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Public Comment on HF 225 Before the Iowa House Health and Human Services Subcommittee

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Good afternoon, Representatives Boden, Andrews, and Baeth. My name is Naomi Lopez and I am the vice president of healthcare policy at the Goldwater Institute, which is based in Phoenix, Arizona. I reside here in the Midwest with my children in Springfield, Illinois.

Thank you for allowing me to offer my public comments regarding HF 225 as you consider this important issue protecting the right to try to save one's own life without having to beg the federal government for permission to do so.

Imagine that there is a new treatment for a rare disease. It's custom-made for you, based on your own genetic profile. It offers you hope, but you can't access it, even though your doctor says it could save your life. The reason? Federal regulations are ancient by today's standards, and they're not designed to allow these new, genetic treatments.

Iowa has an important opportunity to lead the nation in solving this problem—and save lives—by championing a new law called Right to Try for Individualized Treatments.

The federal barriers to lifesaving treatment are not hypothetical. Iowa lawmakers have already been a leader in putting patients' rights first and cutting through medical red tape. Under the original Right to Try Act which Iowa enacted in 2017, patients gained the right to seek treatments that are safe enough to be used in clinical trials but remain under clinical evaluation for final FDA approval. The federal Right to Try act was later signed into law in 2018 and is now the law of the land.

We know that Right to Try works, and we've seen a great example. An aggressive form of brain cancer, glioblastoma, has a five-year survival rate of only about 5 percent. Too often, patients are left with no promising treatment options.

Thanks to the liability reforms and reduced red tape that is part of the Right to Try law, some patients who were ineligible for the clinical trial can now access an immunotherapy treatment that is in a clinical trial. Instead of being sent home to put their affairs in order, these Right to Try patients have a median survival of 20 months of life, up from fewer than seven months with conventional treatments.

The trouble is, this law needs to be upgraded and modernized to account for rapid advancements in medicine, such as gene therapy, which aren't covered under the old law. That's where Right to Try for Individualized Treatments—or "Right to Try 2.0"—comes in. This proposal does not change the operation or future success of the original Right to Try law. It does create a new, safe, and physician-directed pathway for those patients with rare and ultra-diseases who don't have treatment options in clinical trials or who need an individualized treatment approach made specifically for them.

Many of the medical innovations being pioneered today have made it possible to take an individual's genetic information and create a treatment for that individual person. But the current clinical trial evaluation system—created more than a half-century ago—is based on treatments for large populations, not an individual patient.

The result is that an individualized treatment is still subject to the same clinical trial process as a single treatment that is intended for hundreds or thousands of patients. But that doesn't recognize how these new individualized treatments work. Right to Try for Individualized Treatments accounts for new innovations—and it helps get those innovations to the patients who need them.

Iowa can continue to lead on the important goal of getting the right treatment, to the right patient, at the right time. Removing the government red tape that stands in the way of a doctor's treatment options does not require additional taxpayer investment and can be achieved in a manner that ensures patient safety and informed consent.

Iowa lawmakers have the authority, as well as the legislative vehicle, to unleash the potential of today's medical innovation to further benefit patients.