

I'm Karen Stanley representing the League of Women Voters Delaware, New Castle County. I've been an advanced practice nurse for over 40 years in the disciplines of oncology care, pain management, and palliative care. I have served as co-chairwoman of Kaiser Permanente's hospital Bioethics Committee. I became an advocate for patients and families starting at the bedside and continuing to the halls of Congress as national president of the Oncology Nursing Society.

I am here to speak for patients who are afraid of the dying process and the rigors of their illness. The majority of this country believes omens of life options as outlined on HB 140 and I support their right to be comforted in this way. None of us can know the fear and existential shock of a terminal illness unless we've been there.

I'd like to finish my comments with a reminder about evidence based practice, the golden rule for best practice in medicine. We all want to receive evidence based treatment. The state of Oregon law, on which HB 140 is based, has produced 20 years of best practice evidence. Their rules of participation are rigorous and their experience has demonstrated that their right to legal autonomy has not resulted in ethical or legal overrun of stated boundaries. I believe the same would be true for the citizens of Delaware.

Thank you.

Karen J Stanley, RN, MSN. FAAN
Nursing Consultant
Pain and Palliative Care
Bear, DE

Mr. Chairman and Members of the Committee:

I am Joe Fitzgerald, lobbyist for the Catholic Diocese of Wilmington, here on behalf of Bishop

Malooly and the Diocese to express profound opposition to **House Bill 140**. As with previous

iterations of this bill, our opposition is rooted the Church's belief in the sanctity of life and dignity of

the individual, both of which are objective and non-negotiable truths and principles of our faith.

Additional concerns are as follows:

1. The bill would legalize and normalize participation in the intentional taking of human life by members of the medical profession.
2. This bill lacks adequate safeguards to protect persons with disabilities, the elderly, and those suffering from mental illness. Once lethal drugs have been prescribed, this law has no requirements for assessing the patient's consent, competency, or voluntariness. Who would know if the drugs are freely taken since there is no supervision or tracking of the drugs once they leave the pharmacy and since no witnesses are required at the time of death?
3. The drugs prescribed under the law are so highly addictive and easily misused that they are put into the same drug category by the Federal Drug Enforcement Administration (DEA) as cocaine, OxyContin, and fentanyl, to name a few. Each prescription would contain ONE HUNDRED of these pills, exposing our communities to a new source of addiction and lives lost too soon to drug misuse.
4. The law appears to limit eligibility to terminally ill patients who are expected to die within six months but don't distinguish between persons who will die within six months with treatment and those who will die within six months without treatment. This means patients with treatable diseases like diabetes and disabilities requiring ventilator support are eligible for lethal drugs since they would die within six months without treatment. Furthermore, diagnoses of terminal illness and predictions of life expectancy are notoriously inaccurate.
5. Despite medical literature showing that nearly 95 percent of those who commit suicide had a diagnosable psychiatric illness (usually treatable depression) in the months preceding suicide, HB 140 does not require a psychological evaluation unless the prescribing doctor or the doctor selected to give a second opinion request it.

6. The bill would require physicians and others to make misstatements on official records. The bill states that the underlying terminal illness must be listed as the cause of death on the death certificate, when in fact the cause was suicide.

In closing, we urge members of the committee to vote "NO" on any motion to release HB 140.

IN SUPPORT OF HB 140

As an ICU nurse in the 1970's, I witnessed many prolonged and painful deaths resulting from medical advances that could keep a human body alive, but held no hope of returning the patient to anything resembling a normal or near-normal existence. During that decade, there were many failed attempts to pass legislation allowing "living wills," referred to today as "advance medical directives," which recognize the rights of dying people to control decisions about their medical care. Today, advance medical directives are both legal and widely accepted.

Hospice care, also introduced in the 1970's, met strong resistance in the beginning. Today, hospice care is widely available and is one of the most respected branches of medicine and nursing, bringing comfort to the terminally ill and their loved ones.

These histories of advance medical directives and hospice are examples of how our society has come to terms with the reality of death within the context of modern medicine.

When "living wills" were finally made legal in Washington, D.C., where I was living and working as an ICU nurse, I may have been the youngest person, at age 28, to sign one. I knew even then that I wanted to have as much control over end-of-life decisions for myself as I possibly could. Now, decades later, my support of the Ron Silverio/Heather Block End of Life Options Act is consistent with my life-long conviction that each person should have the right to make end-of-life decisions that are in line with their values. I particularly appreciate that this legislation is intended only for those patients *and* healthcare professionals who *voluntarily* choose to exercise their rights under this legislation.

In eight states and Washington D.C., with legislation pending in more than a dozen other states, the terminally ill have the right to request and receive medicine to bring about a peaceful death, in the presence of loved ones and in their own home.

Let's make Delaware the next state to give its residents the legal right to seek medical aid in dying to end their pain and suffering when death is imminent.

Please support the Ron Silverio/Heather Block End of Life Options Act.

Judith Butler, R.N., Ph.D.

1403 Shallcross Ave., #201

Wilmington, DE 19806

Dear Mr. Chairman and Members of the Committee:

On behalf of the League of Women Voters of Sussex County, and the large number of older voters in Sussex County, we respectfully support HB 140. We ask that the bill be released from Committee to be voted on in the 150th General Assembly, and ultimately become the law in Delaware.

First, terminally ill individuals have a fundamental human right to self determination on end of life decisions. These decisions must be left to the individual to make based on matters of conscience and religious beliefs without interference from the state when medically required under the safeguards provided in the bill. The League recognizes that some Delawareans hold different beliefs, which the League fully appreciates and honors. Those beliefs, however, are ones of personal conviction that cannot be imposed on others who hold different beliefs and, consistent with those beliefs, wish to make end of life decisions.

Second, decisions on end of life decisions must be made voluntarily by a terminally ill adult individual with decision-making capacity.

Third, medical care providers who support end of life decisions should not be subject to civil, criminal or professional liability for complying with the request from a terminally ill adult to provide assistance and medication to end a life in a humane and dignified manner following the procedures set forth in the bill.

Fourth, end of life decisions should not impact on the terminally ill adult's life insurance, annuity or other benefits.

Finally, the revisions to Chapter 25B, embodied in HB 140, should not be restrictively construed or applied to negate the individual adult's fundamental right to make end of life decisions in a manner consistent with that person's own conscience.

Respectfully submitted,

Martha Redmond,

President League of Women Voters of Sussex County.

Testimony in favor of House Bill 140, known as the Ron Silverio /Heather Block Delaware End of Life Option Act

Good afternoon. My name is Sturges Dodge. I live in Rehoboth Beach, and am here today to urge you to vote to pass House Bill 140.

My interest is intensely personal. Death attendant to catastrophic disease has been a significant feature in my life, beginning with my mother dying from cancer at age 37 when I was just 14. She was sent home from the hospital after exploratory surgery found her abdomen riddled with cancer. It took her 4 months to die at home on morphine for pain. She did not get to say goodbye properly to her children, who were away at school or kept out of the sickroom. Her father died of cancer within two months and her mother, suffering with COPD, died two months later, and may have ended her own life.

More recently, within the past year, I lost my stepmother to congestive heart failure and my twin brother to lung cancer and COPD. Both had hospice services, and although their passings were relatively quick and painless, the days and hours leading up to the deaths were filled with fear, anger, and anxiety for both the patients and their family members. In addition to these losses, I have also within two years lost 2 friends to cancer, both in severe pain and 1 in fear and confusion due to mild dementia, and have had 3 others close to me diagnosed with serious cancers, two of whom are likely terminal. I, myself, am at an increased risk of dying from breast and skin cancer.

The choices I observed that my loved ones and family had were limited; suffering with pain and anxiety, taking medication, with isolating mental sedation and other unpleasant side effects, or trying to move away from familiar surroundings and support to establish residency in a state that permitted death with dignity. At the time of my mother's and grandparents' deaths, the last option was not available anywhere in the country. I believe that if an option had existed for my mother, stepmother or brother to end their lives on their own terms, they and family would have had a much easier time accepting their imminent deaths, greatly reducing fear and possible regrets, and facilitating final desired communications between loved ones.

Our country was founded on a principle of the right to "Life, liberty and the pursuit of happiness", but most states, including Delaware, don't permit the latter two in the end stages of life. I would like to have the right for myself and those I love to leave this earth with dignity and to live in a state that shows its people as much kindness and mercy as I am currently legally allowed to show to a suffering pet.

Thank you

Health and Human Services Committee –Testimony Against HB140 Bess McAneny
RN MS 53 years.

HB 140 allows doctors to determine that someone will die of a terminal illness in 6 months to offer them a lethal dose. As a nurse and personally I have experienced medical mistakes and therefore question the reliability of the terminal diagnoses. In the case of Jeannette from Oregon , she received a terminal dg. and prepared for the overdose decision. Fortunately, her doctor pleaded with her to get other opinions and she has lived a full life with her family for 18 years. In the case of my son in law at 24 years an assumed diagnoses of a drug overdose for his stroke resulted in a wrongful death from an untreated cerebral aneurysm leaving my daughter and two little girls devastated. My Panamanian student's wife pleaded for Camilo to receive proper psychiatric care and hospital admission but he was sent home neglectfully to die by suicide. Doctors can make mistakes.

I looked for the criteria for **terminal illness** in six months in states like Oregon and found that the guide is the one used by Hospices. I was shocked to find that the definition includes only a **brief narrative covering** some clinical support for the dg. and in the doctors opinion the disease will follow its course.-not proof enough for me of reasonable doubt. Yet some patients are discharged from their dg.??Then I found an audit report from the Center for Medicare Services that noted some people were admitted for "failure to thrive, dementia, and debility" and it needs improvement. This should concern everyone here in this room. I don't know what criteria DE will use since it isn't stated but I do know that probability of dying in 6 months is a crap shoot game at best. I also see that a bill that is not transparent in every detail and forces doctors to offer lethal dose death as **informed consent** is a flawed bill opening the door to abuse and wrongful deaths -the perfect crime since the person is dead , the records closed, and no prosecution for the doctors.

A few revisions

Good afternoon, I am Dr. Mary McCrossan, a family physician from Wilmington

I believe the efforts behind HB 140 are largely motivated by compassion. Care of the disabled and dying is not easy. Decisions can be difficult. I know some of the physician supporters and I respect their integrity.

However, I am here to speak in opposition. A chief concern has to be ethics. Physicians core ethical values are: beneficence, non-maleficence-doing no harm, autonomy and justice. These concepts are not just nice to talk about theories but are bedrock components of maintaining medicine as a profession that serves all well. Although the bill would support autonomy for some, it threatens these other values.

Broader societal values are also of concern here. To legalize the intentional taking of the life of a terminal patient is to implicitly devalue that life. This is a walk backwards from equal protection toward moral relativism, which ultimately threatens the most vulnerable among us.

I understand proponents hope to narrowly apply any new rules to only the terminally ill. But our ability to accurately identify those patients is limited. Our critical care colleagues tell us that even in the ICU with extremely dire situations, they are often wrong in predicting the possibility and quality of recovery.

HB 140 has increased discussion of end of life care. It raises good questions we need to ask. Especially in a state like ours that still has a long way to go in providing adequate palliative care.

But stepping away from societal value for each life and key medical ethics is the wrong answer

Thank you.

FULL WRITTEN TESTIMONY FOR THE RECORD IN SUPPORT OF HB 140
SUBMITTED BY BY SALIA SHEN

Testimony in Support of HB 140:

"The Ron Silverio/Heather Block Delaware End of Life Options Act"

Good Afternoon: Honorable Members of the House Health and Human Development Committee,

Thank you for the opportunity to provide testimony in support of HB 140, "The Ron Silverio/Heather Block Delaware End of Life Options Act".

My name is Salila Shen, and I live in the village of Arden, North of Wilmington.

I stand before you today first as a daughter, and second as a licensed clinical social worker. I learned about hospice work during my graduate school internship at Compassionate Care Hospice. I discovered that hospice was "a calling" for me, as many involved in this sensitive work do. Over the years, I worked for three of the other hospices in Delaware. It always felt like a privilege to support patients who were nearing the end of their lives; to be part of a team that provided care, guidance, and support; and to bring reassurance to family members that their loved one would be kept comfortable, at this time of profound vulnerability, and increasing loss of function and control.

I still believe I am meant to do end-of-life care, but I have been unable to do it after witnessing my mother's excruciating death with my brother by my side, and a hospice nurse at the foot of the bed, unable to do anything to stop her suffering.

The day following her death, I wrote this email to the hospice team that cared for my mother:

"My mother died last night at 6:25 PM. Unfortunately, it was a very traumatic death and I am shattered. She had an intense seizure with terrible jerking of her head and body, and then what appeared to be a heart attack, moments apart -- I am not sure what happened. The LPN who was there said she had never seen anything like this. The intensity of her dying process was overwhelming and unexpected. This has turned my whole perception of hospice upside-down to see such suffering. I feel no

sense of being able to promise anyone that we can keep people comfortable during their deaths after this."

It was the worst moment of my life. I had failed my mother and my entire family. After all, I was the one working "in the field", right? I had promised them that hospice provides "comfort care," right? Not always. I could no longer work for hospice. I felt, and still feel, that the promise of comfort care is an empty one, without the option of medical aid in dying.

To be fair, many hospice patients do have a peaceful death. My brother, mother, and I sat at my grandmother's bedside for her last 8 hours while she peacefully breathed in and out, until she simply didn't inhale after her last effortless exhale. But I am here today because of my mother. She suffered, even though she was in the best situation anyone could be. She had my brothers and me taking care of her, and had hospice care from the company I worked for at the time. But something unexplainable was happening – she was expected to die of kidney failure within a few weeks after stopping dialysis, but she lived 9 weeks, with increasing challenges. Instead of relaxing into a peaceful, increasing sleepiness -- which happens often to patients with end-stage renal disease – she died in an agonized, pain-filled contraction. My heart was scarred, and I am permanently changed as a person.

My mother was the most sensitive, kind, caring, and generous person I knew, who was a wonderful caregiver herself. She was ready to stop doing dialysis. She didn't want to leave us but was getting worn out by the treatments. She deserved to be comfortable, out of pain, able to breathe, and in peace at the end of her life. Not to endure a gradual and prolonged loss of organ function, resulting in a painful death, even with hospice care. She deserved to have the choice about when to end her life, and to say "Goodbye" to us when she was ready to. And we deserved to sit with her and support a peaceful passage, instead of being left with those heart-breaking images of our beloved mother carved into our souls.

No one should have to feel that helpless in the face of losing someone they love.

Eight states and the District of Columbia currently authorize medical aid in dying. HB 140 allows terminally-ill individuals with decision-making capacity to evaluate their end-of-life options. Hospice is an important part of the puzzle but it is not enough.

Once the bill passes, I believe many people who are receiving hospice care might submit requests for medical aid in dying, yet may not end up using it. But, it will have given them peace of mind. And for those who do need it, it will allow them a peaceful death instead of suffering. And family members whose loved ones make this choice will not have a horrifying memory, but can instead be with them on the day of the patient's choosing, and share their love and appreciation for each other, and say, "Goodbye", knowing that the patient will be truly comfortable in the dying process.

Please vote "Yes" to get this bill through this Committee so it can be considered by the entire House.

Thank you,

Salila Shen, LCSW

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I am Dr. Neil Kaye and am a past president of the Psychiatric Society of Delaware, co-chair of the PSD ethics committee, and a member of the Medical Society of Delaware's Government Affairs Committee and Ethics Committee.

The medical profession has adhered to Codes of Ethics since the 5th Century BCE. Included in these are such famous works as the Oath of Hippocrates and the Oath of the great teacher/philosopher/physician Maimonides. America was founded in 1776, Seven years later, in 1803, Thomas Percival introduced our country's first medical ethics standards. These codes were adopted by the AMA in 1847 and have been revised continuously, most recently in 2008. What has never changed in any of these codes is the requirement that physicians focus 100% of their efforts on healing. Nurses, psychologists, and social workers have similar ethical codes.

Physicians are terrible at predicting death. At 6 months out, fewer than 33% of predictions end up being correct. HB 140 relies on the physician informing patients of their life expectancy. If we can't do that with even a 50% accuracy, how can we be asked to help them in deciding to commit suicide instead of seeking additional treatment or compassionate palliative care?

The myth that physicians can provide a speedy and pain free death needs to be confronted with the reality of the evidence. Nothing in our training teaches us how to help people kill themselves. There are no courses in medical school, no CME's, no conference lectures, no journals, and no controlled experiments to guide us. We are trained to heal, not to harm, and certainly not to kill. The American "experiment" with PAS, begun in Oregon, and wrongly adopted by a minority of other states, shows that the average time to death is 2 hours, but has been as long as 140 hours. 10% of these people vomit up the drugs they took, 2% awaken from their comas, and 33% took 30 hours to die. 25% were depressed, yet only 2% were ever referred for psychiatric treatment. And, there is a "contagion effect," Oregon's overall suicide rate is now 40% above the US average. "Normalizing" suicide is not a message this legislature should send to the teenagers of our great state.

I will not succumb to the euphemism of PAD/MAD, we are here to discuss PAS. The most recent revision of the AMA Code of Medical Ethics, Section 5.7, specifically addresses PAS. It says: "PAS occurs when a physician facilitates a patient's death by providing the necessary means and/or information to enable a patient to perform the life ending act. Permitting physicians to engage in assisted suicide would ultimately cause more harm than good. PAS is fundamentally incompatible with the physician's role as healer, would be difficult or impossible to control, and would pose serious societal risks." Nurses, psychologists, and social workers have similar ethical codes.

Instead of engaging in PAS, physicians must aggressively respond to the needs of patients at the end of life. Physicians should not abandon a patient once it is determined that cure is impossible; must respect patient's autonomy; must provide emotional support and communicate effectively; and must provide comfort care and appropriate pain control.

Creation of a strong end-of-life system is long overdue. Legislative leaders can emphasize proper access to palliative care and hospice. In that strong system, it is critical that the medical profession redouble its efforts in providing optimal treatment at the end-of-life to limit suffering,

both physically and psychologically. Together, we can foster real conversations about end of life using tools like the Delaware Medical Orders for Scope of Treatment (DMOST). Patients and their loved ones can form a plan that allows the patient to die peacefully, with dignity, and without taking drastic measures.

There are numerous specific problems with wording in HB 140. Should it be unfortunately released from this committee, numerous changes and amendments will be necessary to address problems such as the fiscal costs to the State for inmates and DPC patients who wish to avail themselves of this newly created legal right. Lines 75-78 create substantial medical malpractice risk for the physicians involved. True informed consent is impossible in these circumstances.

There will be amendments needed to deal with the direct conflict to the Federal CRIPA (Civil Rights of Institutionalized Persons Act) requirement to prevent suicide and the mandatory reporting and action required under Delaware law (Title 16) when a doctor encounters a person who may be suicidal. And, if Oregon, WA, and CA are “examples,” they have faced yearly efforts to relax the laws and to expand the population of people who would die, with recent efforts to include people with mental illness, those who are disabled, and minors. Amendments to require law enforcement personnel (LEP) to be present and for the attending doctor to be present to answer questions and to assist the family and patient are only logical and should be mandatory. Antidotes to the lethal medications should be on hand in case the person has a change of heart. If the medication is not used, LEP should collect the unused controlled substances/narcotics for proper disposal so more opiates aren’t diverted onto the streets. A fiscal note to address the burden on the judicial system to rapidly review and process “capacity to commit suicide” cases will also need to be included. Witnesses to any of the documents should have to know the planned deceased for a minimum of two years and be able to testify that they are personally aware of the individuals desire to die by suicide while having no ability to profit from the death.

Helping people to kill themselves is not and should never be part of a treatment plan. Death is not just a medical event. It is a life event with dimensions in the physical, emotional, psychological, and spiritual realms. Death is not a problem that can be solved with a prescription. PAS advocates need to accept that they cannot determine or decide the exact hour or manner of their own death.

On behalf of the medical profession, caring doctors, and the patients of Delaware, I ask that you vote to not let this dangerous bill out of this committee. Instead, as a legislative body, please focus your efforts on fulfilling the recommendations of Delaware Health Commission’s 2016 End of Life Report. But, until our Code of Professional Ethics changes, please don’t force such legislation on the House of Medicine.

In closing, I ask you to continue to oppose HB 140. Thank you.

Neil S. Kaye, MD, DFAPA
Distinguished Life Fellow of the American Psychiatric Association
National Alliance for Mental Illness-Delaware Advisory Board
Governor Carney’s Behavioral and Mental Health Commission-member

Chairman Bentz and members of the House & Human Development Committee, thank you for allowing me the opportunity to explain why the Medical Society of Delaware and the Psychiatric Society of Delaware both oppose HB 140. I am Dr. Neil Kaye and am a past president of PSD, co-chair of the PSD Ethics Committee, and a member of the MSD Government Affairs Committee and Ethics Committee. *DHA joins us in opposition*

Last session the Medical Society of Delaware implored the General Assembly to be cautious on this sensitive topic, and we renew our call for caution this session. While some doctors clearly support PAS, and MSD recognizes that even some members favor PAS, our professional organizations, MSD and PSD have never wavered from our opposition, reflecting the majority physician position.

The medical profession has adhered to Codes of Ethics since the 5th Century BCE. Included in these are such famous works as the Oath of Hippocrates and the Oath of the great teacher/philosopher/physician Maimonides. In 1803, Thomas Percival introduced our country's first medical ethics standards. These codes were adopted by the AMA in 1847 and have been revised continuously, most recently in 2008. What has never changed in any of these codes is the requirement that physicians focus 100% of their efforts on healing.

The AMA Code of Medical Ethics, Section 5.7, specifically addresses PAS. It says: "PAS occurs when a physician facilitates a patient's death by providing the necessary means and/or information to enable a patient to perform the life ending act. Permitting physicians to engage in assisted suicide would ultimately cause more harm than good. PAS is fundamentally incompatible with the physician's role as healer, would be difficult or impossible to control, and would pose serious societal risks."

Instead of engaging in PAS, physicians must aggressively respond to the needs of patients at the end of life. Physicians should not abandon a patient once it is determined that cure is impossible; must respect patient's autonomy; must provide emotional support and communicate effectively; and must provide comfort care and appropriate pain control.

While PSD/MSD's positions remain opposed, the dialogue over this topic continues within the profession – both at the state and national level. But, if and until our Code of Professional Ethics changes and our end of life system is made robust, please continue to oppose HB 140.

Thank you.

Neil S. Kaye, MD, DFAPA
Distinguished Life Fellow of the American Psychiatric Association
National Alliance for Mental Illness-Delaware Advisory Board
Member-Governor Carney's Behavioral and Mental Health Commission

Hello, My name is Julie McIndoe and I am from Newark.

If you need a specialized, complex medical intervention there is no better place to be than the United States. I've benefited from this. I am an organ transplant recipient.

About 12 years ago, I was diagnosed with an autoimmune condition that destroys the liver. Medicine slowed it down but in 2012 I needed a transplant. I was very sick and I was very frightened that I would become too sick to survive the operation and would have to go off the waitlist. I knew other people with this disease who did not qualify for a transplant and I knew how some of them had died.

I spent the last two months of my wait in the hospital because my symptoms could not be managed at home. One symptom was fluid weeping through my skin. The nurses tried bandages and towels but I was constantly cold and damp. Try to imagine walking around in your hospital gown and socks leaving a trail of bodily fluid. I was not embarrassed, I was just cold and damp, and I knew it was not going to stop unless I got a transplant. It got worse when I became bedridden. It was impossible to keep the sheets and blankets dry. And no medicine or therapy could help.

I developed numerous skin tears and bedsores. Some of my bandages needed to be changed every 4 hours. It took 30 minutes each time and it hurt. The weight of sheets and blankets on my skin began to hurt. It was not a crushing pain, it just never stopped.

What I saw in the mirror scared me. I was so jaundiced people thought I might be Indian or Pakistani. Some visitors literally did not recognize me. My fatigue was so bad I could not manage conversations of more than a few sentences.

One day, when my husband and I were alone, I finally broke down and cried. "I want this to stop." I cried and cried and said this over and over again. I was NOT giving up. I wanted to live and I still had hope.

Patients will go with their doctors right up to the proverbial edge. There is a point, however, where medicine can go no further. We need hospice. Hospice is heroic medicine, just like organ transplant. But this hearing is not about hospice. It's about what to do when pain and suffering cannot be managed in any setting.

I don't think I would ever use this law. But I know what unrelenting suffering feels like. And I know that I can't tell someone else that their suffering is bearable. Only the individual can make that determination. Please let this bill move out of the committee.

We stood by Representative Baumbach last year when he introduced HB 160, and we are here again today for HB 140 because Delaware United STRONGLY supports the right of select qualified terminal patients to be able to choose how they want to pass.

This is not a choice that we make lightly as an organization, just as it is never one that is taken lightly by the individuals using these laws in other states. However, we firmly believe that adults with a terminal diagnosis, who are willing to go through the process outlined in this bill, should be able to make that choice for themselves.

In the over twenty years this choice has been available in other states in the US, there have been zero instances of any slippery slope arguments that detractors claim will come if this bill passes. The safeguards here in the United States against anyone even possibly abusing this legislation are unlike any other in the world, so there is simply no ground for comparison of any other nations approach to this issue.

For many, this is a question of morality, of faith. It is a personal question, one in which no one wants to ever have to make a choice. If you had a terminal diagnosis with no hope of reversal and in your final days you would be in extreme pain with no escape, and you were given the choice of either continuing on with no access to medication to end your suffering or the option of having the medication should you choose to use it, what would you choose?

For terminal patients in Delaware, this choice doesn't exist. For them, there are only a few options, and for many, maybe even most, these options are sufficient to keep them comfortable and happy in their final days and weeks with us.

However, they are not sufficient for all patients. For some, the pain will be intractable, relentless, and cause great suffering. For some, the option to end their lives with dignity and peace is all they could ask for, and why shouldn't they? Who are we to deny them that?

This question, what would you choose, is not one that the state should be deciding for you. It is quite possibly the most deeply personal question that a person could ever have to answer, and it should only be answered by those actually having to answer it.

No one is demanding that anyone like this question, or anyone's decision regarding it, only that they respect the right of these individuals to make the decision for themselves.

In the end, these patients will pass regardless of the decisions we make for them today. None of them likely want to go, many have families, loved ones, and much more life to live. But we cannot control the cards we are dealt in life. For those that wish to have this option, even if they never use it, we should not stand in their way. We should be compassionate, kind, and show them the respect that they require in this most challenging time.

Please release HB 140 from committee today and support it when it comes to the floor.

Good afternoon, I'm Judy Aungst.

There was nothing left to do. Medical samples were sent each day to the medical school, NO medication worked. One lung was filled, the other 3/4s, the oxygen tent was futile, also trying to drain the lungs. The patient was dying from double pneumonia and now also affecting the heart, causing damage. But the nursing care continued 24/7 with the doctor still visiting.

That was me at 2 and a half years old.

Yes, now I have scarred lungs and was under the care of a cardiologist during my childhood.

Fast forward.....in my college years I had rheumatic fever which was misdiagnosed for 2 months. By that time the heart became enlarged and I had endocarditis, I also developed pleurisy.

Then early in my marriage a cardiologist evaluated me, also knowing I wanted a large family, told me I would be DEAD before I had a large family. Multiple doctors told me at the time of my pregnancies that my biggest risk was heart failure at the time of delivery. I took that risk making sure I made it to a hospital but I always trusted in God. Most of my pregnancies were preeclampsia with complications. I also had an injury, a broken sternum with pericarditis, in between pregnancies. I always had limitations but learned to live with them and I'm under excellent cardiac care.

This bill, not giving patients any hope, can cause depression with projected diagnoses so far in advance. Any age is vulnerable.

Don't take HOPE away.
Vote against HB 140

The Delaware House of Representatives will soon be considering SB 34, which is important legislation designed to help hold pharmaceutical manufacturers accountable for the role their opioid products have played in the addiction epidemic ravaging our state and country. It would accomplish this by placing a modest impact fee on the opioid prescriptions sold in our state, exempting prescription opioids administered in hospitals, provided directly to patients by hospice, or dispensed by veterinarians.

The legislation would raise an estimated \$8 million to fund opioid addiction prevention efforts and addiction services including inpatient and outpatient treatment programs, short-term and long-term residential treatment programs and sober living facilities treating substance use disorder for the under-insured and uninsured and emergency assistance relating to prescription opioids, including purchasing Naloxone. This amount of money is a drop in the bucket for major pharmaceutical companies, which are some of the wealthiest companies in the world, but would go a long way to funding our efforts in Delaware.

Opposition to this legislation, which is almost entirely made up of the pharmaceutical industry, have stated this will simply raise the cost of prescription drugs for consumers. The fact of the matter is, there is absolutely no reason that has to be the case and it ultimately demonstrates need for this legislation. The pharmaceutical companies, whose products played a pivotal role in the creation of this crisis, have continually failed to acknowledge any role or take on any accountability, financially or otherwise. That will continue to be the case unless we compel them to do so. SB 34 is that call to accountability.

Delaware taxpayers have been on the hook for countless millions of dollars to fund direct services to those struggling with addiction, criminal justice costs to combat illegal drug sales fueled by the epidemic, and other societal costs associated with this crisis. That is before we account for the human costs associated with this epidemic that, on average, claims the life of more than one Delawarean a day. All SB 34 does is ask pharmaceutical companies to finally take some responsibility for funding those efforts.

For example, if a fee of \$10 is levied on a drug manufacturer and the manufacturer passes on the full amount to the wholesaler while retaining its full profit margin, then economic principles would suggest that another company would sacrifice some profit margin and pass on only \$9 of the fee, thereby capturing the market. Eventually a competitive equilibrium will be found and this back and forth game will be played at every step of the supply chain.

There is little possibility that some part of the supply chain will leave Delaware without a competitor stepping in and ensuring patients have access to the pain medication they need.

Regarding the second argument against Senate Bill 34 and the prospect of significantly higher costs for patients, I find little evidence to suggest patients will have higher costs when filling a prescription. According to recent analysis of the Prescription Drug Monitoring Program, nearly 90 percent of the prescriptions for opioid derived pain medication are generic. Most insurance plans including Delaware Medicaid, set a fixed dollar copay for generic medication, such as \$4, \$5, or \$10 for each fill. For Delaware Medicaid these copays range from \$.50 to \$3. In general, copays rarely change especially just for one drug or type of drug, but drug prices change all the time (and often in the upward trajectory).

I do not expect copays to change based on this fee, just as they don't change for drug price increases. It is in the interest of insurers to have patients take generic medications given there fraction of a cost compared to branded medications. For branded medications, which account for only 10% of the prescriptions, there is often significant margin in the form of rebates manufacturers provide to insurers that can absorb this fee. It is unlikely patients will experience higher prices at the pharmacy counter due to this fee.

In summary, it is my opinion that this fee would have little effect on patients access to medication or cost at the pharmacy counter. The funds raised by this fee will serve a much greater good in treating people with opioid use disorder than the higher costs caused by the fee.

Thank you and I am happy to answer any questions.



AMERICANS
for TAX REFORM

May 8, 2019

To: Delaware House Health and Human Development Committee
Re: Testimony on Senate Bill 34

Chairman Bentz and Members of the House Health and Human Development Committee,

My name is Doug Kellogg, I am State Projects Director for Americans for Tax Reform.

ATR was founded in 1985 by Grover Norquist - at the request of President Reagan - to advocate for tax reform. Today, we continue to advocate for taxpayers, and work for policy that protects taxpayers, consumers, entrepreneurs, and fosters a vibrant economic climate that enables taxes to be few, low, and simple.

I am here today to testify in opposition to Senate Bill 34 with Senate Amendment 1, which would impose a direct tax on opioid medication and create a Prescription Opioid Impact Fund.

The legislature's focus on a public health crisis is understandable, and necessary. Unfortunately, turning to taxes and fees will not work, and could make matters worse.

The proposed tax can amount to a significant 20 percent of the cost of certain drugs. The cost must be passed on to consumers. A federal court ruled that New York's 2018 opioid stewardship law barring costs from being passed on to consumers was unconstitutional.

This will drive up costs for Delaware residents in need of pain medication, who are legitimately prescribed that medication under the supervision of a doctor. It does not make sense to punish patients who are in pain.

Multiple studies show, it is not just those who are prescribed pain medicine who will pay, the costs from the tax and compliance will also be passed on to everyone in the state through higher insurance premiums.

Higher costs for medication can impact hospitals, and taxpayers too, as costs go up for public hospitals, Medicaid and other programs like the Prescription Assistance Program. This is the state is taxing itself.

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A report by economist Alex Brill, and Women In Government, shows the damage a tax would cause: **“the tax would do little to discourage inappropriate use, could have the unintended consequence of promoting illicit opioids for some, and would raise the cost of health care generally.”**

In fact, people without health insurance feel the higher costs as well, since they have no way to deflect them if they need to buy medication. If costs become too high for pharmacies, they may stop filling prescriptions, creating access issues for Delaware patients.

What is most frightening about a tax on pain medicine, is its potential to drive those struggling with addiction, or affordability, into using dangerous, illicit fentanyl, which new CDC data show is the most deadly part of the crisis

Deaths from black market fentanyl, largely from China, and Mexican cartels, spiked to 5,000 in 2014 and rocketed to over 26,000 in 2017, according to Bloomberg News.

In fact, overall overdose deaths have risen, while existing policies have already driven down opioid prescriptions to an 18-year low.

Further, a paper from researchers at the University of Pittsburgh Medical Center casts doubt on the connection between opioid pain medicine and the rise in overdose deaths – showing that trend began before the broad prescribing of this kind of pain medication.

That is not to say there is no room for policy changes. In Little Falls, Minnesota, community-based solutions are working. They focused on treatment for people struggling with addiction, instead of just jail time. According to PBS, the Minnesota Health Commissioner reported the local hospital “has seen patient pill use decrease by 724,000 pills per year and have tapered about 670 patients off of controlled substance prescriptions.”

We hope you will consider other, proven options to address the overdose crisis we are seeing, and reject a misguided tax on opioid pain medicine.

Thank you.



Your Generics & Biosimilars Industry

Statement in Opposition Delaware Senate Bill 34 May 8, 2019

AAM is the nation's leading trade association for manufacturers and distributors of generic and biosimilar prescription medicines. Our core mission is to improve the lives of patients by advancing timely access to affordable, FDA-approved generic and biosimilar medicines. Our members provide more than 36,000 jobs at nearly 150 facilities and manufacture more than 61 billion doses of prescription medicines in the United States every year. In 2017, manufacturers of generic medicines saved Delaware \$778 million.

AAM opposes Delaware SB 34. It is critical that we combat the misuse and abuse of prescription medication while maintaining legitimate, uninterrupted access to medicine by patients in need. It is a public health imperative that patients take medicines as prescribed and adhere to the instructions of their healthcare providers. Generic drug manufacturers, who believe that patient safety is of the utmost importance, play a key role in producing affordable FDA-approved therapies.

The fee in SB 34 would overwhelmingly impact generic drug manufacturers. According to the "FDA Analysis of Long-Term Trends in Prescription Opioid Analgesic Products: Quantity, Sales, and Price Trends" from March 1, 2018, generics represented over 90% of MMEs sold in 2016 and had an average price of less than 2.5 cents per MME.¹ This is in line with prescribing trends for all generic drugs, including non-opioid drugs.² Although generic medicines are 90% of prescriptions dispensed in the U.S., they account for only 23% of total spending on prescription medicines. As drafted, SB 34 would impose a 1.25 cent per MME fee on all generic opioids. Not only is this *more than half the average price* per MME of a generic opioid, but perversely it is less than the 1 cent per MME fee imposed on brand opioids – even though the average brand opioid price was reported by FDA to be 20 cents per MME in 2016.

Governor Carney has implemented meaningful initiatives to address the opioid crisis and they are working. In 2017, Governor Carney, with the help of then-Attorney General Denn, signed into law 3 pieces of legislation that expanded access to substance abuse treatment, strengthened oversight of opioid prescriptions, and expanded insurance coverage for treatment. Governor Carney also increased access to naloxone, created the Behavioral Health Consortium and Addiction Action Committees to better coordinate care and treatment, and launched HelpsHereDE.com. In Delaware, the total volume of opioids prescribed in the first quarter of 2018 was 18% lower than volume prescribed during the same period in 2017.³ Additional recommendations for continuing to combat the crisis in Delaware are being implemented pursuant to the July 2018 Blueprint for Transforming Opioid Use Disorder Treatment in Delaware drafted by the Johns Hopkins Bloomberg School of Public Health and the March 19 Substance Abuse Disorder Treatment Policy Recommendations for the State of Delaware submitted to the state by the Pew Charitable Trusts.⁴

Taxing Opioids Is an Ineffective Deterrence Strategy and Will Have Unintended Consequences. A recent study done by Matrix Global Advisors commissioned by Women In Government outlines the ineffectiveness of

¹ Food and Drug Administration. (March 2018).

FDA Analysis of Long-Term Trends in Prescription Opioid Analgesic Products: Quantity, Sales, and Price Trends

² AAM 2018 Generic Drug Access & Savings Report;

https://accessiblemeds.org/sites/default/files/2018_aam_generic_drug_access_and_savings_report.pdf

³ "One Year After New Regulations Issued, Delaware Opioid Prescriptions and Quantities Dispensed Continue to Drop," Delaware Department of State Press Release, April 19, 2018 (<https://news.delaware.gov/2018/04/19/delaware-opioid-prescriptions-quantities-dispensed-continue-drop/>)

⁴ Delaware Secretary of State, *Delaware Opioid Prescription Rates Falling Seven Months After New Regulations Enacted*. November 8, 2017

opioid taxes⁵. Pills that are misused are mostly acquired from indirect sources that would not feel any of the punitive effects of the tax. According to the report, only slightly more than one-third of people who misuse prescription medication have been prescribed them by a doctor. Taxing prescription opioids will also have no impact on the damage that illegal opioids cause on our communities. Taxes on prescription opioids have unique characteristics and do not operate like those imposed on tobacco, alcohol, or fuel and would be ineffective at discouraging misuse. Instead, the impacts of the tax would only be felt by the burden imposed on the health care sector. Once the impact of the tax has had a chance to influence the market, health insurers would see their costs rise which would cause them to raise their premiums. This increase will ultimately fall on the customer. As the cost of doing business in the state increases, manufacturers may elect to leave the market altogether. This could leave patients who depend on prescription opioids in Delaware with reduced access to the medication they need to live their lives.

Patients Need Effective Treatment for Pain. Chronic pain is real and affects 30-60 million Americans. Improper pain treatment leads to higher utilization of health care and increased societal costs. Most patients taking opioids do not abuse their medicines. Millions of patients who suffer acute trauma, undergo surgery, or suffer from pain as the result of chronic disease such as cancer, rheumatoid arthritis, and other ailments rely on effective pain treatment. Appropriately treated pain allows patients to perform basic daily activities - walking, bathing, working, and can reduce the likelihood of lower self-esteem, depression, and suicide. Legislation to prevent opioid abuse should be carefully crafted to avoid the unintended consequence of denying patients with legitimate pain access to low cost generic medications. It is possible that within the robust marketplace of generic prescription opioid manufacturers in Delaware, some will find that the impact fee created by this measure makes the cost of doing business in Delaware too high to remain in the market. Any vacuum created by their departure could be absorbed by larger companies thus driving up costs, not only for generic opioids but across all generic drug portfolios, for consumers and the state.

Proposals to Tax Opioids Would Undermine Generic Competition and Increase Prices for Patients. Many generic products operate on thin profit margins, which are extremely susceptible to minor market changes, including new regulatory requirements. Because generic products, including opioids, function on such low margins, new taxes or regulatory burdens would significantly increase costs for generic manufacturers. Manufacturers of affordable opioid medications may find there is no possibility of providing affordable products that can exist in a competitive market. As manufacturers are forced to deal with these realities, it is not unlikely that some will exit the market, reducing competition and increasing costs for patients and the system. Fewer generic competitors will result in higher generic prices and increased reliance on higher cost brand drugs.

Nothing in SB 34 will address the growing use of illicit fentanyl and other synthetic opioids. The CDC has divided the opioid epidemic into three "waves" with the current wave, the Rise in Synthetic Opioid Overdose Deaths, being the deadliest – responsible for nearly the same amount of deaths as prescription opioids and heroin.⁶ According to the National Institute on Drug Abuse's March update, between 2011 and 2017 there was a thirteenfold increase in deaths from illicit fentanyl, with deaths increasing from 13 in 2011 to 178 in 2017. During this same period, heroin deaths increased from 15 to 121. It is now the illicit drug trade that is driving the crisis in Delaware. Legislators should focus on addressing illicit opioid use and continuing to make improvements to existing prescribing measures instead of penalizing generic manufacturers.

For these reasons, AAM respectfully urges Delaware legislators to oppose SB 34.

⁵ Brill, Alex. State Opioid Taxes: Economic & Health Policy Implications. January, 2019

⁶ CDC, "Understanding the Epidemic," www.cdc.gov/drugoverdose/epidemic/index.html (updated December 19, 2018).

**Testimony for the Record
Submitted to the Delaware Senate
for Hearings on SB 34
April 9, 2019
Jeromie Ballreich, MHS, PhD
Assistant Scientist
Johns Hopkins University**

Impact of Opioid Drug Fee in Delaware

I am Dr. Jeromie Ballreich, and I am a faculty member and director of the Master's in health economics program at Johns Hopkins University. My research interests include economic evaluation, health policy with a focus on domestic pharmaceutical policy, and pharmaceutical market dynamics. The opinions expressed herein are my own and do not necessarily reflect the views of The Johns Hopkins University. I am pleased to testify today on Senate Bill 34.

Last June, I testified for a similar bill, Senate Bill 176. Both bills set a fee on the morphine milligram equivalent per prescription and uses the raised funds to address the opioid epidemic in Delaware. Since last summer, critics have raised arguments against the proposed opioid drug fee. In my testimony today, I will address many of these arguments. Very simply, the fee will have a monetary impact on the various entities in the pharmaceutical supply chain, but it will not cause companies to leave the Delaware market en masse nor will it raise patients costs at the pharmacy counter.

Critics of Senate Bill 34 present two arguments against the bill that they claim will result with Delaware patients unable to get access to needed pain medications. First, they claim the fee will raise the cost of doing business too high and companies will leave the Delaware market leaving pharmacies without access to pain medications. Second, they claim SB 34 will result in higher patient copays at the pharmacy counter, adding a significant financial burden to patients that need pain medications.

Regarding the first claim, it's true that any fee raises the cost of business. However, the pharmaceutical market is complex with multiple entities involved with supplying medications to patients. These include drug manufacturers, wholesalers, pharmacies, pharmaceutical benefit managers, insurers, and patients. In markets with multiple entities involved in the supply chain and a competitive environment, the fee burden is often spread across the multiple entities. The exact amount of fee borne by each entity is based on economic principles such as market power or availability of substitutes, and competitive forces play a key part.

Did you know, that by the time someone finishes their first month of prescription opioids, 1 in 10 will be physically, if not also psychologically, addicted? How about that by the end of the second month that number jumps to 1 in 3? How about the fact that 80% of new heroin users reported that they started into the drug through an addiction to a prescription opioid?

Delaware is taking great strides in helping combat the opioid epidemic in our state. From prescription monitoring through the PMP, to ensure responsible prescribing, education requirements for prescribing doctors, to increasing rehabilitation services in the state. While these are all important pieces of the puzzle, one piece amongst many others is still missing.

Holding drugmakers responsible for their actions and their blatant lies. Companies like Purdue Pharmaceuticals knew its products were highly addictive and continued to downplay this fact to doctors across the country. Yet, many of those in charge of that effort walk free today, while millions have died as a direct result of their actions. There is no fine in the world that could undo this harm, however, that does not mean they should not help pay for the damages they have caused.

For years, these companies have gotten rich off of lying to doctors. That was the case with Oxycodone and Tramadol, two of the most addictive and widespread opioids still on the market today. Now, these same companies are cashing in on treatment through drugs like Naloxone and Suboxone to undo some of the damage that they caused themselves.

Delaware needs treatment centers, but that is not enough. We need wrap-around services, community support groups, funding for treatment beyond a 14 day drying out period, and all of this cost money. Should taxpayers be on the hook for the damage that these companies have caused, making trillions of dollars in the process?

Delaware United proudly endorsed Stephanie Hansen, the prime sponsor of this bill and a fierce advocate in the fight against opioid addiction in Delaware, and we are even more proud today as this bill makes it before this committee. We ask you to pass this out of committee today but would like to end on one other thought.

Please do not stop fighting for this issue. We need more than reactive services to treat addiction, we need proactive services to PREVENT it in the first place. We need funding for non-opioid therapies for pain management for all Delawareans, and resources to really spread wide the public education campaigns being built in the Addiction Action Committees working on this front. So, please, remain dedicated to this cause, we cannot afford to keep losing Delawareans to a preventable cause.