Testimony of Guy Page, Advocacy Director
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To the Vermont House Human Services Committee
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Thank you for inviting me to discuss how Act 39 is working, and whether or not Vermont needs the safeguards. I will try to limit my discussion to how Act 39 is working to events that have happened since the law was enacted in 2013. However I may mention a prior event to provide context and because you do have several new committee members.

The VAEH is comprised mostly of physicians who oppose physician-assisted death. VAEH contends that Act 39 creates added risk of unwanted death for Vermonters facing terminal illnesses, especially those with inadequate health insurance and family and peer support. We agree with the Vermont Center for Independent Living that assisted death adds to the already considerable risk of unwanted death for elders, people with disabilities, and people struggling with suicide.

Even before I heard Commissioner Chen's testimony yesterday, I was troubled by the lack of detailed, accessible official reporting. The Vermont Department of Health website shows that the only required "reporting" is essentially negative: the cause of death on a death certificate should cite natural causes, because "There is no medical or epidemiological reason to list the terminal mechanism of respiratory failure due to the medication overdose." Yet it would be of great value for public health research. The death certificate – a public record – may not disclose how the person actually died. This is incomplete if not actually misleading. Has any thought been given to listing the underlying cause of death with the addendum, "per Act 39". This could be a first step to serious study about why terminally ill Vermonters choose to end their lives. This committee should seek to determine whether Vermont's recipients of lethal drugs are in a health insurance financial crisis; face family and/or caregiver pressure; have been evaluated for depression or desire to suicide by a psychologist with end-of-life expertise; or are being abused. Of the small but growing number of Vermonters requesting these lethal drugs, we have no way of assessing whether these real life issues affected their decision. Specifically, you could exercise your role as oversight committee of the Health Department and request a summer study. You could also amend the law to require collection, study and appropriate sharing of this relevant information.

And even if you take none of these steps, you could at the very least wait a year, letting time serve you. This law is just two years old. Let another year inform you, and then take whatever action seems best regarding safeguards, with plenty of time to spare before July 2017 sunset.

Your committee can best serve the needs of these at-risk Vermonters by collecting and sharing needed information about their needs and their risks.

Consider this: earlier this year, I mentioned to a legislator my concern about a family member pressuring a terminally ill person to seek lethal drugs. I was told this scenario of "family members trying to get grandma to take pills so they can get her inheritance a few weeks early" just wasn't realistic. Let me tell you what is realistic – so realistic that it's happening. I recently met a Vermonter suffering from years of cancer whose relative and chief caregiver is advocating for the lethal medication. The caregiver isn't a bad person…just very, very tired, and in their own words is just too tired to keep doing this. And now that the pills are legal and available, death by prescription beckons as a way to stop the caregiver's fatigue.

Yesterday Oliver Brody said Maggie Lake's daughter "prevailed on her" at one point to continue living. Clearly Maggie had a loving, supportive family. I am concerned that other Vermonters with less support will be "prevailed on" too – but to <u>not</u> continue living. Prevailing happens.

It is chilling to read the testimony of Caledonia County medical ethicist Pete Gummere on the new Repeal Act 39 website, in which he recounts hearing a family member say of a terminally ill person, "I want him dead, dead, dead."

Will tweaking Act 39 prevent this kind of abuse? Realistically, no. Vermont has robust child protection laws and reporting practices enforced by law enforcement, dedicated social workers, and society's zeal to protect children. And yet still children die in their homes. Vermont's laws, police, and social workers all would protect the elderly and disabled; yet many are victimized, sometimes unto death. With assisted death having such minimal legal, reporting, and police services by comparison – so minimal that the proximate cause of death cannot even be accurately reported – what hope is there that all at-risk Vermonters will be protected? And is even one unwanted death as a result of Act 39 acceptable? I say no. If you disagree, I would respectfully ask you, how many.

VAEH is concerned about how Act 39, and a doctor's affirmative duty to inform terminally ill patients of all options per the Patients' Bill of Rights passed before Act 39, would seem to require physicians to tell terminally ill patients that lethal drugs are among their options. The vital relationship of patient-doctor trust is threatened if a doctor must tell a patient that maybe he or she should consider ending their life.

On the matter of inadequate end-of-life insurance – I know of a Washington County man who was forced to sell his most precious possessions to pay his terminally ill wife's nursing home bills. He loved his wife dearly and would sacrifice anything for her. But it is easy to understand that some families, facing financial drain, would implicitly or explicitly pressure the terminally ill family member to pursue relatively inexpensive lethal drugs.

Act 39 was passed two years ago in expectation that adequate universal insurance coverage was just around the corner. Much has changed. An important assumption – that no Vermonter would have cause to swallow lethal drugs to relieve their families of the financial burden of costly end of life treatment – is now unsupported. Without adequate end of life insurance coverage, unwanted death by

cheap lethal drugs remains a risk. People in other states have been told, “we won’t pay for your cancer treatment but we will pay for your pills.” Is this happening to Vermonters? As a heath care oversight committee, will you take the time to find out?

As to the unintended connection between unwanted suicide and legalized assisted death, I must tell the story of my eldest son. As a teen he was a constant suicide risk. Through the wise, compassionate help of state social workers, he escaped his teen years alive. Some years ago he sat in the well of the House and listened to testimony at a large public hearing some years ago. Not having made the connection myself, I asked him afterwards what he thought of the meeting. My brilliant, troubled son began to shake in angry fear. “Those hypocrites,” he said. “They’ve been telling me all this time that suicide is never OK.” When I said the law is meant for adults at end of life, his teenage hypocrisy meter just pegged my response as one more example of “do as I say, not as I do, it’s all right for adults, not OK for kids.”

My last story illustrates the best path for Vermont and addresses a concern raised by Oliver Brody. Before she died on March 7, my mother was under the care of Dr. Zail Berry, a palliative care professor and physician and a longtime member of the Vermont Alliance for Ethical Healthcare. I believe I heard Dr. Berry testify before this committee, perhaps eight years ago, that end-stage cancer patients can be both conscious and substantially pain-free. This assertion proved true for my mother. Despite an aggressive cancer that was shutting down her body, my mother was talking and laughing just a few hours before 11 pm March 6, when she went to sleep, and died the next morning. I don’t know what my mother thought about Act 39. I do know the circumstances of her passing were, to me, an example of what Vermont must strive for: the highest standards of palliative care education and practice for Vermonters at end of life.

As I reach the conclusion of my testimony, I am struck by how many of the stories I have told are my own. I lead a pretty typical life. I think that most Vermonters would, in a safe, constructive setting, tell their real-life stories. I ask this committee to take the time, and take the lead.