Testimony – NY Health Act – Public Hearing, Kingston, NY
11/25/19

My name is Madeline Hunter and I am a resident of Ossining. I would like to thank you for the opportunity to share my particular story in support of the NY Health Act. I am 71 years old, retired and am insured through traditional Medicare, a Part D drug plan and a Supplemental plan. For the past 18 years, I have also been living with an incurable, but treatable blood cancer called Multiple Myeloma. I am here because of the financial and emotional impact this illness has had on me and the thousands of patients like me who I know, coach, support and encourage.

If I am really lucky, my treatments will give me many more years to come. The bad news is that this ride is a very expensive proposition for me. During my most recent course of treatment, I have been taking a drug called Revlimid. This drug is manufactured and distributed by Celgene. Although Revlimid has kept me in remission for the past 6 years, the out-of-pocket cost has been stunningly high and increasing every year. In 2007 when the drug was first introduced the average US co-pay was about $115 per month. The average co-pay now is over $800 per month.

Until 2018, Celgene typically raised Revlimid prices at least twice each year. In 2018, this practice was again in the news as a campaign issue for the former Celgene CEO, Bob Hugin, when he ran for the US Senate in NJ. The company then stated it would only raise prices once annually and be guided in these increases by the annual percentage growth of medical spending in the US. For the year 2018, my co-pays increased 8% at the same time as the average growth rate of medical spending was 5.5%. It is clear that Celgene lied. Since medical spending continues to increase in the US, the ceiling for Revlimid's price has not been reached.

Additionally, the company has exploited loopholes in our system to delay the entry of others into the generic market. In fact, in July of 2019, Celgene Corporation agreed to pay $55 million to settle a class action lawsuit over its efforts to block generic competition in order to repeatedly raise prices on my medication. Since this is merely just a slap on the wrist, it does not change the reality that a more affordable version of Revlimid is unlikely to make it to market before 20206. I must add that since the average myeloma patient is on Medicare and we all know that Medicare cannot negotiate drug prices with companies like Celgene, this unchecked greed continues. This exploitation of patients has caused me, my family and thousands of other patients undue stress beyond what is caused by our diagnosis alone.

(This paragraph will not be part of verbal testimony) Representatives from the pharmaceutical industry have told me on many occasions that patients need not be alarmed by the cost of drugs for myeloma. They reiterate that any patient in need can get access to these life-saving drugs through foundations for co-pay assistance that are set up to defray the high costs of co-pays. Celgene, as one example of this working in practice, makes charitable donations to these foundations, and anyone who meets the income requirements would be eligible for assistance from them. There are numerous problems with this system of patient support. Firstly, the funding for these foundations is used up periodically throughout a year. I know far too many people who were left without co-pay assistance during 2019 when, for example, the Leukemia and Lymphoma Financial Assistance fund closed suddenly due to lack of donations from their pharma donors. A second problem is that while in the short run the patient may be thrilled to get financial help, Medicare must still pick up the remaining cost of the drug that has been dictated to them by Celgene. This amounts to many thousands of dollars each month for each patient. We taxpayers pay this remaining money! This is untenable!

Beyond the financial stress of managing my myeloma, I have also had to make some life decisions that are directly related to being chronically ill. The year after I met my sweetheart, Ames, I was diagnosed with myeloma. He is one of those truly remarkable people who turned into our relationship rather than fleeing. We have built a wonderful life together, but we are not married. And the reason we are not married is because of myeloma. Given my uncertain medical expenses and the high possibility of needing very expensive in-home nursing or nursing home care at the end of my journey with myeloma, we choose to stay unmarried as one way to protect some of our assets. This was a very difficult decision for me to make since it had solely a financial rationale.

Since being diagnosed with myeloma, I have turned my life towards helping others with this disease. I lead the second-largest patient and family support group in the US for myeloma. I see people in pain, challenged by their day-to-day lives with an illness that has an uncertain path; challenges that are only made worse by the confusing and costly healthcare system. As people fight cancer, they want to spend time with their loved ones, doing what matters most. Not navigating the byzantine labyrinth of private health insurance policies.

As legislators, you have such a unique opportunity now within our country to stand for a change that is positive and unifying for the residents of NY. Please pass this bill and solidify our state as one that stands for the moral high road in truly caring for all who live here.

Submitted by Madeline Hunter

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