Good morning and thank you Chairman Pellegrino and Council Members. My name is Kimberly Goulart, and I have the honor of working with Compassion & Choices (C&C) and its more than 35,000 members to improve end of life care options for Americans. C&C is the oldest and largest organization in the country focused on ensuring that Americans have access to the full array of end-of-life care options including palliative care, improved pain care, hospice care, and legal aid-in-dying. Compassion & Choices has more than 25 years of experience in advocacy and service. Much of the work we do is accomplished through the grassroots efforts of our members and volunteers who generously give their time to support and strengthen their communities through direct service to terminally-ill patients and their families. C&C also works with policy makers on the local, state, and federal levels to ensure that the law facilitates an environment where patients are fully informed of all their options and are empowered to make their own decisions about their end of life care, in consultation with family and medical providers.

Since its inception, C&C has focused its resources on arming patients and their families with the tools to effectively and openly discuss the medical options available to them at the end of life. As we encountered an increasing number of patients around the country, we have learned that dying patients needlessly suffer due to a lack of essential information. As a result, many spend their last days in agony. Too many patients make one of the most important decisions of their lives – how they will live their final days – without being fully informed of their legal rights and in some cases, all of their medical options. Doctors have a responsibility to put the information and power to choose in the patients' hands.

Refusal clauses, sometimes referred to as conscience clauses, can undermine that very basic principle of being fully informed of and having access to all of their medical options. Refusal clauses allow physicians and other medical professionals to refuse to perform a procedure for moral or religious reasons. Depending on how they are written, these policies can also allow medical professionals to refuse to provide a referral to another medical professional that will provide a particular service, or even to inform the patient of the option of that procedure. While the refusal clauses frequently specifically address the religious or moral objections to sterilization procedures and abortion, they are often broadly drafted to extend to any procedures which may be controversial or viewed as morally objectionable. In the area of end of life care, institutions and individuals opposed to withdrawing feeding tubes, aggressive pain care management, providing support to a patient choosing to voluntarily stop eating and drinking, or to the practice of palliative sedation could claim these are objectionable and are thus within the scope of refusal laws.

This is particularly worrisome for patients at the end of life who are often unaware of their options, hesitant to initiate conversations with their providers about certain options, and often unable to remove themselves from their current health care setting in order to seek treatment elsewhere. When dying patients are suffering in the final stages of terminal illnesses, they should be able to receive counseling on a full range of options. This thereby empowers them to make fully informed medical care decisions, including the legal and medically accepted options of refusing life prolonging interventions, opiate pain management, palliative sedation, and voluntary stopping eating and drinking (VSED).

It is well documented that pain is frequently under-treated, despite requests by patients and families. Some health care professionals, including those at the bed side, have personal and religious beliefs opposing pain relief, even in circumstances in which professional norms require it to be offered. These laws can remove any obligation on behalf of any employee of a health care entity to inform patients of all of their treatment options or to refer a patient to another provider if that patient requests treatment options with which that employee does not personally agree. The very notion of denying patients access to any such information runs afoul to the fundamental healthcare principles of autonomy and informed consent.

Many patients trust their provider to give them with the full range of information on all of their options. Refusal clauses that empower providers to deny patients appropriate counseling and referrals leave many patients unaware that other options are even available or that they have a right to seek treatment elsewhere. At a minimum, and in order to maintain at least some level of autonomy, patients should have notice that a facility or provider might refuse to offer information or referrals regarding certain types of treatment based on the provider's personal moral or religious views.

The right of medical professionals to exercise their moral and religious beliefs should not be accommodated at the expense of the right of the patient to have access to a the full array of medical care, and in particular the right of dying patients to be given the information and access to services they deserve to be able to end their life with as much self determination, peace and dignity as possible. We, at Compassion & Choices, will continue to fight to ensure that all Americans have access to the full-range of end-of-life care options, and we will continue to advocate against policies that limit patient access to information or services as they approach the end of life. Thank you for this opportunity to address the panel.