

**Opening Statement of Chairman Johnson**  
**“Exploring a Right to Try for Terminally Ill Patients”**  
**September 22, 2016**

Good morning and welcome.

As members of Congress, we meet dozens of people every day – all with different stories. And it is one of our greatest privileges that when we are entrusted with these stories, we have a unique ability to act.

More than two years ago, Trickett Wendler entrusted me with her story. People would say she was suffering from ALS, but really she was fighting ALS. She was tirelessly advocating for any hope that could help her and others win their fight against a disease with a near certain outcome. She was fighting for the right to try to save her own life.

Trickett passed away on March 18, 2015.

In February of this year, I met then six-year-old Jordan McLinn, full of life and curiosity. A nearly 100 percent fatal form of muscular dystrophy is robbing him of his strength, and soon he won't be able to walk, brush his teeth or hug his mother.

Yet there was hope. A promising treatment was in the pipeline for FDA approval. And thankfully, just this week approval was granted; but only after months of unnecessary delays and years of study and trials – delays that mean Jordan and others may never regain muscle function they lost waiting for the federal government's permission to use a treatment almost everyone agreed was safe and could potentially save their lives.

For Jordan, Trickett and retired Navy pilot Matt Bellina, who now fights his own battle with ALS, I introduced the Trickett Wendler Right to Try Act of 2016. It simply says patients, who have no alternative and are facing death, should have the ability to try to save their own lives – the right to hope.

The bill is really a federal counterpart to the incredible bipartisan movement that has led to adoption of Right to Try laws in 31 states. But it's unclear what effect those state laws have until we make certain the federal government will respect them.

Despite the legal uncertainty there are doctors willing to jeopardize their practice to give patients needed, but unfortunately unapproved, treatments. One of them is Houston oncologist Dr. Ebrahim Delpassand. Even though the FDA has told him no, he bravely continues to treat patients under his state's law. Now nearly 80 patients, whose chance of survival would be, as he puts it, “close to none,” are alive thanks to his treatment.

For the millions of patients fighting for a chance to try, we must do what we can to help them. Right to Try is not a cure, and it's not a miracle, but it is a way to hold on to hope.