

Thank you for accepting my testimony in support of HB 2004, the Kansas Right to Try Bill . I was diagnosed with ALS six years ago .At the time I was a veterinary technician with a specialty in Emergency and Critical Care .I had been able to easily carry an eighty pound dog. Within one month I could only lift forty pounds and had begun to slur my words .When the neurologist said I had ALS he explained that most people will only live two or three years .My nerves and muscles would stop communicating .Eventually each muscle would stop working ,and I would slowly become paralyzed until I died .The whole time I would be aware of and able to feel everything .I was 38 years old and now I didn't know if I'd ever see 40.

I am one of the lucky ones .My progression is fairly slow and I have wonderful family support .Every ALS patient progresses in different ways . But it is important for you to understand that each one of you have the exact same chance of getting ALS as I did .If you have ALS in your family or served in the military you actually have a greater risk than I did .

There is one drug approved for use with ALS but it only extends life by 2-3 months .Many patients choose not to take it due to side effects or cost .We need more .This is where Kansas Right to Try comes in .Almost every drug trial I have seen will only include patients who are within 24 months of the onset of symptoms .Considering diagnosis can often take a long time ,we are running out of time before we ever get started ! It is estimated that only 15% of living ALS patients qualify for inclusion in studies .It's no wonder that there hasn't been a cure discovered in the 75 years since Lou Gehrig was diagnosed !

I fully support the FDA in its mission to ensure drugs are safe and effective .But we aren't talking about a hemorrhoid cream here .The cost of not speeding up the process through something like Right to Try is high .ALS is 100% fatal .If a drug is voluntarily used under Right to Try and 50% of the subjects die...then that means 50% would not die. I would be thrilled with those odds !The worst case scenario would be for my death to be hastened by making the choice to take an unapproved drug .I've already assumed that risk as a part of two drug trials before I was "aged out". Even if a trial fails there are still lessons to be learned .That would be an important legacy .

There is nothing more valuable than hope and HB 2004 would give me more hope .Please pass this Bill . Should you have any questions you are welcome to email me at bmfrescue@hotmail.com .

Thank you ,
Kelli Johnsen