

Staci Penner, Newton KS, Biosimilar Testimony: Patient Advocate for the Arthritis Foundation

Good afternoon Chair Hawkins and members of the House Health and Human Services 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.

When my daughter, Laniese, was 9 years old, she was diagnosed with polyarticular arthritis. Our family immediately sprang into action to ensure that Laniese would receive the medical care she needed so that she could continue to play basketball, run cross country and participate in track. We travel 200 miles every five weeks for my daughter's biological infusions. These biologics have been a lifesaver for my daughter and many of the 2,800 children in Kansas who have juvenile arthritis.

Laniese definitely knows when it is time for another infusion – for about a week prior, she has increased fatigue, inflammation and pain. Within 12-18 hours of the infusion, she is back to being able to keep up with her peers and team mates!

There is a significant cost associated with biologics (in fact Laniese's \$6000 deductible is met in January), but we feel very strongly that Laniese is thriving because of the biologic and are thankful that we have health insurance.

Biosimilars and interchangeable biologics would lower these costs and make these treatments available to more patients. A big concern of ours regarding biosimilars and interchangeable biologics is communication between providers, pharmacies and patients. These medications are powerful and often come with side effects and as with any drug have the potential of serious adverse effects.

In fact, for the first 3-8 hours after an infusion, Laniese is very fatigued, irritable and feels like she is in a fog. This is just one example on why it is so important for doctors to be alerted about their patient's medication. They need to know about any potential side effects.

We have put our full trust in our physicians. We always discuss Laniese's treatment plans at length prior to making a final plan. What truly concerns us in regards to the interchangeable biologics is the chance that the dispensing pharmacy is not required to notify the physician or the patient when an interchangeable is used. If my daughter were to have a reaction, as her parent I would need/want to know what med she had been given. There would be no way to track side effects and adverse events to each particular biosimilar or interchangeable biologic if the patient and physician were unsure of what medication was actually administered. This would undermine the relationship between the physician and patient. This is why we fully support the passing of HB 2107 with the communication component included.