief Support





Representative Clint Moses Chair, Committee on Health, Aging and Long-Term Care Wisconsin State Assembly Room 12 West State Capitol PO Box 8953 Madison, WI 53708

Dear Representative Moses,

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Sincerely,

Annette Bennett-Otto, APNP

Agrace

Agrace.org



Representative Clint Moses Chair, Committee on Health, Aging and Long-Term Care Wisconsin State Assembly Room 12 West State Capitol PO Box 8953 Madison, WI 53708

Dear Representative Moses,

Wisconsin would benefit from a Palliative Care Council because palliative care adds so much to patient care and not everyone in the world of health care in Wisconsin is aware of this. As a practicing nurse practitioner and the Director of a local Supportive (Palliative) Care program at Agrace HospiceCare, I am writing to respectfully request that you support **Senate Bill 703 & Assembly Bill-736** authored by Representative Pat Snyder and Senator Jesse James to create a palliative care council.

This legislation will create a palliative care council to improve awareness of and access to this specialized type of care that provides patients relief from the symptoms, pain and stress of serious, life-altering illnesses, such as cancer, congestive heart failure, chronic obstructive pulmonary disease, kidney failure, Alzheimer's disease, Parkinson's disease, as well as other serious medical conditions. Palliative care is meant to enhance a person's current care by focusing on quality of life for them and their family and support system. Palliative care will also provide needed support and validation to other providers in the patient's care, such as their primary care provider and specialists for end organ disease.

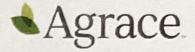
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Sincerely,

Danielle DiGennaro, MSN, ANP-BC, ACHPN Director of Supportive Care at Agrace HospiceCare

> 5395 E. Cheryl Parkway Madison, WI 53711 (608) 276-4660 Agrace.org



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Sincerely,

Diana Charlebois, APNP Agrace



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Sincerely,

Branos, MD

Anthony Braus, MD Agrace



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Sincerely,

Partin Neun Do

Dr Patricia Neuman, DO Medical Director, VP of Medical Services Agrace

Agrace.org



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Sincerely,

Susan Ferguson, MD

Susan Ferguson, MD Home Care Physician Agrace



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Sincerely,

0h-JoAnn Long

Palliative Care Nurse Practitioner Agrace

Agrace.org



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Sincerely,

Linda Norton, MSN, APN, APNP, ACHPN Palliative Care Nurse Practitioner Agrace Support Care



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Sincerely,

dia 712 Weiss

Lydia ML Weiss, DNP, APNP, AGPCNP-BC, ACHPN Agrace

Agrace.org



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Sincerely,

Nicola Klass

Nicole Klaas, APNP, FNP-BC Agrace



Representative Clint Moses Chair, Committee on Health, Aging and Long-Term Care Wisconsin State Assembly Room 12 West State Capitol PO Box 8953 Madison, WI 53708

Dear Representative Moses,

Wisconsin would benefit from a Palliative Care Council because palliative care adds so much to patient care and not everyone in the world of health care in Wisconsin is aware of this. As a practicing nurse practitioner, I am writing to respectfully request that you support **Senate Bill 703 & Assembly Bill-736** authored by Representative Pat Snyder and Senator Jesse James to create a palliative care council.

This legislation will create a palliative care council to improve awareness of and access to this specialized type of care that provides patients relief from the symptoms, pain and stress of serious, life-altering illnesses, such as cancer, congestive heart failure, chronic obstructive pulmonary disease, kidney failure, Alzheimer's disease, Parkinson's disease, as well as other serious medical conditions. Palliative care is meant to enhance a person's current care by focusing on quality of life for them and their family.

Many other states have already taken the step of creating a similar advisory group to increase awareness of access to this specialized type of care. In fact, 25 other states from coast to coast have formed such entities. There are many good people delivering health care across Wisconsin who have still not worked directly with a specialist in palliative care. This is where a Palliative Care Council would play a valuable role to assess its availability, identify barriers, and pool wisdom to recommend legislation and policies.

Some worthwhile innovations in medicine catch on immediately. Others, like palliative care, benefit from nurturing. I strongly endorse the creation of a palliative care council in Wisconsin.

Sincerely,

Tara Groth, APNP

Agrace