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Statement on the Right to Try for Individualized Treatments before the Kentucky Interim Joint Committee on Health Services

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Dear Chairs and Members of the Committee,

My name is Naomi Lopez, and I am a senior fellow in healthcare policy at the Goldwater Institute. Thank you for allowing me to offer my public comments on the Right to Try for Individualized Treatments as you consider this important issue to protect the right to try to save one's own life without having to beg the federal government for permission to do so.

I'd like to begin with the story of a little girl named Keira Riley.

Keira was diagnosed as a baby with metachromatic leukodystrophy, or MLD, a rare genetic disease that progressively destroys the brain and nervous system. Her older sister, Olivia, had the same disease, but by the time physicians discovered it, treatment was no longer an option.

Keira's story was different. Because her disease was diagnosed early, physicians knew there was a gene therapy that could save her life. It wasn't designed for thousands of patients. It wasn't even designed for hundreds. It was designed for children like Keira.

The problem wasn't the science. The problem wasn't her physicians. The problem was that our regulatory system was built for another era of medicine. It was designed for treatments intended for large populations, not therapies developed for an individual patient.

As a result, Keira's family left the United States and traveled overseas so she could receive the treatment that offered her the best chance to live. No American family should have to leave this country to pursue a potentially life-saving treatment designed for their child. The Rileys' race against time to try to save Keira is what inspired us to craft the Right to Try for Individualized Treatments.

Today, Keira is a thriving 6-year-old. She loves gymnastics, riding her bike, and doing all the things any healthy child her age enjoys. Tragically, Olivia, who is now 8, is in hospice care.

In many ways, however, this legislation is really the next chapter of a story that state lawmakers have already helped write. Kentucky lawmakers are already familiar with the original Right to Try movement.

Beginning in 2014, states across the country recognized that patients facing life-threatening illnesses sometimes had exhausted every approved treatment yet still could not access investigational therapies that had demonstrated sufficient safety to enter clinical trials.

States acted first. Forty-one states ultimately enacted Right to Try laws. Congress followed, and in 2018 President Trump signed the federal Right to Try Act into law. It remains one of the strongest examples in healthcare policy of states leading and the federal government following.

But medicine continues to advance rapidly. Today, we can increasingly identify the precise genetic mutation causing disease and, in some cases, develop a treatment tailored to that individual patient.

These therapies don't always fit within the traditional clinical trial framework because they aren't intended for hundreds or thousands of patients. Sometimes they are intended for only one.

Our regulatory system, however, still largely treats those therapies the same way. That's the gap this legislation is designed to address.

Consider that 95 percent of the more than 7,000 rare and ultra-rare diseases that have been identified lack an FDA approved treatment. About 80 percent of these diseases are genetic in nature. The original Right to Try law was a tremendous step forward, but it was written before many of today's individualized therapies even existed. As medicine has advanced, our laws must advance with it.

Right to Try for Individualized Treatments does not replace the original Right to Try law. Instead, it builds upon its success. The original law remains available for investigational drugs that have entered clinical trials.

This legislation creates a separate pathway for individualized investigational treatments for patients with life-threatening or severely debilitating diseases who have no satisfactory treatment options. Like the original Right to Try law, it is built on patient choice. Participation is entirely voluntary. No patient is required to seek treatment, no physician is required to recommend or provide it, and manufacturer or facility is compelled to participate.

For those who choose to do so, the legislation preserves physician oversight, informed consent, institutional review, existing standards of professional accountability, and existing liability protections. It simply modernizes the law to reflect advances in medicine that were unimaginable when today's regulatory framework was developed more than fifty years ago.
States are leading once again. Nearly twenty states have enacted Right to Try for Individualized Treatments or similar legislation. And earlier this summer, legislation was introduced in Congress to establish a federal pathway as well.

That raises an obvious question. If Congress is considering this legislation, why should Kentucky act?

I believe there are three reasons. First, state leadership creates momentum for federal action. The original Right to Try movement succeeded because states demonstrated that patients deserved another option. Kentucky has the opportunity to help build that same momentum again.

Second, state action provides insurance against congressional delay. Patients with rare diseases cannot always wait for Congress. State leadership helps ensure that patients are not left behind while Washington debates.

Third, this legislation represents an economic development opportunity. The next generation of medicine will increasingly involve gene therapies, cell therapies, genomic medicine, and individualized treatments. States that welcome responsible medical innovation are more likely to attract research, investment, manufacturing, physician expertise, and clinical partnerships.

Healthcare policy and economic development increasingly go hand in hand. Kentucky has an opportunity to lead on both.

Like the original Right to Try movement, this legislation doesn't lower safety standards. It is about modernizing a legal framework that was written before today's medical breakthroughs were even imaginable.

The original Right to Try movement showed what happens when states lead. Patients benefited. And then Congress followed.

Kentucky lawmakers have the authority, as well as the legislative vehicle, to unleash the potential of today's medical innovations to further benefit patients. Thank you for your consideration of this important reform, and I'd be happy to answer any questions about the legislation.

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