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Subcommittee on Primary Health and Aging
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Is Poverty a Death Sentence?

I would like to thank Chairman Bernard Sanders, Ranking Member Dr. Rand Paul, and the members of the subcommittee for holding this hearing today.

My husband Mike and I are the parents of a 26 yr old son whose numerous chronic life threatening illnesses started in 1987, at age 2 when he was diagnosed with Common Variable Immunodeficiency, a mild form of the "Boy in the Bubble Syndrome" requiring expensive monthly intravenous infusions for his lifetime. When he was 3 my husband's employer based health insurance co, changed the physician's diagnosis from Common Variable Immunodeficiency to AIDS, for the sole purpose of rationing Craig's health care by denying future claims. The Maryland State Commissioner of Insurance convinced them to change the diagnosis back to CVID by threatening their ability to do business in the state of Maryland.

Craig had 7 surgeries in 3 years, Nephrogenic Diabetes Insipidus, Anemia, atypical Anorexia, fevers up to 105 degrees 5-15 times a month for years, acute kidney failure four times, Meningitis and many more diagnoses. During his childhood, he was followed by 12 specialists at The Johns Hopkins Children's Center. At age 10, Craig was diagnosed with Hodgkins Lymphoma. He was treated for cancer with my UFCW union health insurance coverage. While getting chemotherapy, it was discovered, during a crisis, that he had an Adrenocorticotrophic (ACTH) Deficiency. During treatment for a serious reaction to his previous round of chemotherapy, an insurance company clerk told Craig's Johns Hopkins Pediatric Oncologist to discharge him from the hospital because the "for profit" health insurance company did not pay for pediatric oncology inpatient stays without active chemotherapy infusions. We took Craig home but 3 hours later he was readmitted through the emergency room with a fever of 104 and complications that could have killed him. B*ecause of his diagnoses and our 20% co-pay of a $250k medical bill in 1995,* Craig became eligible for SSI with Medicaid co-eligibility, as his secondary insurer. Two years later, at age 12, Craig reached his lifetime maximum on my health insurance, so Medicaid became his primary and only insurer. By 1999, I had to leave my job to take care of Craig and his ever increasing diagnoses.

My husband, Mike, was seriously injured at work in December 2003, requiring 2 surgeries and two years of rehabilitation therapy. A year to the day after his injury, Mike's employer cancelled his health insurance and Worker's Comp Insurance paid for medical treatment of his injury only. In Sept, 2005, Mike felt very sick while taking a walk. I wanted to take him right to the Emergency Room, but because he no longer had health insurance he refused to go due to the cost. Ten days later he had a massive, near fatal heart attack with severe damage to his heart and had a Defibrillator surgically implanted. Six months later when his condition worsened he had emergency quintuple bypass surgery. If a Medicare-like insurance plan had been available, (health insurance not dependent on employment status), Mike would have been diagnosed at the first sign of illness, had a much cheaper surgery and treatment for milder heart disease and would most likely have been working several months later adding to the tax base, instead of being permanently disabled.

The hospital applied for *Medicaid and SSDI* (Social Security Disability Income) for Mike and Medicaid covered his medical expenses associated with catastrophic illness. As soon as he received Medicaid approval Mike was eligible to be placed on the Heart Transplant list (without any insurance, public or private, a human being in the United States is denied the "privilege" of a life saving transplant.) To be eligible for FULL Medicaid coverage without a spend-down (deductible) in the state of Maryland, the net income standard for a family of 2 adults (with no dependent children) is $392.00/mo. Mike's monthly SSDI, our only income, was too high to qualify for full Medicaid without a spend-down. He had to accrue a deductible of paid or unpaid medical expenses of $3,500.00 every 6 months after which Medicaid picked up medical bills for the rest of that 6 month period. By the time that deductible was met, *he ended up with coverage only every other 3 months or so, with uncovered expenses we may never be able to pay off.*

Five months after his heart attack, Mike received confirmation of eligibility for SSDI. But unlike Craig's SSI with co-eligibility for Medicaid, with SSDI, as per Federal regulations, there is a 24 month wait for eligibility for Medicare. Why? Only the most seriously ill are considered for SSDI. We have no choice but to believe that the Federal Government wanted Mike to die so Medicare didn't have to pay his medical expenses. Mike survived and is now submitting bills to Medicare. My spousal eligibility for Medicaid ended when Mike's Medicare coverage began in February, 2008, so I became and continue to be uninsured. From the time of Mike's heart attack, I knew I would be the permanent head of household. I immediately started looking for employment. I checked the biggest online employment websites on the internet including that of Maryland's largest employer, THE STATE OF MARYLAND, but all the jobs I qualified for were contractual, no benefits. I had been forced to choose between applying for jobs I was qualified for, without health insurance benefits, thereby losing financial eligibility for Mike's Medicaid if hired, most likely resulting in his death, or not working and being forced into an unwanted life below the poverty level, thus qualifying him for partial Medicaid benefits and eligibility for a place on the transplant list.
I chose my husband's life over earned income.

I have had Crohn's Disease for most of my life and I was diagnosed with Type ll non-insulin dependent Diabetes in 2001. I was overcome with exhaustion in 2008, unable to get out of bed without feeling faint many days of the week. With the constant stress of being the caretaker for my very ill family and financial worries, I thought I was suffering from severe depression. Without health insurance or a job, I felt I could not afford an office visit and assumed I could just think my way out of my depression. After a year of suffering, I finally gave in and went to my doctor. Being diabetic, she took a finger stick Glucose level. My supposed depression was actually a Glucose level of 500. I was working my way up to a diabetic coma. I am now a Type ll Insulin Dependent Diabetic. During that office visit in 2009, I found out I was eligible for Maryland's PAC (Primary Adult Care) program. It allows me to see a family doctor only, and pays for my medications.

Contrary to popular belief, most uninsured people don't go to the emergency room for minor illness. Who wants to spend 4-8 hours sitting in an emergency room? We go when we are so sick or in such pain we are frightened into believing that our lives are in jeopardy. And for those people who think the uninsured are well cared for in any emergency room for any illness, the emergency room will diagnose and stabilize you, but they do not treat chronic illness. I have had two hospitalizations in the last two years with bills totaling over $12,000. With no insurance and without the ability to pay out of pocket and with Mike's 2005-2008 deductibles of $15,000+, we get calls from medical collection agencies starting at 8:30 a.m. to 8:30 p.m. 7 days a week.

With pre-existing illnesses, even with the Affordable Care Act's regulation of no pre-existing conditions clause forcing insurance companies not to refuse to insure us and out of pocket spending limits of $11,000 per year for a family, private coverage is still financially unaffordable for us. Even after passage of the ACA we find that care is still rationed by for-profit insurance companies that threaten our health. Two weeks ago my husband tried to refill his Lipitor, covered by the Medicare Part D insurer, Anthem – Wellpoint, that they have covered for the last 6 years. Lipitor limits Coronary Artery Disease, the main cause of my husband's heart attack and lessens the possibility of strokes. I called the insurer to find out why coverage was denied. I was told Lipitor was no longer part of their covered formulary and I needed to have the doctor fill out a Formulary Exemption form.

The doctor's office called for, received the fax and filled out the formulary exception form, but there was no return fax number on that form. Mike was now ten days without his medication. I called the insurer to ask what was going on and was told the doctor was faxed the wrong form. In anger, I told them if my husband had any medical issues due to their mistake, we would be filing a malpractice suit and I was contacting the Washington Post as soon as I hung up. I was then told the doctor could *call in a pre-authorization* (new information I was never told about with Mike's past medication formulary exemption changes) and they would approve his Lipitor within 72 hours. The pharmacy called later that day to let us know his prescription was ready for pick-up. Over the last 24 years I have become an expert at fighting for coverage and overturning insurance denials for my family.

In 2009, went back to school and in August, 2010, I passed a 6 hour national medical coding certification exam. I was employed by an MRI facility from December 2010 through April 2011, but was laid off when my employer lessened their patient case load by dropping patients insured by one insurance company due to reduced insurance reimbursements for MRI's in this region. I have been searching for a job since April and I still can't find employment. I'm not lazy, I have been a full time but unpaid, medical case manager for Craig for the last 24 years and now for Mike, too. I spend hours each day in front of the computer filling out applications and sending resumes, the 21st century way to search for jobs with very little success. I have heard there are at least 1,000 resumes for every job listed!

We have not always been uninsured. In my lifetime, I have had just about every kind of health insurance available in the United States. As a young single woman, I had an affordable individual private insurance policy, then, my husband's employer based family insurance, for seven years during some of my son's worst illnesses (I was a rooming in parent while Craig was a cancer inpatient and worked part-time evenings) I was a UFCW union member so my family had insurance through my union, we've had Medicaid and my husband is now on Medicare/Medicaid. I can't tell you how frustrating access to care is without one single affordable national health insurance option. Our easiest and fullest access to health care has been with government funded but privately administered (Medicare and Medicaid) healthcare coverage.

We are not a rare occurrence in the United States. Our friends, formerly upper middle class, are small business owners. With the economy of the last several years their business has fallen considerably. They were forced to drop their individual family coverage due to the cost of $26,000/yr in premiums with 50% – 60% co-insurance, co-pay and deductible out of pocket expenses for medical care and are now uninsured. Another friend, a nurse, who had to stop working because of medical disabilities, had an individual single insurance plan and was paying $700/month for about 50% co-insurance, co-pay and deductible out of pocket coverage. She was finally sick enough to qualify for SSDI and is now on Medicare. Even with an AARP Medicare Supplemental insurance plan, its a great financial relief for her.

Although my son Craig has the intelligence and capacity to earn an unlimited income, unless he can find a permanent job with benefits, not a contractual job offering no health insurance benefits, he will be limited to a salary of less than $30,000.00/yr so as not to jeopardize his much needed Medicaid coverage. He will never achieve the American Dream of home ownership but then, of course, he will never lose his home to medical bankruptcy, either. Why not let people earn as high a salary as their capabilities allow, paying into the tax base *and* pay a premium, based on their income, into the Medicaid program helping to keep it funded while keeping their lifesaving coverage?

Under the status quo, since access to health care in the U.S. is dependent upon employment status, jobs and health are so tightly intertwined they cannot be separated. It's cheaper for the United States to make sure all of its citizens have access to affordable, quality health care. A citizen able to access care is healthier. Healthy people work and add to the tax base and seek **less or no social service assistance** from the state or federal governments. A healthy working citizen adds to the economic growth of the United States.