

**Testimony Submitted by Berna Heyman to the  
U.S. Senate Special Committee on Aging  
Sudden Price Spikes in Decades-Old Prescription Drugs  
for the Hearing on April 27, 2016**

Good afternoon and thank you Chairwoman Collins, Ranking Member McCaskill, and distinguished members of the Committee for holding this hearing. My name is Berna Heyman, and I am here today to share my personal experience as a patient with Wilson Disease who has been confronted with sudden and dramatic increases in drug pricing.

Having WD is like being stuck in a tunnel. This genetic disease is bad enough with its many uncertainties, risks of organ or cognitive failure. But the exit to the tunnel is barricaded because of the obscene drug cost. The cost increased by a factor of more than twenty over the past five years. The drug is essential. People can die without it. The drug company deserves the right to make a profit. But it is unconscionable that one company, Valeant, can hold WD patients hostage.

WD is treatable. With proper medication, progress of the disease can be halted and a patient can live a normal life. Treatment is aimed at removing excess copper and preventing its re-accumulation. Treatment for WD is lifelong.

I was undiagnosed for 60 years, making me one of the older individuals to survive that long without medical intervention. I was shocked when a radiologist informed me I had cirrhosis of the liver. A DNA test confirmed I had WD and I immediately began taking Syprine.

I was a librarian at the College of William and Mary in Virginia for 34 years, with good health and drug insurance. Upon retirement, I was insured through Medicare, including Part D, along with supplementary insurance.

Syprine has been around for more than 30 years. It is an old drug. As I understand it, Valeant did not spend a cent on research and development for this drug. Valeant purchased the drug in 2010 and began increasing prices. My co-

pay for Syprine was under \$700 per year until 2013. By 2014, my projected co-pay exceeded \$10,000 per year with my insurance paying over \$260,000. That is untenable. Something has to be done.

My doctor and I applied for Valeant's patient assistance program and I was denied financial assistance. I then wrote Michael Pearson, the CEO of Valeant, asking why there was such dramatic price increase. Valeant Customer Service replied: "the investments we make to develop and distribute novel medicines are only viable if there is a reasonable return on the company's investment."

The President of the Wilson Disease Association and my doctor communicated with Valeant representatives and were told I did not qualify for aid because I was on Medicare. I also applied to the Patient Access Network Foundation (PAN) and was told my income precluded support from their foundation.

My doctors and I then discussed switching to an alternative. In October 2014, I switched to Galzin, a zinc salt. Galzin works differently than Syprine. It inhibits the absorption of copper rather than extracting it.

Is this treatment sufficient for me? We are still monitoring its effectiveness.

Galzin costs me about \$480 per year. The only reason I changed was the cost, even though none of the cost is covered by my insurance. My health was stable with Syprine and my doctor and I made the change only under duress. Galzin is not the preferred treatment for me.

A year after I stopped taking Syprine, a reporter from *The Financial Times* interviewed me and then talked to Valeant about my case. Later that day, a Valeant representative called offering to help. He noted that while Valeant strives to help everyone, there are limits because of the government. He said he might be able to work with me as an exception. I told him I did not want to be an exception. I wanted everyone to have the same opportunity. If the money for assistance comes from insurance companies, 'we' are still paying. If the money

comes from the government, 'we' ultimately pay the price. Shifting who pays doesn't solve the problem.

Then a local florist called inquiring where to deliver flowers. They told me Valeant sent the flowers with a note saying it was a pleasure taking to me and to let them know if they could be of assistance. I refused the flowers and asked that the sender be informed of my refusal.

My doctor and I received letters stating I was enrolled in the assistance program and receiving free Syprine — which was not true. A message was also left on my phone asking if I still needed help. All of this happened more than a year after I stopped using Syprine.

This is my story. I am fortunate. But I do not want others to face these same challenges. I don't have answers but as a victim of this disease and the outrageously high cost of the preferred drug to treat the disease, I do question how Valeant can justify, financially and morally, increasing the price of Syprine since it is an old drug, out of patent, and had been reasonably priced until they began manufacturing it.

Thank you for the opportunity to address the Committee today and for the opportunity to hopefully contribute to some action to stem this contemptible development in the pricing of orphan drugs. I look forward to answering any questions you might have.