Second Thoughts Connecticut
Advocates against the legalization of assisted suicide

Testimony regarding SB 938
An Act Concerning the Department of Public Health's Recommendations for the State-Wide Adoption of the Medical Orders for Life-Sustaining Treatment Program

Senator Gerratana, Senator Somers, Rep. Steinberg, and members of the Public Health Committee:

We in the disability community have a motto: Nothing About Us Without Us. Four years ago, we opposed a bill to establish a MOLST pilot, in part because a policy that affected not only our lives, but also our deaths, was being made without our input. Thankfully the Department of Public Health, and particularly Suzanne Blancaflor, got the message and has since fully included us in the process. Three of us—Cathy Ludlum, Jim McGaughey, and myself—have served on the DPH MOLST Task Force (now MOLST Advisory Council), spending countless hours trying to make sure we have robust patient protections against abuse and unintended death. We are here to support SB 938, albeit with some important concerns that we hope will be addressed by this committee.

Others from the field of hospice and palliative medicine will be testifying regarding the potential benefits of MOLST. We at Second Thoughts Connecticut are here to offer balance and show why the new safeguards and guidance in SB 938 are absolutely essential. These safeguards are adapted from attorney Jason Manne's model POLST statute, which unfortunately is no longer available online. There are significant problems with the POLST paradigm nationally, including in our neighboring states, and it is vital that we in Connecticut differentiate what we are doing from the mistakes of other states.

SB 938 limits the use of MOLST to people who are nearing the end stage of a serious life-limiting illness or are in a condition of advanced chronic progressive frailty, unlike the dangerous POLST laws of New Jersey and Nevada, which recommend POLST for people with five years life expectancy. A woman in New Jersey with anorexia who could likely have been carefully re-fed was allowed to use a POLST form to order her own starvation: http://www.dailyrecord.com/story/news/2016/11/21/judge-rules-anorexic-morris-county-woman-cannot-force-fed/94032374/ Nevada mandates that doctors promote POLST for anyone with either five years life expectancy or whose condition falls under that state’s expansive definition of "terminal," encompassing many people with long-term disabilities. The risk of unintended death is significant when used with people who could live a long time. Someone who fears a lingering death may refuse life-sustaining treatment, wind up in a car accident or go into anaphylactic shock the next day, and be denied what would have been wanted lifesaving care. This is why the lime-green Connecticut MOLST form requires an eligible diagnosis to be listed on the front page, above any of the treatment preferences.

Moreover, to further minimize this risk, the legislation mandates that patients be fully informed of the risks as well as the benefits of MOLST in documenting their treatment.
preferences. Unlike an advance directive, MOLST is an immediately effective set of medical orders. If an advance directive may not be powerful enough, MOLST may in some circumstances be too powerful, risking denial of wanted and beneficial care. It is particularly important that patients give fully informed, stable (over both time and different scenarios), and authentic consent to MOLST.

Section 1(b) of SB 938 requires the signature of the patient or legally authorized representative, along with a witness on the MOLST form as a safeguard against both forgery and unilateral medical provider completion. The latter is a significant issue. Disability Rights California (California's Protection and Advocacy agency) issued a scathing report of a case where a hospitalist wrote out a unilateral POLST for comfort care only overriding the patient's POLST and repeatedly expressed wished for full treatment, resulting in the patient's premature death: http://www.disabilityrightsca.org/pubs/702601.pdf. Moreover, no one was held accountable for disregarding the patient's wishes and killing him. We would appreciate amending the bill to include explicit criminal penalties up to and including murder charges when such forgery or unilateral medical provider completion results in the involuntary earlier death of the patient.

Section 2(b) requires nuanced conversations about goals of care before filling out the MOLST form. While MOLST is supposed to be about having these conversations, this is all too often not the case in other states. The California Association for Nursing Home Reform (which has documented many problems with POLST in that state: http://www.canhr.org/reports/2010/POLST_WhitePaper.pdf) has noted the widespread tendency to use the POLST as a checklist, foregoing these critical conversations. This section also requires training of professionals engaging in MOLST conversations, which is unique to Connecticut. A PowerPoint CT MOLST training presentation is available on the website of Middlesex Hospital at https://middlesexhospital.org/files/dmfile/FLISMOLST-PRESENTATION1.pdf.

The same section requires that these conversations genuinely elicit patient preferences and not use biased information to steer people away from otherwise wanted and beneficial care. We have seen training videos from California and New York (http://www.uctv.tv/shows/POLST-Having-the-POLST-Conversation-18360; http://www.youtube.com/watch?v=dSZ3UGAiwI), a "cue card" from California (http://med.fsu.edu/userFiles/file/POLST%20Cue%20Card-short%20version%20with%20Doc%20Tool.pdf), and a number of “fact sheets” which are clearly aimed at manipulating patient choices toward refusing life-sustaining treatment. Over the past 3½ years, our organization along with Not Dead Yet worked with Gundersen Health System’s Respecting Choices program to revise what had been two extremely biased “fact sheets” regarding tube feeding and breathing support, widely used with POLST programs nationally. Many other groups and individuals in the disability community, including the CT Office of Protection and Advocacy and The Arc of the United States, supported our efforts. While we have been successful in getting Respecting Choices to revise their fact sheets (http://www.gundersenhealth.org/respecting-choices/news-events-research/in-the-news/groups-collaborate-on-decision-aids/), more work needs to be done to get other advance care planning organizations to do likewise.

This extreme bias against tube feeding, CPAP and BiPAP breathing devices, and ventilators is life-threatening to tens of thousands of disabled people, including members of our organization, who use these devices long-term to live happy and productive lives. Our lime-
green MOLST form uses neutral language, referring to “medically assisted” nutrition and hydration, instead of the biased “artificial nutrition and hydration” as is currently used in our state’s advance directive statutes (§19a-570 through 19a-580g inclusive). In contrast to our neighboring states, full treatment options are consistently listed first on the form, in order to avoid steering people toward less aggressive care, and options that are not typically issues for EMS personnel are on the second page with options to check “undecided” or “did not discuss.”

This bill also recognize that issues of undertreatment affect not only disabled people, but also others, including African-Americans, Latinos, and those of lower socioeconomic means.

In addition to what is spelled out in SB 938, DPH has issued guidance to further prevent misuse of MOLST. We have developed a guidance document regarding proper use of MOLST for disabled people. Many people with significant disabilities are often misperceived as having end-of-life conditions. We clarify that MOLST is inappropriate for use with people with long-term stable or mildly progressive disabilities who are not approaching an end-stage condition. This has been a problem in other states. John Kelly, New England Regional Director of Not Dead Yet and director of Second Thoughts Massachusetts, was "MOLeSTed" by Massachusetts MOLST; he and other disabled people were presented with the MOLST form as if it were mandatory. He writes of his experience:


Three months ago, my nurse brought me the Massachusetts MOLST form, with its preferences for certain treatments in extremis. She had been told that they were to complete these forms with every disabled person she follows. I found the form oppressive, and have never in my life seen a questionnaire in which “No” was on the left and “Yes” was on the right. I thought these forms were for people near death.

I asked her what she had been instructed about the form, and whether there were any materials for me. A few minutes earlier, she had given me the notification form for my annual flu shot. But nothing to accompany the MOLST form. She didn’t receive any training, either. And while I was confident filling out the form, others may not be. I believe people should receive notice that they will be hit with this kind of form, and be able to have another person present when the discussion happens.

I know people in my community who have been badgered about having a DNR. We hear stories in the media about disabled children having DNRs slapped on them. We have friends who use ventilators, and don’t think that they are extreme interventions. Two of my best friends – a writer and a playwright – used ventilators for years.

The characterization of a feeding tube as “artificial” is insulting. I am very happy with my suprapubic tube, a simple rubber catheter that takes care of my urological needs very well. My writer friend also got a feeding tube and she loved it for keeping her alive. The food that went into it was cooked with just as much love as anything someone else would put in their mouth.

One of my friends works for a man with a head injury. When the nurse approached him with the MOLST form, he became extremely agitated, as this kind of harassment has
gone on for years. He says over and over that he wants to stay alive, and gets angry when questioned on that decision.

I hope this lengthy discussion shows why the safeguards in SB 938 are important, and in some ways, revolutionary. That is why we piloted MOLST first, prior to full statewide implementation. It will continue to require a lot of educating of the medical profession to get this done right. We need to keep testing for the "klutz factor" and to see that people actually do get the treatments they want. Nationally, most research on the POLST paradigm is unfortunately contaminated by investigator bias, with POLST advocates doing almost all of the research claiming to support the paradigm. While the evidence tends to indicate that refusal orders are usually honored, the same cannot necessarily be said regarding full treatment orders. There will be an independent evaluation of the pilot to see that patient wishes are consistently honored.

Having noted a number of major problems with the POLST paradigm, I do want to emphasize that it is very much in our interest to solve the problem of overtreatment. As staunch opponents of assisted suicide / "aid-in-dying," we want to make it clear that people have the right to refuse unwanted and burdensome life-sustaining treatment. In this area, statewide implementation of MOLST should help to ensure this right is respected in practice.

Nonetheless, I would strongly suggest a few changes to the bill, in addition to criminal penalties for forgery and unilateral medical provider completion mentioned above. While reciprocity between states in this area would normally be a good thing, the numerous flaws in other states’ POLST paradigm programs, including those of our immediate neighbors, should require that out-of-state forms conform to Connecticut’s robust patient protections before being honored. In particular, a number of states including New York do not require the signature of the patient or legally authorized representative, and the overwhelming majority do not require a witness. Without the patient’s signature, there is no way to ascertain that the choices on the form are truly the patient’s authentic wishes. Even with a signature, the many other issues mentioned above make it questionable whether POLST/MOLST orders in most other states reflect the voluntary, informed, stable, and authentic wishes of patients.

The problem here is that §19a-580g of the Connecticut General Statutes requires “health care instructions” from other states be honored in Connecticut if they comply with the laws of either state. We are asking for clarification that this should apply only to advance directives and not to POLST paradigm forms. Eligible patients (and their legally authorized representatives) from other states who come for treatment in Connecticut should be encouraged to have the MOLST conversation here if they come with another state’s form. Oklahoma, a state with strong protections against steering disabled people toward dying (including the Oklahoma Nondiscrimination in Treatment Act), limits the use of non-compliant out-of-state forms to 10 days: [http://webserver1.lsb.state.ok.us/cf_pdf/2015-16%20ENR/hB/HB3017%20ENR.PDF](http://webserver1.lsb.state.ok.us/cf_pdf/2015-16%20ENR/hB/HB3017%20ENR.PDF)

The definition of “legally authorized representative” in section 1(a)(3) needs to be tightened. The definition should make clear that the term “parents” refers to parents of minors, and that the term “guardian” similarly refers to guardians of minors who have been appointed by the Probate Court in accordance with provisions of relevant statutes. James McGaughey,
who has more expertise in this area as past executive director of the Office of Protection and Advocacy, should be submitting testimony regarding this issue.

New legislation in Oregon (SB 893) allowing for euthanasia by advance directive as an expansion of that state’s “Death with Dignity Act” raises a new concern that MOLST forms could similarly be used to pre-order lethal prescriptions to be administered after patients lose capacity. We would strongly urge that such orders be prohibited, preferably in statute, and if not possible, in regulations.

Finally, I would urge consideration of how we deal with cases where the patient’s wishes conflict with provider conscience. The solution would normally entail transferring the patient to a compatible provider. Our particular concern is the case where the patient wants life-preserving treatment, including nutrition and hydration, and the provider objects. Second Thoughts Connecticut, along with the Euthanasia Prevention Coalition–USA, on whose board of directors I serve, has serious concerns regarding Connecticut’s advance directive statues permitting nonconsensual withdrawal of food, fluids, and treatment from patients deemed to be in a “terminal condition” or “permanently unconscious” (C.G.S. §19a-571). Statewide implementation of MOLST is an opportunity to ensure that patients who want life-preserving treatment, food, and fluids receive them, with treatment pending transfer as a requirement to prevent involuntary euthanasia.

Connecticut should be proud of being the first state in the nation to fully include people with disabilities in designing its POLST paradigm program and doing so in a careful and thoughtful manner. These are complex issues; it is important to take the time to get them right.

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