SB 841 Testimony of Erin Vago
Banking and Insurance Committee
Senate of Pennsylvania
October 25, 2016

Chairman White and Members of the Banking and Insurance Committee:

My name is Erin Vago, and I am 17 years old. My sister was diagnosed with Juvenile Arthritis almost 9 years ago, so I have been living in the world of arthritis for a long time. As a sibling of someone who has arthritis, I learned the terrible intricacies of the disease while not experiencing it directly. I was forced to sit and watch while arthritis slowly took many freedoms from my sister, unable to lift a finger to save her from her awful situation. My mother, father, and I did and still do what we can to help when she is unable to do things for herself, such as fix her dinner, tie her shoes, push her in her wheelchair, and whatever else she is in need or want of. Until September 24th of 2013, however, I did not understand how truly complicated arthritis is. That day, I received my own diagnosis of Juvenile Idiopathic Arthritis and my life was changed.

Theatre has always been one of my passions; I have been performing since the age of 6. It has gotten increasingly difficult for me, though, to participate in shows, especially with roles that are physically demanding, because of my ever-increasing pain and fatigue. Often when I get home from rehearsals I have no energy left to do other things such as schoolwork (when I was in school), chores, or my other hobby, crafting. Since being diagnosed with arthritis, I have also gained the diagnoses of Irritable Bowel Syndrome, Postural Orthostatic Tachycardia Syndrome, and Fibromyalgia. These illnesses together with arthritis make it very difficult to persevere through each day, let alone function like a “normal” person.

The type of arthritis that I was diagnosed with has a co-morbidity with a skin disease called psoriasis. When I was diagnosed, I began experiencing more pain than what I had previously had, this pain from the joints specifically. I started finding uncomfortable patches of dry, rough, scaly skin on my neck and my chest; psoriasis was making itself known in my body. I realized that the feeling of not feeling rested when I woke up each morning was a new and scary symptom: fatigue. None of my symptoms were severe; I was dubbed “Laura-Lite” by my doctor, meaning I was a very similar case to my sister only more mild, but the symptoms were present enough that my doctor decided to put me on a drug in the NSAID category called Nabumetone. We knew that Nabumetone would not help my psoriasis, so we treated it with Vitamin D and a steroid cream. For about a year Nabumetone curbed much of my pain, but did nothing for the fatigue, which started to grow in its severity. I also began experiencing more pain, including what I called “sunburst pain” in my left knee, pain that started in my kneecap and radiated outwards, traveling halfway up my thigh and halfway down my calf. I started to move more quickly up the drug ladder, skipping around the medications that had failed for my sister and trialing one that helped her for a time, a DMARD called Sulfasalasine, in addition to the Nabumetone. Together, they controlled some of my pain, but the relief was not enough and we moved on to Methotrexate, starting with the pill form and then switching to self-injection form. Then, last year I was put on my first biologic. Our goal of putting me on a biologic was that it would control my arthritis pain, my psoriasis, which was now harder to control with the steroid cream, and my fatigue. We started with injections once every two weeks, then moved to once every ten days, then switched to once a week. My first biologic just wasn't controlling my symptoms enough. The day after I did my injection, I would wake up stiff and sore, not getting the day after injection pain-free “high” that most people on biologics get. My doctor decided to take me off of that first biologic and put me on another, a newer drug with a different targeting mechanism. Unfortunately, the side effects of this new biologic were too severe for me to endure, so my doctor and I decided to pursue yet another biologic. The third biologic I used is a 5th tier biologic that is commonly administered by IV infusion, and is a more aggressive drug. We were hoping that it would widely control my pain, clear up my psoriasis, and lessen my fatigue. The day before I was to have my first infusion, I received a call that insurance was denying my usage of this drug, because I hadn't been on another drug that used the same defense as my first biologic. I had to travel back down the drug ladder to try yet another drug that was a self-injection drug that is very painful when administered. Unfortunately, this new biologic had a 3 month trial period and only a 50% chance of working for me. Neither my doctor nor I are very optimistic that 50% is enough for it to work, so the next 3 months will be a time of watching and waiting. This does not bode well for my other diagnoses, however; none of my other conditions are under control, especially my Fibromyalgia. Fibromyalgia does technically fall under the umbrella term of arthritis, but different drugs are used to treat it.

In many cases of those who have arthritis, is necessary for us to jump around the drug ladder in order for us to find the correct treatment unique to the manifestation of our condition. Insurance make it very hard for us to do that, they have a “step therapy” that requires us to move up the drug ladder, drug by drug, step by step. For many cases, this results in children and adults having to wait a long time, in some cases multiple years, while putting unnecessary chemicals and toxins into their bodies, to get to the drug that finally helps them, when they could have had it when their doctor first thought to prescribe the medication. I am here, telling you my story, for the purpose of those people, that they will be able to access the treatment they need, when they need it.

Each of these changes in drug therapies is expensive. My family has to deal now with two daughters with multiple chronic diseases. The medications needed to give both of us a good quality of life are very expensive. My parents accumulated significant medical debt before we got some financial assistance. They will be paying for our chance at a healthier life for many years.

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