



Global Healthy Living Foundation
515 North Midland Avenue
Upper Nyack, New York 10960 USA
+1 845 348 0400
+1 845 348 0210 fax
www.ghlf.org



TESTIMONY - STATE BIOSIMILAR SUBSTITUTION

Missouri 98th General Assembly

House Emerging Issues Committee Consideration of HB-1366

Speaker:

Joni Johnston

Patient Advocate

Global Healthy Living Foundation

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Disclosure: I have no disclosures to make regarding my travel here today. The Global Healthy Living Foundation accepts grants and charitable contributions from pharmaceutical companies, government, private foundations and individuals. We have received scientific briefings from pharmaceutical companies, as well as from our independent medical advisory board.

Good morning Mr. Chairman and committee members.

My name is Joni. I'm a patient advocate and member of the Global Healthy Living Foundation's 50-State Network. I have been a resident of Missouri for the past 15 years. My legislators are Assemblymen Jeff Pogue and Senator Dan Brown. I want to thank you for allowing me to speak today in support of the passage of House Bill 1366.

Four years ago, my doctor cried as he told me that I have rheumatoid arthritis. The same debilitating disease that I'd seen torture and ultimately kill my father.

As a teen and young adult I, like the adults around me, heard only the word "arthritis" and assumed that my father was dealing with the same problem as others with joint issues that come with overuse and aging. I thought that with some exercise and some aspirin he would be fine. I didn't know there was no cure. I didn't know that rheumatoid arthritis was a chronic inflammatory disease, or that it caused your autoimmune system to damage your joints, eyes, brain or any internal organs, until it attacked my father's lungs. I learned enough about RA then to change my attitude about my father's "arthritis".

When my own symptoms started I didn't think of RA as a possible cause. I thought I knew everything I needed to know about RA. I knew there might be a genetic link and that I too might end up with it. I knew that it could happen to people as young as 6 months, but I had read that if I didn't have it by the age of 37 that I was "in the free and clear

It wasn't until my hands and wrists started swelling and hurting to the point I could not use them that I went to the doctor. He ran some blood tests, diagnosed me with severe RA, and sent me on my way to a rheumatologist appointment.



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I learned that day that the sooner RA is diagnosed and aggressive treatment to control the damage started, the better the chances of remission. The clock was ticking; I had already wasted a couple of years because of my believing I knew what I needed to. I thought of my Dad, his deformed hands, the nights I had come downstairs to find him crying in pain, or unable to remove his shoes or jacket each time I tried to move my arm or close my hand and the pain left me crying out.

The rheumatologist decided to put me on a biologic. Miraculously, within a few weeks I started to get some relief, my fatigue levels were reduced along with much of the swelling and pain. It wasn't remission, but I had my life back. I was able to take care of my daily tasks for a few months.

Unfortunately, due to my unique allergies, over time my body reacted negatively to treatment and I had to stop taking it. My symptoms all returned and increased over the next few months; to the point when my youngest son, a Navy Seabee, became a Daddy I couldn't lift the baby because of a severe flare in my hands and wrists. The first biologic had failed, one down, a few more to go.

The rheumatologist then prescribed a second biologic. It took a few weeks, but this one started to reduce my inflammation levels and pain significantly. These therapies are life changing. When you find one that works, you hold on to it for as long as you possibly can.

My experience with RA has taught me a few things. I've learned to be a better patient and not to assume I know all there is to know about a disease. You must listen to your body and go to the doctor with any strange symptoms. Honest transparent communication with my medical team is critical to my well-being. They deserve it from me and I deserve it from them.

It seems odd to say this, but through all this I was lucky. Lucky because my doctor and I always knew what drug I was on. Imagine, with my several adverse reactions to drugs, the danger I would have been in if we didn't know exactly what drug I was taking.

Without laws in place to require communication to occur between my pharmacist, physician, and me, my medication could be substituted without my entire treatment team knowing. This would be a major threat to my health and the relationship with my physician. As a patient who has experienced first-hand the differences between these biologic medicines, mandatory communication between my treatment team could mean the difference between me being at work or in the emergency room.

At its core, HB 1366 boils down to two words: Trust and transparency. The patient-physician relationship and positive health outcomes do not exist without them.

GHLF and I urge the members of this Committee to support HB 1366. I appreciate your thoughtful consideration of my remarks and I would be pleased to provide any further information that you may require. Thank you for your time and attention.





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