

**Testimony Submitted by Patricia Bernard to the
U.S. Senate Special Committee on Aging
February 7, 2018**

Good morning. Thank you Chairman Collins, Ranking Member Casey, and distinguished Members of the Committee for inviting me to testify before you today.

My name is Patty Bernard. I will turn 81 in July, and I have rheumatoid arthritis. I have lived with diagnosed RA since I was 55. Before the diagnosis and treatment, I experienced excruciating pain -- day-in and day-out. Every bone in my body ached. The pain made ordinary tasks difficult, often impossible. I would come home from work and take hot, hot showers. It was the only thing that relieved my pain – even just temporarily.

I finally visited a rheumatologist and learned that I had RA. In fact, at that time, my doctor informed me that 79-percent of my body was inflamed. It was very difficult to hear the doctor tell me I had RA. My cousin had the disease, and I saw what it did to her body. She was in a wheelchair, and her hands were like clubs. That night, I went home and cried.

My doctor tried many drugs, but they didn't help. As I entered my 60's, my symptoms grew worse. My doctor discussed adding gold injections. Just as I was ready to try that, something new came on the horizon – a drug called Enbrel. I was one of the first in Maine to try this therapy. I got my first shot of Enbrel at the doctor's office. The doctor warned me not to expect it to work right away. But that day, as I was driving back to work, I could feel something going through my body. That afternoon, I felt so much better. It was incredible. I just couldn't believe it.

Enbrel gave me my life back. I no longer woke up in the morning with excruciating pain or came home in the evening aching in agony. Because I had insurance through my job, I paid anywhere from \$10 to \$30 each month depending on my company's insurance plan. Every other week, I was able to give myself injections. Besides that, I was finally able to live an ordinary life. I went to work. I walked, I swam, and I took the stairs because I could.

For 19 years, I depended on Enbrel. My employer-sponsored insurance switched several times over the years. But, every time, my employer went out of his way to find an insurer that would cover my Enbrel.

Although I didn't really want to stop working, I retired in December 2016 at the age of 79. I would no longer have insurance through work. In the transition to Medicare, I was devastated to learn that I would have to pay \$3,800 a month if I were to remain on Enbrel. \$3,800 a month! I do not have that type of money. I would wake up in the middle of the night panicked. I feared I might have to sell my house. I was afraid that if I went without this medication I would end up back in so much pain and even in a wheelchair. The anxiety started causing heart palpitations that put me into the hospital on more than one occasion, one time over Christmas.

My rheumatologist proactively helped to find me an affordable option. He suggested a treatment called Remicade. It was not self-administered like Enbrel. Instead, I would have to go into the doctor's office to receive the infusion. Worse, there was no way to know whether or not it would work. I was scared. I knew that Enbrel had worked well for nearly two decades, and stopping it felt like going backwards. I even called Medicare, and told them, "I don't understand. I am actually saving you money by administering the Enbrel myself." They said that's the way it is.

I was nervous the day I went to the doctor's office for my first injection of Remicade. Thankfully, after a year on this treatment, it has worked. It is not convenient compared to administering the drug myself. I have to go into the doctor's office in Portland once a month, and each infusion takes about two and a half hours.

I do not understand why I would need to pay nearly \$4,000 in a single month for a drug that for years I had for no more than \$30 a month. I am grateful that I do have something that works so that I can be productive for my family, church, and other friends who aren't as fortunate as I am. But, I feel very strongly that people should be able to access the treatment they need at an affordable cost.

Thank you for the opportunity to testify and I am happy to answer your questions.