Public Health Committee
JOINT FAVORABLE REPORT

Bill No.: HB-5148
Title: AN ACT CONCERNING PREGNANT PATIENTS EXERCISING LIVING WILLS.
Vote Date: 3/23/2018
Vote Action: Joint Favorable
PH Date: 3/20/2018
File No.:

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SPONSORS OF BILL:

Public Health Committee

REASONS FOR BILL:

To permit pregnant patients to exercise a living will.

This bill repeals a law which currently provides that (1) living wills and other advance directives are not valid if the individual is pregnant and (2) provisions on liability and the removal of life support do not apply to pregnant women. The bill instead requires advance directives to indicate for pregnant women whether they:

1. intend to accept life support if her doctor believes that doing so would allow the fetus to reach a live birth,
2. intend the document to apply without modifications, or
3. intend the document to apply differently.

RESPONSE FROM ADMINISTRATION/AGENCY:

None

NATURE AND SOURCES OF SUPPORT:

Kaley Lentini, Legislative Counsel, American Civil Liberties Union of Connecticut (ACLU-CT): Kaley Lentini, representing ACLU-CT, submitted testimony in strong support for House Bill 5148. Under current Connecticut law, a woman's health care wishes are automatically nullified if they are pregnant, forcing them to receive medical life-sustaining treatment when they are permanently unconscious, incapacitated, or terminally ill, despite contrary instructions in their advance directive. The government should not direct physicians

to disregard the health care wishes of pregnant people simply because they are pregnant. In 1990, the U.S. Supreme Court recognized the constitutional right to refuse medical care by stating "…a constitutionally protected right to refuse lifesaving hydration and nutrition." Connecticut should position itself along with New Jersey, Vermont, and other states, by supporting HB 5148, because a person should not lose their right to refuse medical care just because they are pregnant.

American College of Obstetricians and Gynecologists – Connecticut Chapter (CTACOG); and Connecticut State Medical Society (CSMS): A key principle in medical ethics is informed consent. It is unethical to perform medical interventions that are (or would have been) contrary to a patient's wishes or beliefs. Requiring women to be subjected to invasive life support systems violates their dignity. It is important to remember that pregnancy itself actually increases the risk of tragedy for many women, especially those with preexisting health conditions.

Brenna Doyle, Deputy Director, NARAL Pro-Choice Connecticut: If enforced, current state law infringes on women's constitutional rights to refuse medical treatment and to terminate non-viable pregnancies. Among other disparities, current law disregards fetal health and the individual's expressed intent. If implemented, a pregnant individual can in essence be reduced to an incubator. In addition, fetal death is the overwhelming outcome in most of these cases and there have been no reported live births of fetuses when incubation started at 14 weeks or earlier. HB 5148 fixes a glaring violation of women's' constitutional rights.

Madeline Granato, Policy Manager, Connecticut Women's Education and Legal Fund (CWEALF): In Connecticut a pregnant woman will be placed upon life sustaining systems regardless of her intent or the viability of the fetus. Connecticut's current law is among the most restrictive in the country and infringes on women's constitutional rights to refuse medical treatment and to terminate non-viable pregnancies.

Medical conditions that incapacitate mothers often have severe consequences on fetal health; as well as any aggressive, life-sustaining medications that must be administered in order to keep the host body viable for the fetus.

Susan L. Yolen, Vice President of Public Policy and Advocacy, Planned Parenthood of Southern New England: Connecticut's living will statute was adopted over thirty years ago and the provisions in HB 5148 would offer an individual creating an advance directive to identify their wishes in the event of a pregnancy. HB 5148 will also encourage necessary conversations among family and medical providers. In a recent poll, 77% expressed support for a law that would allow pregnant women to create a living will to be exercised in the event of a life-threatening medical condition was to arise.

Katherine S. Kohari M.D., Assistant Professor, Yale School of Medicine Department of Obstetrics, Gynecology & Reproductive Sciences: Pregnant women deserve the right to participate in their own medical care and to act as mothers by making medical choices for their unborn children. While working in the subspecialty of Maternal-Fetal Medicine I care for women with medical conditions that may be exacerbated by pregnancy and even patients with terminal diagnoses who may not be able to communicate their medical wishes. When caring for my high-risk pregnancy patients it is my and other doctors' practice to discuss and

distribute living wills and healthcare proxy forms. Given the importance of living wills in my practice, my colleagues and I were surprised to learn that, during pregnancy, a patient's living will and healthcare proxy form are invalid. All other patients have the right to control their medical care; why should a pregnant patient lose this right when she falls unconscious?

Mark R. Mercurio M.D. MA, Chief of Neonatal-Perinatal Medicine, Yale School of Medicine: The concept of patient autonomy, and the opportunity to direct one's own healthcare, is foundational to modern medical ethics, and to modern American medicine. Advance directives and living wills are appropriate and foundational to medical care; however, the law does not extend that same right to pregnant women. I believe that withholding the right of self-determination to pregnant women is an injustice. I support HB 5148, which I believe represents a more just approach to this issue that current Connecticut law provides.

Laura, J. Morrison M.D., Associate Professor of Medicine, Yale School of Medicine: My patients are often facing great medical complexity and potentially life-limiting illness. Occasionally, women will face life-threatening illnesses while pregnant, such as: the diagnosis of a new cancer with complications; a new condition, like a stroke or developing organ failure; or a previously diagnosed condition worsens during pregnancy. Palliative medicine practice in the U.S. prioritizes the elicitation of patient goals and values in the process of shared medical decision making around serious illness. Families, legal surrogates, and medical teams are all encouraged toward focusing on patient wishes with cultural, religious, spiritual, and other domains. If a pregnant patient were unable to participate in decision making about her care, the legal surrogate would be supported to act on the patient's wishes, expressed previously in verbal form or in a living will document.

Current state law explicitly excludes pregnant women, which conflicts with the prioritization of patient wishes in palliative care, by leaving women unable to express preferences for future care related to potential pregnancy. HB 5148 would reverse this policy and align the law with the standard of care and best practices of palliative medicine and benefit all parties within a patient's care circle.

Andrew Tyler Putnam M.D., Assistant Professor, Yale School of Medicine: In the course of my career I have seen several pregnant women diagnosed with cancer after their pregnancy had begun; as well as, a pregnant woman maintained on life support after a motor vehicle accident. The purpose of Advanced Directives is to allow any patient the right to determine what will happen to them medically if they are incapacitated and unable to advocate for themselves. Artificial life-sustaining methods are not comfortable and often cause great suffering. I believe that all adults should have the right to be protected from these procedures if they desire. I am urging the committee to move forward with HB 5148 as I believe the bill is a good solution for both patients and physicians.

Mathew Lifson, New Haven Connecticut: Connecticut's pregnancy exception law is one of the worst in the entire country, on par with Texas and Alabama. Currently, advance directives for pregnant women are non-existent and if a pregnant patient with an advance directive falls into a coma, the document becomes void and she must remain on life support until the hospital is able to remove the fetus, via an unauthorized Cesarean. Similarly, if a pregnant woman does not have an advance directive, she must be kept on life support regardless of the wishes of her partner and family.

An extreme feature of Connecticut's pregnancy exception law is that it requires mothers to be kept on artificial life-sustaining methods even if there is a zero percent possibility of the fetus attaining/reaching live birth. Another extreme is the absence of an exception for women who are conscious but terminally ill and medically incompetent. Connecticut's current law violates two constitutional rights: by disregarding women's advance directives it violates the right to refuse medical treatment; and secondly, it violates the right to terminate a previable pregnancy.

HB 5148 will align itself with other states that have repealed their pregnancy exceptions and will give women the affirmative right to specify how their healthcare instructions should apply during pregnancy. HB 5148 is similar to Maryland and Virgina's laws, which work by adding a voluntary section to the sample advance directive form, allowing women to include any additional instructions or modifications if they are pregnant when their advance directive is needed. Two major benefits of this bill are: (1) it unambiguously returns control to patients and; (2) it alerts women to the need to make their preferences on this issue known. I am urging the committee to please move forward with this bill.

Matthew Drago, Neonatologist and Bioethicist, Yale University: Connecticut's current pregnancy exception law violates the fundamental ethical principle of autonomy. The principal of autonomy promotes a patient's right to voice their wishes and values in medical decision making in order to ensure that they receive the compassionate care we strive to provide. Incapacitated pregnant women should have the same freedom to control their medical care that any other citizen would have if they were rendered unconscious; especially during pregnancy, where a woman will not only be her own voice but that of her unborn child.

I have had the experience with two patients who became permanently unconscious during pregnancy and me and other physicians decide how to manage care for the mothers and fetuses. During situations such as these, a living will is the best source of information. Connecticut's pregnancy exception is medically unethical and violates a basic dignity that all patients should have by taking away a patient's right to refuse invasive life support systems and unauthorized Cesarean sections.

Connecticut's pregnancy exception law was clearly written to benefit fetuses but it is medically wrong to assume that continuing a pregnancy, by maintaining a mother on life support will always be in the child's best interest. Factors such as the health of the mother, health of the fetus, and life-sustaining medications will affect the potential to save a fetus. Given these risks, HB 5148 is ethically sound because it returns the decision-making power to patients and their families.

Leanne Harpin, Fairfield Connecticut: Under current Connecticut law there is an absence of statutory language regarding the validity of advance directives in the case of pregnancy. With clear language lacking it leaves terminally ill and mortally injured pregnant women unable to utilize their advance directives. When laws like this are vague it makes an already traumatic situation that much more painful and heartbreaking. Please clarify the law and support HB 5148.

Erin Livensparger, Portland Connecticut: Current law infringes on women's constitutional rights to refuse medical treatment and to terminate non-viable pregnancies, often working

against the best interests of the fetus as well. As a woman who has had difficult pregnancies I understand the hard choices that a family might have to make and I am appalled that this law is still current law. A woman knows that is best for her and her family and if she has a living will it must be respected. Please repeal Connecticut's pregnancy exception and support HB 5148.

Nora Niedzielski-Eichner, Norwalk Connecticut: I am writing as a third-year law student and as a mother. Last year, as I learned of my pregnancy, I also learned of Connecticut's pregnancy exception law and was shocked, angered, and frightened. Shocked, because we live in Connecticut and I expect our laws to be up-to-date, especially in an area as important as healthcare. Angered, because the current law denies pregnant women the right to make their own medical decisions, as everyone else in the state is allowed to do; and, frightened, because there was a remote chance I could end up in a coma and kept on life support against my wishes.

I wrote my first advance directive a number of years ago and they felt even more important to me last year when I was facing a high-risk pregnancy. Nonetheless, Connecticut denied me the right to make my own final decision and the right to designate my partner as the one I wanted to make all other medical decisions. Moreover, from a law perspective, Connecticut denies the rights of pregnant women in the most confusing way possible, by simply removing pregnant women from the category of people who can sign a living will and appoint a health care representative. Many medical professionals, such as the midwifery group that handled by pregnancy and birth, are unaware that pregnant women are restricted from advance directives and will promote this in their offices.

From a constitutional and ethical prospective, Connecticut's pregnancy exception denied me the equal protection of the law for the period of my pregnancy, violating my constitutional right to refuse medical treatment and my constitutional right to make all decisions about my pregnancy.

The current statute exposes women to the risk of a prolonged death that is entirely contrary to their beliefs and wishes without notice and without recourse. Please repeal Connecticut's pregnancy exception and pass HB 5148 so that pregnant women can control their most important health care decisions, just like everyone else.

Kayla Tarlton, New Haven Connecticut: Irrespective to a woman's advance directive, past statements, fetal health, or patient suffering, Connecticut doctors must keep a woman on life sustaining machines until a fetus is able to be removed via Cesarean section. In addition to an advance directive becoming invalid upon conception, it will not be legally binding after the pregnancy, as a pregnant woman has no legal right to draft the instructions. Not only does Connecticut's pregnancy exception cast unconstitutional burdens upon women but it often works against the best interests of the fetus as well. By attempting to continue incubation, with a mother who is comatose, it disregards fetal suffering and future quality of life.I urge the committee to work to insure that the important benefits described in HB 5148 become law in Connecticut.

NATURE AND SOURCES OF OPPOSITION:

None

Reported by: Anne Gallagher **04/05/2018**