

**Staci Penner, Newton KS, Step Therapy Testimony, Proponent for SB 304:
Patient Advocate for the Arthritis Foundation**

Good afternoon Chairwoman Schmidt and members of the Senate Public Health and Welfare Committee. My name is Staci Penner. I live in Newton, Kansas, where I am an occupational therapist. I have experienced the effects of arthritis personally and professionally. As an occupational therapist, I know the clinical side of the disease. As a mother of a young girl diagnosed with polyarticular juvenile arthritis – and myself being diagnosed with rheumatoid arthritis and osteoarthritis – I know the personal battles and struggles that come with the disease. I am here today to tell you more about my family's experiences with step therapy – and why we fight, not only for our family, but for all Kansans to have timely access to the medications that their health care provider recommends. I also wanted to introduce my son, Damon, who has been such a strong support system to both myself and his sister, Laniese. Laniese, my daughter, would have been here, but she couldn't miss school.

When Laniese was first diagnosed with polyarticular arthritis at age 9, our insurance dictated that we start her on a particular biologic. While this biologic did slow the progression of the disease, it did not help much with the symptoms. It took 18 months – yes you read that right- before we could switch to another biologic. This biologic was a game changer for Laniese. BEFORE this new biologic, she was not able to participate very much in her sports and still missed a lot of school. AFTER starting on this new biologic, she is now able to keep up with her peers – and she is now playing basketball, running cross country and participating in track again. I am one proud mom when I am at her games – and I see that huge smile on her face – as she is competing with her peers. She still has struggles with flares and symptoms from her JA, but if she was without the new biologic – she would have an extremely hard time functioning.

Open enrollment for our insurance brings about constant fear as we are afraid that something will change and that our daughter might have to go through step therapy.....again. Step therapy is an insurance company process where she would have to try and fail a cheaper medication before getting the one actually prescribed by her doctor. We are afraid that if her insurance makes her go through step therapy again, her JA will again become out of control. That is why this bill is so important to us – we have documented that she has failed certain medications for her JA and we now have documented evidence that she is stable on her new biologic.

I would now like to share about my own experiences with rheumatoid arthritis. I was diagnosed with RA in January 2016 and by May of 2016, I had failed two medications. When my doctor was trying to decide what to do next, she already knew for sure what our insurance would and would not approve. She decided on a particular biologic – that this new biologic would be the best fit for me, knowing my diagnosis and symptoms. It took 7 weeks and many phone calls from me, my doctor and my

pharmacist to gain approval because my insurance didn't want me to be on this medication.

During this time of waiting, I ended up in the hospital overnight due to RA issues. I had to miss work and family activities – due to vasculitis in my lower legs and the pain in my feet and hands prevented me from being able to complete all of my tasks at work. Once I finally received approval for this new biologic, my vasculitis was under control within that first month – and each month afterwards I have noticed fewer symptoms.

Fast forward to this year. My situation changed again with my RA and I will be starting a new biologic soon – the verdict is still out on how I will respond to this particular biologic.

Our experiences with step therapy are not unique to just our family – or even just arthritis. And as I have documented – the time it took for us to receive proper treatment was unacceptable, **which is why we ask for your support on Senate Bill 304 to put Kansas patients first. Our doctors know the best treatment plan for us, not a health plan's step therapy policies.**