

Colleen Brunetti

Good afternoon. Thank you so much for having me here today.

Just over 10.5 years ago, I was diagnosed with a rare, progressive, and incurable lung disease I called pulmonary arterial hypertension.

Simply put, PH is high blood pressure only in the pulmonary arteries of the lungs. This in turn backs up pressure in the heart, causing it to enlarge, and often fail. Medications run many patients in the quarter of a million dollar a year range before insurance and can cost hundreds to thousands of dollars a month in co-pays alone. Survival is thought to be about 50/50 at seven years.

I'm very grateful Connecticut has invested in this task force. I'm proud to live in a state that takes pro-active measures to do things like protect essential health benefits and insist that insurance companies pay for prosthetics for amputees.

Today, I'm turning my attention to how I hope we can continue to be a proactive state that protects our most vulnerable residents in the health care arena.

Since diagnosis, I have not gone a day when I feel secure in my health status knowing, and seeing every day in my community, that the nature of this disease is that things can turn quickly for the worst with little warning.

After 10 years of living in uncertainty, I know that not only is each day a gift, but that fighting my disease is just simply HARD ENOUGH. What should not also be hard is the struggle too many rare disease patients face in simply accessing the care they need.

I'd like to bring to your attention three areas of concern.

First, the difficulty in paying for high premiums and life sustaining medications. There is a loophole in the ACA that has in fact made that harder.

In short, when CMS issued guidelines for acceptable payment arrangements for high cost medications, they failed to specifically state a majority non-profits could be a source of assistance. As a result, health insurance companies pounced on that as an opportunity to deny coverage to patients by rejecting the premium and cost-sharing assistance that might otherwise come from those charities, and that patients could not otherwise afford.

This undermines the safety net the ACA set up for patients with costly pre-existing conditions, and it is happening in 42 states, including CT.

There is promising activity at the federal level to close this loophole. However, the current political environment being what it is, I for one am not comfortable just waiting for the Federal government to make a fix. I would like to see Connecticut pro-active in protecting patient's rights to pay for their medications in any way possible – including by using charitable assistance funds, and without penalty.

2) Co-Pay Accumulators: A number of health plans have started implementing copay accumulator programs.' These programs prevent manufacturer-provided copay cards from applying to patients' out-of-pocket costs, including their deductible.

My high deductible plan requires \$6,650 out of pocket max for my expenses alone. We anticipate it will increase next year. If I cannot use my \$6,000 co-pay card towards a \$7,120 a month medication, or that co-pay card is accepted but not applied towards my high deductible as it used to be, I am in dire financial straights. It is my understanding that the impact of co-pay accumulators is a distinct possibility for me.

It's not unusual for an insurance company to test programs like this in a few markets and then, if successful, spread it further. The time to push back is now, before people begin to be deeply impacted.

3) Oxygen delivery and service. I have not been allotted enough time to get into what an absolute nightmare dealing with the larger oxygen companies has been. What I can tell you is that when I posted my frustrations on social media, I was flooded with story after story of patient struggles.

There are major national companies who do business in our state, and frankly, they often do it badly. CMS is current re-evaluating their own guidelines for oxygen service. I believe Connecticut once again has the opportunity to get ahead of the curve and mandate best practices and an acceptable level of care and service for the providers of this life sustaining equipment.

Once again, I want to thank you for your time and attention today. I'm really grateful to live in a state that is taking pro-active steps to listen to and address the needs of rare disease patients like me.

I look forward to continuing the conversation.