

Testimony

In Support of H.B. No.6709 An Act Concerning The Right To Try Experimental Drugs

*Public Health Committee
February 23, 2015*

Dear Senator Gerratanna, Representative Ritter, Senator Markley, Representative Srinivasan, and all other distinguished members of the Public Health Commission: I want to thank you for the opportunity to testify on the House Bill 6709, An Act Concerning the Right To Try Experimental Drugs.

This year alone, over five thousand people will be diagnosed with ALS (Lou Gehrig's Disease). ALS is a progressive neurodegenerative disease that attacks nerve cells and pathways in the brain and spinal cord. When these cells die, voluntary muscle control and movement dies with them. Patients in the later stages of the disease are totally paralyzed, yet in most cases, their minds remain sharp and alert. This is a disease that generally allows a person to live two to five years after diagnosis.

Today there is no known cure for ALS. There are also very limited options for treating the symptoms of the disease. Current treatment can slow the progression of the disease but nothing currently approved can stop or reverse the effects. Drug trials are one of the few ways to bring about breakthrough medicines that will make a significant difference. Those fighting ALS are willing to be part of experimental treatments knowing that there is always a chance that these treatments will slowdown the progression or maybe even reverse the effects of the disease. They also know that these results might not happen soon enough to help them but rather those diagnosed in the future.

One major issue we face today is the length of time it takes for the Food and Drug Administration to give their final approval of a medicine. On average it takes ten full years for a drug to be cleared for use by the general public. Today thousands of people are waiting for access to drugs or treatment that are being withheld due to the FDA's onerous approval process. Passage of HB 6709 could literally prove to be a matter of life and death. Those afflicted as well as all of their family members spend "every waking moment in a fierce battle between iron determination and utter despair." I am asking you today to give them this tool. Help so many to fight this battle and in doing so provide them with hope.

Thank you for your consideration of this bill.

Sincerely,

Noreen Kokoruda
State Representative, 101st District.