Family Institute of Connecticut ACTION

February 20, 2015

Dear members of the Public Health Committee:

My name is Nicole Stacy. I am Public Policy Assistant for Family Institute of Connecticut Action. The following is our testimony in favor of Raised Bill No. 6709, "An Act Concerning the Right to Try Experimental Drugs."

We support this bill in principle, with the understanding that there may be valid concerns about its implementation. Some have observed that it could inadvertently create two standards of care: one for patients who are independently wealthy, and one for those who are not. That is not a small concern, but we suggest that there could be more than one way to lessen the disparity; this matter should be further explored. Also, ethical standards (such as informed consent) meant to protect the safety of patients subject to research trials should by no means be cast aside merely because the patient otherwise has a poor prognosis; we do not wish to encourage anyone to take advantage of these patients or treat them as human "guinea pigs."

However, we note that drugs reaching the Phase 1 clinical trial stage have already been studied for several years on average; the odds are significantly against most drugs even making it this far in the approval process.[1] What the lack of final FDA approval really signifies for people who have limited time is an onerous amount of bureaucratic red tape. As the Wall Street Journal reported, the FDA itself appears to have conceded the burden of its requirements: "The current form used by such patients for access to unapproved drugs is so complex that it takes about 100 hours to complete it...The new form will take 45 minutes."[2] We agree that there are far better ways for a dying person to spend 100 precious, irretrievable hours!

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While the new form is a welcome improvement, there is still considerable time and expense involved in producing new drugs. Meanwhile, people die. Research trials are not the sole answer, as many people who could potentially benefit do not qualify.[3] Professor and ALS patient David Huntley points out that "Given the rate of occurrence of ALS and the median post-diagnosis longevity, 10,000 or more of us will die during the time it would take Genervon to complete a phase 3 trial."[4] If only one percent of those patients saw results of any significance, 100 people would benefit. To those 100 – and to everyone touched by their lives – it would be of immeasurable value. Beyond that, it would help to advance the hope of a cure for future generations of people affected by diseases like ALS. False hope? Not at all.

This session, the Connecticut legislature will be debating a bill that would ostensibly give terminally ill patients the "choice" to take their own lives with a drug overdose. What about those who want to be treated so they can live? What are we doing to ensure, to the extent possible, that they have a genuine choice?

Keeping in mind the caveats we already mentioned, we do think this is a step in the right direction, and hope that Connecticut will join the five states that have already passed similar bills with bipartisan support.

Thank you,

Nicole Stacy

1. http://www.medicinenet.com/script/main/art.asp?articlekey=9877
2. http://www.wsj.com/articles/the-right-to-try-revolt-1423527365
3. http://goldwaterinstitute.org/en/work/topics/healthcare/right-to-try/state-lawmakers-three-states-vote-unanimously-allo/
4. http://www.utsandiego.com/news/2015/feb/10/als-patients-fight-right-try-drug/