Ohio Council for Home Care & Hospice

The Voice of Home Care and Hospice

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Representative Anne Gonzales
Chair, House Health and Aging Committee
Ohio House of Representatives
77 South High Street
Columbus, OH 43215

Dear Chairman Gonzales & Ranking Member Antonio,

Thank you for the opportunity to voice our support of House Bill 290 sponsored by Rep. Sprague. My name is John Stacy and I am the Director of Advocacy and Communications for the Ohio Council for Home Care & Hospice. We are a nonprofit trade association representing more than 500 home care, palliative care and hospice providers across the state of Ohio.

We are strongly supportive of the goals of this legislation as it provides an opportunity for terminally ill individuals to have right to try investigational drugs that have not yet been approved by the Federal Drug Administration (FDA). This approval process for new drugs can typically take from 10 to 15 years and many cancer and ALS patients die or endure excruciating suffering while waiting for approval of alleviating drugs. House Bill 290 may provide relief or hope for terminally ill patients.

According to the US Centers for Disease Control and Prevention, more than 100,000 Ohioans die annually from a variety of diseases, injuries and accidents. Nationally 43% of hospice patients have cancer as their primary diagnosis[i] Generally speaking to qualify for Hospice care an individual has to have a life expectancy of less than six months. Of course length of hospice service varies widely by patient based on a variety of factors such as disease, timing of referral and access to care, but according to data reported by the National Hospice and Palliative Care Organization, the median length of service for hospice patients is around three weeks.[ii]

HB 290 clearly states that to be eligible under the proposed Right to Try legislation, a drug, product or device must not only have passed Phase I, the safety testing phase, but must remain in ongoing clinical trials, Phase II or III, moving toward ultimate approval. Secondly, the legislation is not a mandate – to either the patient or the company manufacturing the drug, product or device to participate in this program. Before beginning treatment, the legislation requires informed consent and treatment information to be presented to patients or individuals that are legally responsible for them.

Secondly, the bill clearly defines what a terminal condition entails by specifying that it be irreversible, incurable and untreatable through a method currently approved by the FDA such as progressive cancer, progressive neurological disorder, progressive musculoskeletal disorder or a condition that appears likely to cause death within a period not to exceed twelve months.

At its core this proposal is about allowing individuals to make decisions about their own care. The bill's language is permissive in nature allowing the individual, in consultation with their doctor, to decide the best course of treatment for their situation. Thank you for the opportunity to testify in support of HB 290. I would be happy to try to answer any questions you may have.

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[i] http://www.cdc.gov/nchs/fastats/cancer.htm

[ii] http://www.nhpco.org/sites/default/files/public/Statistics_Research/2015_Facts_Figures.pdf