

Chairman Ron Johnson Opening Statement
“Connecting Patients to New and Potential Life Saving Treatments”
Thursday, February 25, 2016

As submitted for the record:

Good morning and welcome.

I would bet that each of us here today has been affected by a personal story of a loved one or friend who is fighting a life-changing or terminal illness. Many of us have felt that sense of desperation—of urgency—when we learn that we or someone we love is fighting for their life.

I vividly recall the moment that I learned that my infant daughter had a serious heart condition. When she was born, a doctor saved her life by conducting a procedure on her heart. And eight months later, after seven hours of open heart surgery, my daughter’s life was saved thanks to the miracles of modern medicine.

We all should be thankful that we are living in an era of unprecedented innovation and improvement in the ways that we treat serious and life-threatening diseases. It is a credit to the dedicated researchers, the pharmaceutical industry, medical device makers, and doctors who have brought us so many life-saving treatments.

The question that I want to ask today is: How can we do more to ensure that all patients, including those facing terminal illnesses, have access to potentially life-saving treatments? What artificial, regulatory barriers are keeping patients from trying and experimenting with new medicines and therapies when all others have failed?

Back in 2014, I met with a brave woman, Trickett Wendler from Wisconsin, who was fighting ALS. Sadly Trickett passed away last year, but her spirit and her fight are the reason I am passionate about this issue — because I know that today, and every day, millions of Americans are fighting similar life-and-death battles to save themselves and their loved ones.

Over the past year, we have seen an unprecedented bipartisan movement across the country adopting laws that are aimed at allowing patients, doctors and drug companies to use investigational medicines to try to save terminal patients’ lives. These laws have passed with nearly unanimous bipartisan support.

I recognize that the Food and Drug Administration (FDA) faces a challenge striking a balance between protecting public safety and granting access to new drugs. But we must always keep an eye on how we can improve the regulatory process, asking what incentives the system places on regulators and the industry, and what we can do to empower individuals to make choices for themselves.

As the Senate considers whether to move forward on FDA reform legislation, we need to hear from the experts and, more importantly, the patients about what we should do to improve the regulatory process to give more patients a chance to save their lives.

Finally, we recently learned our friend and colleague Claire McCaskill was diagnosed with breast cancer. Fortunately her prognosis is good and she is in good spirits. I know the thoughts and prayers of this committee are with her.

Thank you all for being here today. I look forward to your testimony.