



ACTION

Family Institute of Connecticut ACTION

Testimony in Support of H.B. 5270, “An Act Concerning the Right to Try Experimental Drugs”

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Dear members of the Public Health Committee:

Last year, Family Institute of Connecticut Action testified in support of H.B. 6709, the 2015 “Right to Try” bill. We remain strongly in favor of opening another avenue for terminally ill patients to access treatments that could save or improve their lives, with the same caveats regarding the need to maintain informed consent (which the bill appears to address adequately) and the need for some means of assisting people with financial obstacles to care.

At this time last year, we were aware of five states that had passed Right to Try legislation; since then, nearly half of the states have done so.¹ Given the rapid pace at which these laws have been adopted, it may be too early to tell how many people may ultimately benefit – but to those who do, it could mean a new lease on life.

Dramatic medical advances are occurring even as this bill is being considered. Just a week ago, a very relevant news story broke on an exciting development in cancer research: a trial led by a scientist with the Fred Hutchinson Cancer Research Center was able to induce complete remission in 90% of terminally ill leukemia patients who had run out of traditional options and had two to five months to live. This was accomplished by re-engineering the patients’ own immune systems to better target cancerous cells.²

The treatment is in a very early stage and will certainly need ongoing study; however, we can understand how those odds might be more than acceptable to someone who had already tried everything else and had come to the end of the road.

We disagree with certain criticisms of Right to Try laws – namely, that they “threaten to unravel decades of patient protections” (as one editorial put it),³ or that it is necessarily incumbent upon the state to provide funds to support this policy. The Utah-based Right to Try Foundation, established to raise money to help families making less than \$75,000 a year obtain

treatment, offers an example of a possible private solution.⁴ While we understand the well-intended and generally necessary regulations, and do not advocate abandoning them in most cases, we would paraphrase ancient wisdom and suggest that the FDA was made for mankind, not mankind for the FDA; when its rules no longer serve to protect and preserve life, but actually prevent individuals facing certain death from taking action to save their lives, it is time to re-evaluate the rules.

For these reasons, we respectfully urge the Committee to vote YES on H.B. 5270. Thank you for your consideration.

Sincerely,

Nicole Stacy
Public Policy Assistant
Family Institute of Connecticut ACTION

1. righttotry.org/faq
2. www.bbc.com/news/health-35586834
3. <https://www.bostonglobe.com/business/2015/10/12/right-try-laws-are-wrong-usurp-fda/54tICnBEQ4DHMIkYd1ZldJ/story.html>