

Step Therapy Testimony – Katie Roberts  
Odenton, MD – District 32

Good afternoon Chairperson and committee members.

My name is Katie Roberts and I've lived with a severe and debilitating form of psoriatic arthritis for nearly 40 years, and psoriasis, a painful skin condition, for nearly 30 years. I'm here today as a patient advocate representing the National Psoriasis Foundation & the Arthritis Foundation. I'd like to share with you my experience with step therapy so you can better understand why **HB 1359** is a "makes sense" bill.

For the majority of my 43 year life, I've lived with psoriatic arthritis, a debilitating form of autoimmune arthritis, and psoriasis a skin condition also triggered by the immune system.

*I went undiagnosed and misdiagnosed for many years, despite knowing something was wrong with my body. My diagnoses for psoriasis came first in middle school, then arthritis a while later. My psoriasis popped up, quite literally, overnight following chicken pox strep throat combo, followed by pneumonia. I went from having chicken pox one morning to having close to 75% body coverage of psoriasis within 48 hours.*

At age 17, I was struggling to function – I was in constant pain at all hours of the day, could not walk without an assisted device, and barely had enough energy to take care of basic life needs. I had been an active youth participating in dance, volleyball, outward bound, and many other adventures despite some arthritic pain. And then my arthritis rapidly worsened while in high school.

After an appointment with a Rheumatologist at age 17, I was told I would likely not live long enough to see my 21<sup>st</sup> birthday – my body was slowly shutting down from years of living with an autoimmune disease. It was more than the arthritis and psoriasis. The autoimmune disease had started to affect my digestive system, bladder, liver, kidneys, heart, and lungs.

In 1994, there were few drugs available to treat my illness. After pain medications quickly failed, my doctor and I agreed to a methotrexate and steroid combination, even after recognizing the many very serious side effects of both drugs. This medication combination has historically been used to treat my autoimmune disease, however it's efficacy, at least for me, was limited.

My disease continued to progress over the coming years despite this drug cocktail, ending up in the hospital at least every few months, and having had medical procedures or surgeries to try to remedy the effect of comorbidities that many patients like me face when their disease is not stable. Just about every week, sometimes every day, was filled with thoughts of suicide, and I questioned why this was happening to me.

At 26, I was spending more time in hospitals than out of them. I had been on countless drugs to try and treat the disease and even participated in several experimental drugs protocols at NIH. I had made it past my death date of 21 years of age, but my doctors had encouraged me to make the most of the days I had left, convinced I was nearing the end. My body was failing, and time was not on my side.

Then, a biologic drug was made available. Within 3-4 weeks of starting this medication, I was out of a wheelchair, and within about 6-8 weeks was walking mostly unassisted. My psoriasis went from 80%

body coverage to less than 5% body coverage within 8 weeks. I had hope for the first time in a long time. The medication was giving me my life back.

It was my miracle drug. It literally saved my life. I was able to join the workforce again and go on to have a very successful professional career for many years.

Until step therapy.

My insurance at the time had been covering my biologic injections for more than a year. Mid-plan, they sent me a letter informing me my biologic would no longer be covered under my plan. They indicated they needed me to prove a less-costly drug wouldn't work and to create medical necessity for my miracle drug. This practice is better known today as Step Therapy.

This was devastating to both me and my family. My loved ones saw me at my worst, and they cheered me on as I fought to win back my life while on the biologic. It was as if everything positive and hopeful we had experienced together for those successful years was slipping through our hands again. Fearful of what life would be like without my treatment, suicide once again entered my thoughts.

My doctors vowed to fight and help appeal the insurance decision to no avail.

There were no stipulations on how long I had to be on any particular step medication. My doctor had lost total control of my health care. We didn't know at what point the insurance company would allow me to advance through the various steps of medications, nor was it clear what medications were permitted for my disease in particular.

The decision by the insurance provider did not take into consideration my previous medical history, the length of time I had been stable on the biologic. It also didn't have clear expectations to what my health care treatment future looked like. The step therapy decision also didn't factor in my disease activity as a whole, or that the biologic was helping stabilize more than my arthritis. It was also controlling my psoriasis and associated comorbidities I had developed over years of being on ineffective drugs, including endocarditis (a heart condition), pleurisy (a lung condition), and Crohn's disease. Despite proven medical research that indicated drugs like methotrexate were not effective for advanced and severe psoriatic arthritis and psoriasis, the insurance company forced me to return to previously ineffective drugs.

During the 10 months I was forced through Step Therapy as a patient, I had 14 procedures/surgeries to address other disease activity that had been dormant for the years I was stable on a biologic, including intestinal surgery, a permanent implant in my bladder to prevent it from collapsing, and routine liver biopsies & partial removal of my liver since I had previously experienced liver problems and blood disorders often associated with long-term/high-dose methotrexate (chemotherapy drug) treatments.

Within 4 weeks of going off the biologic, I was back in a wheelchair – that's four weeks to go from a fully functioning active adult to wheelchair. That's how fast this disease can progress if not stabilized.

The costs associated with additional drugs I had not needed while on the biologic, doctor visits, surgeries, and the missed time from work because I was not strong enough or well enough to work, were staggering.

In the end, the total cost of all of the additional medications I had to take to curb full disease activity, the purchase of assisted devices, counseling services to address mental health and anguish, and surgeries exponentially exceeded the cost of the biologic – a drug that I had been stable on for many years and had been scientifically proven to effectively treat my disease.

I was able to return to my miracle drug after the 10 months of failed Step Therapy. I was able to regain my quality of life, but not without permanent health issues that will continue to need attention for the duration of my life. I did not respond to it as quickly as I did the first time – my body was stressed by the additional damage caused in my time without the biologic. It took about 8 months for me to return to a similar quality of life once enjoyed prior to Step Therapy.

I am able to sit here today and share my story because I'm one of the lucky ones. A biologic drug saved my life not just once, but twice. These drugs are powerful, and they work for many other patients like me.

But the real reason I'm able to sit here today and share my story is because of the relationship and trust I have with my team of doctors. I know they will do everything within their power to ensure I have the best quality of life my disease and available medications affords me. I trust them to guide me on the best course of action for my health care.

Step Therapy seemingly sounds like the right thing to do to help curb medical costs, however it falls short in universal application for many of the patients step therapy targets. I encourage you to remember my 10-month fight for my life while on step therapy, the accelerated costs incurred by both patient and insurance company during that time, and to ensure appropriate patient-centered protections are in place so no other person has to experience what I went through. There needs to be a clearly defined path that takes into consideration previous medical history, disease stability, doctor expertise, and scientific research. Physicians must be able to override step therapy when medically appropriate. Patients like me need a policy that reinforces the exceptions process and requires insurance providers to create step therapy protocols that are based on clinical guidelines. A standard appeals process for granting or denying submissions on step therapy can mean the difference between life and, in some cases, death. Non-exigent cases should be reviewed within 72 hours and 24 hours for exigent cases.

I ask that in your role as a representative of the people, that together, we can make sure health care quality and decision making are between the doctor and patient, and trust that our physicians can abide by the first rule of medicine, "do no harm," for their patients.

When reviewing policy, I encourage you to replace the word "Beneficiary" and "Patient" with the name of your child, parent, other family member or loved one to remember that phrases like beneficiary and patient are simply other words to define people. People like me. People like you and your family.

Please make an informed decision about the step therapy reform bill. Say yes to **HB 1359**.

Thank you for allowing me the time to share my story with you today.