

# Second Thoughts Connecticut

Advocates against the legalization of assisted suicide

## Testimony in favor of HB 5270 An Act Concerning the Right to Try Experimental Drugs

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

Second Thoughts Connecticut is composed of citizens with disabilities and advocates primarily concerned about “end-of-life” issues. We oppose the legalization of assisted suicide and support a more balanced approach to advance care planning that avoids disability-phobia and does not steer people to reject beneficial treatment. Consistent with our principles that people have a right to fight to live, we are here to offer our support to HB 5270, An Act Concerning the Right to Try Experimental Drugs.

One might ask what disability has to do with legislation dealing with the right of people diagnosed with a terminal illness to access experimental drugs and devices. As we have often said in the assisted suicide debate, while not every disability is terminal, nearly everyone with a terminal illness has a disability. Furthermore, people with disabilities frequently face life-or-death medical situations.

We are aware of the complex public health policy issues right to try legislation entails. There have been some legitimate concerns raised by critics, such as the possible effect on clinical trials, the extent of the grant of immunity to physicians, and equity in assisting patients of limited means to obtain these drugs or devices. Certainly a careful approach is warranted. The robust definition of informed consent in Section 1 (4) (c) is important. But we also need to remember that those who are seeking to try experimental drugs and devices—people like Debra Gove, the woman with ALS whose moving testimony you heard last year—do not have time on their side. They cannot wait for the cumbersome FDA approval process to work itself out. If it is a matter of try or die, when not trying may mean near certain death in a short time, the risk-benefit ratio is much different than for those of us who presumably still have a life ahead of us.

One objection to right to try legislation needs to be thoroughly challenged—namely the claim that these laws offer false hope to people with terminal illnesses. True, experimental drugs may not work as intended. They may also carry greater risk, although having passed a Phase 1 clinical trial means the safety of the drug has already been studied for a few years. It may well be true that this bill, like the laws of 24 states that have already passed similar legislation, might be preempted by FDA regulations—although an important part of passing these bills is to put pressure on the FDA (and Congress) to increase access to experimental drugs nationally. Meanwhile, people are dying, they are not qualifying for research trials, or like Debra Gove, they received the placebo rather than the experimental drug or device. The likelihood is that a modest percent of them would benefit significantly if they had the chance, which would still save hundreds, perhaps thousands of lives. In addition, it might actually speed up the search for cures for diseases like cancer and ALS. To critics, we have a six-

word retort: **Better false hope than no hope.** Hope is what people facing stage 4 cancer, ALS, HIV/AIDS, and other life-limiting conditions need most.

HB 6709 offers people who desperately need hope a means to go on and fight to live. Let us not stand by idly another year. Let us join those states that have passed similar legislation by overwhelming margins (the Georgia House of Representatives just voted unanimously to approve a right to try bill, 173-0) to give people with life-limiting conditions the hope they need and deserve.

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