

TO GO WITH STORY APPEARING IN THE NEXT EDITION OF THE
VOTER

**Testimony of Cathy Williams Kerns
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Chairman Baucus, Senator Grassley, and distinguished members of the committee. I thank you for the opportunity to speak today about living with a chronic illness as you discuss healthcare reform.

In the fall of 1988 my husband and I owned and operated a successful advertising agency in Orlando, Florida. I began to lose the vision in my left eye and I could not trust my balance anymore. My doctor ordered tests to determine what was wrong.

“You have a very probable diagnosis of Multiple Sclerosis” was the devastating news. MS is an unpredictable, progressive and often disabling disease of the central nervous system. Dr. Ira Goodman told me that at the time of my diagnosis there was nothing I could do but use medications to treat symptoms and follow a healthy lifestyle including exercise and proper diet. He thought there would surely be advancement made on treatment and to not give up hope. There was no way to determine what type of MS course I would be forced to live with or exactly how long I would live.

I continued my corporate life as my disease progressed. We merged our company with another and after a few years I resigned to start my own company helping others living with disabilities. We would maintain our insurance through my husband's corporate policy. We had always saved so we thought we were pretty set for the future.

When my husband retired we chose to take the Cobra policy and look for new affordable and comprehensive medical insurance. The Cobra plan was about \$1,800 per month for the two of us with no dependents. Not affordable healthcare!

My husband is diabetic and I have Multiple Sclerosis. No one wanted to insure us so we paid the Cobra for both of us until it ran out and we continued to pay for the rollover policy with the same insurance company at about \$2,200 per month until Gary qualified for Medicare and Social Security. He's 9 years older than I am so I'm caught with continuing to pay \$1,070.29 each month for my policy which has a high deductible and high total annual out of pocket expense program. Because I have a drug program with my plan my medicines no longer qualify for the maximum annual out of pocket expense.

You see, I take 11 medicines a day and have a very scarred body from taking MS disease modification shots

for the past 15 years. I've been on the same medicine and the monthly co payments grew from just under \$300 to just over \$500 dollars per month. 15 years. In total I was paying well over \$1,000 per month in pharmaceutical co-pay costs per month in addition to the premium. The plan will not let me customize a health program targeted to meet my chronic illness needs; one that might slow my disease progression and help me better manage the disability I live with. I can't seem to make them understand I'll never use the maternity benefits but I could sure use some extra physical therapy. Too bad. They only cover what Florida tells them they have to cover. This is not good health management or affordable healthcare. All of my docs, treatments, therapies and medications must work together for them to work at all. They will only become more important to me as my disease continues to progress.

2 years ago my husband was diagnosed with stage 3 cancer of the esophagus. He survived radiation, chemotherapy and 7 hours of surgery only to have his heart fail. He was placed on life support and we prayed. His medical co-pays and his falling into the Medicare Part D donut hole really ate into our dwindling savings. Someone has to fill that hole!

I discontinued my consulting business activity to give my husband 24 hour per day care. Our only income is now his social security. The devastating financial issues facing our country forced us to close our investment account so we would still have some money saved, albeit not earning much in a CD.

It was always our plan to stay in our home and have someone take care of us but now we are forced to consider selling our home to generate additional income to cover our living expenses.

We investigated a reverse mortgage because of the great equity we have in our home but I am too young to qualify as an owner. I would need to quick deed my half of the house to my husband and, should he pass before I'm 62, I would have to sell the house immediately to repay the loan. This is not a good option because of his declining health. What we planned as lower cost, non-institutional housing is not going to work unless you, as our leaders, choose to create reverse mortgage age limit exemptions, based upon existing home equity, for those people living with chronic illnesses and desiring to stay in their own home.

These healthcare issues apply to all age groups, especially those who, like me, are too young to qualify for Medicare or do not care to fight the approximate 2.5 years an MS patient must wait to be approved for disability. The

system needs to stay strong to service future generations and all my fellow baby-boomers.

I have been able to now qualify for patient assistance for my very important MS disease modification drug and I encourage all patients to investigate any and all methods and programs for aide. Living with my disease can cost at least \$30,000 per year for many patients. We must rely on quality, compassionate and comprehensive care programs for life.

In closing I would like to thank you for hearing my story. I would also like to say that because of organizations such as AARP, the National MS Society and Canine Companions for Independence, all patients living with a chronic illness have resources to turn to for assistance, information, fellowship and hope. Thank you again for your time and attention. May I answer any questions?