

Thank you, Senator Conrad, for the privilege of testifying at this hearing.

In June of 1990, my world was turned upside down by a simple bruise.

Unfortunately, that bruise was the signal of far worse to come and I was soon bleeding profusely from my mouth. I was immediately referred to the Mayo Clinic.

Fortunately, my husband was a Boeing employee and we had health insurance. Mayo ran test after test; prescribed medication after medication; and still I had no firm diagnosis. I was told to go home, spend quality time with my children and enter hospice care when the time came.

On top of this death sentence, the bills started coming in from Mayo Clinic and from Trinity. Our co-pay was high and my husband had no idea how we were going to pay.

My health just kept getting worse and I was soon back in the hospital receiving blood transfusions, the one thing that was keeping me alive. While I was lying there, my husband marched into my room and informed me that he couldn't afford the medical bills and he wanted out. He also wanted my children, but fortunately, the court did not agree.

I had no choice but to turn to the state of North Dakota for TANF and Food Stamp assistance. I was so ill, so lost, so upset that I never even thought about the possibility that my coverage through Boeing would end with the divorce.

When my grandmother questioned me about that, I called Boeing and learned that my ex-husband had terminated the coverage not only for me, but for our children. I then had the option of their COBRA plan as long as I could pay the premiums of \$380 a month. That was like \$3 million to me. Fortunately, my grandmother paid six months of premiums and that allowed me time to get on state assistance.

By this time, it was obvious that a bone marrow transplant was my only hope. If I only had Medicaid, there would be no facility that would accept me. Thankfully, Social Services chose to continue paying the COBRA premiums as it would be cheaper in the long run.

I was already floundering in medical bills. I was becoming more lost, confused, and scared. My health just continued deteriorating. I was spot bleeding in my brain, which caused huge headaches and temporary blindness. I had pleurisy in my lungs and my heart. I was bleeding faster than they could replace the blood.

Finally, a referral was made to the University of Washington hospital but I could not go without approval for the procedure from my insurance company and they were giving me the run-around. They denied it, saying it was experimental. I had to involve the family's attorney in order to budge them.

And, then, when the Fred Hutchinson Cancer Center had an opening for me, the insurance company again denied it. I can't tell you how scared I was. Something, I'm still not sure what, changed their decision again.

I was so very sick I was told I was probably not going to live more than a couple of weeks, but they started me on Cytosin chemotherapy. In this case, the treatment was as sickening as the disease I had, but finally on the 45<sup>th</sup> day of treatment my blood counts started increasing. As they increased, I lost fluid around my heart and lungs. My bleeding slowly stopped. For the first time in a year, I could lay flat and sleep.

After the bone marrow transplant on March 31, 1991, I was put on cyclosporine, an anti-rejection medication. The cost of this drug was \$800 a day. And, that was just one of 25 different medications that I was on.

I finally felt like I had a new lease on life and I returned to Minot and my children. At this point, the state was still covering my insurance premiums. As I grew stronger, I moved back to Washington state and started working as a social worker.

I was working. I was making my way, but I still had to file bankruptcy because of the mountain of medical bills I had.

Then, in 2004, the chronic grafts vs. host disease was affecting my skin, my mouth, my liver, and my memory. Co-workers noticed that I was becoming very forgetful. After 7 years of employment, my supervisor asked me to resign. I went out on long-term disability which pays me \$240 a month.

I returned to Minot to be close to family and because I thought it would be cheaper to live here. Because I still had children in the home, I was, thankfully, able to return to the TANF program, and Medicaid continued paying my medical premiums.

Am I well now? No, the impact of the massive doses of chemotherapy is really showing up. I am losing the sight in my left eye and will likely be blind in both eyes. My teeth are gradually crumbling, and I need to guard against chipping at all times. The grafts vs. host disease continues to take its toll. In addition, because none of the over one thousand blood transfusions I had was filtered, my body is being attacked by the extra iron, causing constant pain in my arms and legs. I will likely need a liver transplant.

And, the latest blow? My youngest child just left my household. What does that mean for my continued assistance through the state? It means everything. As of July 31, I lost Medicaid coverage. I lost every kind of assistance.

I am completely terrified as I cannot qualify for Medicaid help again until I have a disability determination from Social Security. I applied for disability in 2005, and I was

denied at the initial application and the reconsideration level. I am now awaiting an Administrative Law Judge hearing, which thankfully, you, Senator Conrad, were able to expedite for me.

With only \$240 a month in income, I am struggling to keep a roof over my head; to keep my utilities on; to put food on my table. Poor health, high medical bills, and now the uncertainty of whether I will be able to get any medical help for at least a time keeps me up at night.

I don't know what the answer is to making our health system better for average people with serious illnesses, but I do know that something has got to be done. And soon. Too many people don't have insurance or are forced into bankruptcy, like me, in order to afford the health care they need to live.