

Testimony of

Maureen Kurtek

June 11, 2008

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Pottsville, Pennsylvania

Senate Judiciary Hearing entitled:

"Short-change for Consumers and Short-shrift for Congress? The Supreme Court's Treatment of Laws that Protect Americans' Health, Safety, Jobs and Retirement"

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Chairman Leahy, Ranking Member Specter and Members of the Committee:

A health insurance company should never be allowed to jeopardize a person's health while they look for ways to save money. But when they do they should be held accountable.

My name is Maureen Kurtek. I am 44 years old and live in Pottsville, Pennsylvania.

I am a registered nurse by training and last worked in an ICU.

I have lupus. I was diagnosed in 1989 when I was 25 years old. I suffer from complications of thrombocytopenia, which is a low platelet count and antiphospholipid syndrome (APLS) which means I produce blood clots.

For the low platelet count I began treatment with large doses of steroids. Because of the negative effects of chronic steroid use, I was evaluated at Thomas Jefferson University Hospital in Philadelphia. My doctors agreed that a therapy called IVIG would be beneficial to me and enable me to taper the use of steroids.

IVIG (Intravenous Immunoglobulin IG) is the IGG portion of the blood which helps to fight infection by building up a patient's resistance. People with autoimmune diseases such as myself do not have a normal resistance to germs, which is comparable to a person undergoing chemotherapy.

My doctors were right. Periodic IVIG therapy enabled me to avoid high dose steroids. IVIG therapy raised my platelet count and boosted my immunities.

IVIG therapy is expensive. My first series of treatments in 1998 cost about \$14,000.00 and was paid for by Pennsylvania Blue Cross and Blue Shield through my husband's employer.

I had two more treatments, one in 1999 and one in 2001, paid for by Pennsylvania Blue Cross and Blue Shield.

In January 2003, my platelet count was very low and my doctor recommended another IVIG treatment. At the time, my husband had just changed jobs and our health insurance company was now Capital Blue Cross.

I immediately called Capital Blue Cross to preauthorize the treatment, which according to the Plan; they would pay for as long as it was medically necessary.

It was indeed medically necessary for me.

I first called Capital Blue Cross on January 17, 2003. The first representative wanted to look into whether the treatment could be provided by home health instead of in a hospital.

The next Capital representative on the same day told me she thought the treatment was "experimental."

I repeatedly asked to speak with a supervisor and was told that Capital was continuing to look into this and would report back to me once a decision was made.

Every time I called, I was told that "someone was working on it." I was also told that the supervisor had a note on her desk with my name and number.

Capital knew I had received this treatment three times in the past, and Pennsylvania Blue Cross paid for it.

Capital did not call any of my doctors.

Due to the fact I could not receive the IVIG, my doctor increased my dose of prednisone, which suppresses the immune system and keeps my platelet count up, so that I would not bleed to death while I was waiting to hear from the insurance company.

It took the insurer 53 days to determine that IVIG therapy was necessary for my medical condition.

By then I had nearly died. Due to not receiving my treatment, I became septic with a white blood count of 24,000 and a low blood pressure of 69/34. I developed an infection my body could not fight since my platelet count was so low.

On March 1, 2003, I was taken by ambulance to Pottsville Hospital and thereafter transferred on an emergency basis to Reading Hospital for what proved to be an acute flare up of my lupus and catastrophic APLS. According to my doctor, this condition could have been prevented or dramatically diminished had I received the medically necessary IV IG therapy during the time period when I requested pre-approval.

It was not until March 11, 2003 while I was an inpatient at the Reading Hospital that I received a voice mail message at home from Capital that the IV IG therapy would be covered under Capital's comprehensive health coverage under the Blue Cross portion of the contract and would be covered at 100% as long as the services are medically necessary.

The very first treatment I received after being admitted to the hospital was emergent IV IG therapy. While at Reading Medical Center, I was in critical condition in septic shock with multi system organ failure. The doctors told my husband I had a five percent chance of survival. My platelet count was 20,000.

After going into septic shock, I went into kidney failure and due to having Systematic Lupus Erythemous with A/B syndrome, my body also started to throw clots at the same time as it bled out. I had blood clots in my hands and feet while I also suffered uncontrollable hemorrhaging of the sinuses causing blood to

enter my lungs. I was bleeding from every orifice in the body including the eyes and mouth at the same time as I suffered from blood clots. All of this could have been prevented had I received the IVIG treatment I had received many times before.

During my hospitalization, I was in respiratory failure and required ventilation on a respirator and within 24 hours had an emergency tracheotomy due to bleeding into my sinuses. My extremities were clamped down and clotted, and I experienced excruciating pain in my fingers and feet. I was so weak it took four nurses to roll over in bed. I couldn't do anything. I could not even hold a toothbrush I almost died because of this injustice and parts of me actually did die.

As a result of the extraordinary delay in approval of IVIG therapy, I had half of my right foot amputated, have developed osteomyelitis of my right foot, have lost the tips of five fingers, I have discoloration and redness in my face, including scarring of my nose, have difficulty breathing through my nose, have undergone surgeries, am required to take Lovenox, 2 injections daily, have developed peripheral neuropathy, and am required to wear special shoes.

There is no doubt the insurance company unnecessarily delayed approval of IVIG therapy while trying to find a way to deny coverage, and my family and I paid a heavy price.

I filed a lawsuit against the insurance company not only because of the harm they caused me but also to prevent them from doing this to someone else. The judge dismissed my case because the ERISA law does not allow people like me to sue for the harm the insurance company caused me. Because the law insulates them from any liability for their conduct, they have every incentive to delay or deny treatment in an effort to try to save money. Instead the ERISA law as the late Judge Becker stated "has evolved into a shield that insulates HMOs from liability for even the most egregious acts of dereliction committed against plan beneficiaries"

Because of ERISA, there is a monetary incentive for insurance companies to mistreat people like me who have health problems and are unaware of our rights. According to the law, the only remedy in court for me would have been to file an injunction to force the insurance company to pay for the treatment. I did not know I could do that and even if I did, I did not have the time or money to hire a lawyer. I relied on the insurance company who kept telling me someone would get back to me soon.

I am privileged to be here today to tell you about how the ERISA law has hurt me and my family. I'm wearing a tear shaped necklace given to me by family members who had to watch me cry tears of blood. Instead of protecting the American people, this law favors the insurance industry.

At the time I was sick, I had a 13 year old son who did not know whether his mom would even make it through the night. I had a husband who didn't know whether in a few days he would be a single parent and have to raise a child while trying to support a family on a modest income. And, all of this pain and suffering was caused by an insurance company that failed to provide me with a treatment that I had received six times prior at the same hospital under the same insurance provider with good effective results. Previously, this treatment had helped my body increase its ability to fight infection and keep my platelet count at a normal level. This treatment was prescribed for me by at least seven doctors and two specialists and was never considered to be experimental by them. This treatment, although expensive, was necessary for me. And, my insurance company delayed my treatment.

I stand before you today with a tracheotomy scar on my neck, five amputated finger tips and an amputated right foot where I still experience phantom pains. Life ceased as I had known it. I can no longer jog or dance. I can not wear stylish shoes on special occasions such as my son's graduation, and I have to wear an orthopedic shoe which I can assure you is not the dream of any woman. During my time in the hospital, I missed my son's spelling bee, piano recital, his confirmation at church and baseball games. These are events I can never get back.

Due to this law, insurance companies can get away with denying care and delaying treatment without any consequences. This is wrong. We need to change this law so no families will have to suffer the way mine has.

Thank you for your time. I would be happy to answer any questions.