

Center for Independence of the Disabled, NY**Partnership for Coverage Hearing
Testimony by Deborah Moore
October 30, 2007**

Hello, my name is Deborah Moore, and I live in the borough of Queens, in NYC. I am here today to share my personal experience as an illustration of the complex needs of people with disabilities. I hope that from hearing my story, you will consider our needs when moving forward on a universal health care plan.

I separated from my husband, who had become a drug-addict, in the mid-90s. In addition to my day job, I began to freelance at night to support myself and our daughter, doing accounting and computer consulting. After four or five years of this, I was diagnosed with Fibromyalgia and Chronic Fatigue Syndrome, as well as Post Traumatic Stress Disorder. Not wanting my pain, exhaustion, and fear to affect my daughter, I began seeing a psychiatrist.

The years of doing two jobs had been a strain to my already declining health, and the worse I felt, the harder it was to work. Eventually I came to the horrible conclusion that I was disabled. I was put on Social Security Disability (SSDI) in 1996 and got food stamps, but had to wait two years to be eligible for Medicare. During that period I paid about 350 dollars a month for Oxford health coverage.

Since being on SSD, I have had a number of other health problems. I was in a serious accident that caused nerve damage in my left arm, and I broke my left wrist a month later. This has resulted in pain 24/7; horrible cramps like lightning bolts in my arm and hand, and three of my fingers have been in a fixated claw for five years. In the same year, I had a skin cancer removed, as well as most of my cervix, due to cervical cancer.

In 2005, I was in the hospital for over a week with a terrible kidney stone attack. Then I developed liver failure and had to have my gallbladder and part of my liver removed. At the hospital, I contracted a drug-resistant staph infection that lasted so long, it created a deep hole in my stomach. When I was first went home from the hospital, I had a nurse and an aide for three months. Then my insurance for that ran out, so I spent the next nine months in bed. This year alone, I have had surgery on my legs because of bad circulation, serious problems with anemia, and a small stroke causing difficulty with balance and vision.

I have depleted my savings, and find it very difficult to make ends meet. I get help from friends and local religious organizations for necessities such as food, etc, but I live in constant worry that I will not be able to keep my head above the water. Luckily my daughter is insured by Child Health Plus, for which I pay a small premium of \$9 per month. As she herself is having emotional problems, I am so grateful for the comprehensive coverage she has with CHP.

My care, however, is not so affordable. I pay \$98.50 per month for Medicare B, and I now pay \$664 a month for Oxford health insurance, which goes up every year. The reason I need Oxford is that my drugs for all my illnesses total over \$1200 per month, (I have attached a list of those medications to my submitted testimony) and most of my



Re:

Medicare doctors expect to get their 20 percent co-payment immediately. This is still less money than going on Part D, because when I would fall into the "donut hole" I wouldn't have the money to pay over \$3,000 in two to three months. Without medication, my health would deteriorate greatly in that time.

I get approx \$1,700 a month Social Security Disability. I also belong to an organization that subsidizes part of my rent to keep me living on my own with my daughter, instead of losing her and having to go into an institution. I do not belong in an institution, and I will do anything to keep my daughter and me together, which is what she wants as well. I give her everything I have, and I believe that that is why God put me on this planet. It would seem so selfish of me to be here, accepting help, if it did not benefit my daughter as well.

To say the last ten plus years have been difficult physically, mentally, and financially would be an understatement. I realize that as bad things have been for me, there are other disabled people who may have even more complex needs than I do. I feel there are many of us who can't speak and articulate their fears and experience because of their disabling conditions. It would be so unfair and catastrophic to the disabled of New York State if any plan going forward does not include an awareness of their needs. The disabled population is often forgotten, such as in the case of the "miracle" Part D plan-- which for me was a nightmare I needed to stay away from at all costs. Part D was supposed to enable me to live with less stress and more dignity, but I couldn't even consider it because of the "donut hole". I hope that New York State will not forget us in the same way. Thank you for your time.

Re:

Below, I list the 20 or so medications, for which I pay \$5 or \$10 copayments. This will clarify my medical illnesses and my drug situation, so you can see I have no choice to continue as I have. I have done a lot of research, and there is no better way. Unfortunately, the sicker I get, the harder it is to "keep all my plates spinning in the air":

Drug #	Name	Purpose
1	Effexor XR	Chronic Chemical Depression
2	Wellbutrin XL	Chronic Chemical Depression
3	Tricor	High Cholesterol
4	Rozarem	For Sleep:2 every other day
5	Ambien CR	1 every other day w/Ambien
6	Requip	Restless Leg Syndrome
7	Asacol	Ulcerative Colitis
8	Levabid	Ulcerative Colitis
9	Nu-Lev	During Ulcerative Colitis Attacks
10	Neurontin	Pain, Nerve Problems, Fibromyalgia
11	Avinza	24hr lasting morphine for severe pain
12	Oxy-codone	for breakthrough pain 2-7 times daily
13	Klonopin	Extreme Anxiety
14	Glucophage	Diabetes
15	Beginning inhaled insulin as well next month	
16	Botox	injected into left arm every 3 mos to relax fixated clawed hand
17	Detrol LA	incontinence and bladder weakness
18	Xopenex	Chronic Obstructive Pulmonary Disease
19	Spiriva	long range treatment for COPD
20	IV Iron	severe anemia and low blood volume
21	Baclofen	Cramping in surgical incisions and L arm

Above are Prescription Drugs as of 10-16-07 and for what illness. This list changes in type of drug or dosage almost monthly.