Testimony Submitted by Heather Block to the
U.S. House of Representatives Committee on Energy and Commerce,
Subcommittee on Health
for the Hearing on "The Obama Administration's Medicare Drug Experiment: The Patient and Doctor Perspective."
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Good morning and thank you Chairman Pitts, Ranking Member Green, and distinguished Members of the Committee for inviting me to testify today.

I rarely share my cancer story as I find every cancer story is unique to the person and boring or frightening to everyone else. But due to the importance of this hearing, I would like to share my story.

I found a lump in my own breast while managing aid projects for the State Department and the UN in Afghanistan. I was mystified, as no one in my family had ever had cancer. I returned to the US for a diagnostic mammogram and it was negative. So I returned to Afghanistan. My doctor suggested it might be a mastitis infection from an injury. There was a chance I had bruised myself when I fled an attack that May. Running and jumping into a police truck will leave some bruises. I ignored worsening symptoms, as the mammogram had been conclusively negative.

Within three months, I returned again to the US for a second mammogram and it was invasive breast cancer. I continued to work through a mastectomy and six months of chemo, by then managing the monitoring and evaluation of aid projects in Iraq. A year after my oncologist said I was cured, I learned while in Baghdad, that the cancer had returned. It was now in my liver. There was a chance to surgically remove the cancer from my liver, as they saw no other organs compromised. But cancer cropped up in my lungs within days of a pretty brutal liver re-section.

Stage four, no cure. I was reeling with the news and my oncologist told me that 50% of women survive two years and only 20% survive five years. And I would remain in treatment for the remainder of my life. He even told me to start spending my savings, as he knew I was a big saver due to my unstable work environments.

At 4.5 years, I am living beyond most projections. But this isn’t a feel good story. My personal Catch-22 is that while drugs are keeping me alive, I am also going through my savings at an alarming rate. My oncologist jokes that he wouldn’t have told me to spend my savings if he’d known I’d stick around so long. I spend a ridiculous amount of time and energy trying to cut costs and drafting budgets based on living longer with less money and rising drug costs. And trying to figure out how to move closer to my cancer center when I cannot sell my house. It is the only asset that cannot be taken from me if I end up filing for medical bankruptcy.

I was so relieved when I found out that I qualified for Medicare, even though I was well under 65. For those unaware (as I was, pre-cancer), one can qualify for

Medicare after 29 months on Social Security Disability Income (SSDI) if you are unable to work. My drugs are billed through Part B, as most cancer treatment drugs are.

My relief was short lived when I realized that the drugs are exceedingly expensive, and I am always on the hook for the 20 percent co-pay. Medicare pays ~$2000 for my monthly treatment right now. There is no out-of pocket-maximum for Medicare Part B. This means I am responsible for paying 20% of every cancer drug I receive forevermore.

This is why I was pleased to hear about the Demo. The CMS demo proposes to curb the tide of rising drug prices in a 5-year evaluation, not a complete overhaul of Medicare Part B. It is measured and fair, and it’s a way for the government to begin to shift pricing practices incrementally, based on what they learn. By evaluating payment models over a five year period, CMS can determine the best practices without forcing me to change doctors, hospitals or affecting my drug coverage.

We need to assess each model’s ability to lower program expenditures while maintaining the quality of care. How else can Medicare continue to ask me to pay for 20 percent of increasingly expensive prescription drugs without any evaluation of whether my money is being well spent? And who wants to wonder if their doctor is basing their prescribing decisions on how much they’re going to get paid rather than what’s the best course of treatment? I want to know that the drugs that are being used to treat my cancer are the ones that will do the best job and not just make my doctor the most money. Every patient deserves that.

In all of the uproar over this proposal, I have yet to hear anyone say that the current system is working. Where did the payment formula even come from? And why would anyone push to keep a system where prescribing choices could be motivated by money? It seems common sense to remove any possibility of financial incentive and instead create an appropriate handling/storage fee.

I also think it's worth mentioning that my 20% coinsurance is based on whatever Medicare pays. Regardless of whatever rebates or discounts my provider might see, I'm still paying full freight. Why isn't anyone worried about what that means for me, especially if there's any question about whether I'm getting the best drugs for my condition?

I am betting that most patients don’t know that one component to be studied reduces or even waives the 20% co-pay and I am hoping that my zip code is selected for that part of the demo. These proposals simply put new options on the table to evaluate value-based purchasing tools that are already being used in the private sector. As a taxpayer and a patient, this is exactly what I want our government to be doing – getting the best value for our money.

Frankly, we need to start somewhere. The price of drugs is not sustainable. CMS needs to test ways to hold down prescription drug spending. Patients like me shouldn’t have to choose between getting access to life-saving drugs or paying our mortgage. No one should have to fear bankruptcy just as much as cancer.

Finally, I’d like to share America’s little secret, we already have drug rationing. It’s called affordability. Drug innovation is meaningless without affordability.

Thank you for the opportunity to address the Committee today and to support any efforts to stem the rising prices of drugs under Medicare Part B.
I look forward to answering any questions you might have.