

Personal Testimony – Public Hearing of the NY Health Act – May 28, 2019

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 70 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 a blood cancer that is 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.

Myeloma is not yet a curable cancer but there are treatments available to help manage the disease. My journey with Myeloma has included a stem cell transplant and several different drug protocols which have been used during a series of remissions followed by eventual relapses. This roller coaster ride is how it goes living with Myeloma.

The good news is that if I am really lucky, I will be on this roller coaster ride for 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. It is a relative of Thalidomide which has been around since the 1950's. Although Revlimid has kept me in remission for the past 5 years, the out-of-pocket cost to me has been stunningly high and increasing every year. In 2007 when the drug was first introduced the average co-pay was about \$115 per month. The average co-pay now is over \$800 per month. This represents an 18% increase on average every year for 12 years. Adding the co-pays, insurance premiums, and my other related medical costs, my total out-of-pocket costs for the past 5 years have ranged from \$15,000 to \$20,000. And these increases are not over!

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. My co-pays increased 8% from December of 2018 to February of 2019 at the same time as the average growth rate of medical spending was 5.5%. It is clear that Celgene lied. It is not coincidental that this deception happened at exactly the same time as it was announced that BMS would acquire Celgene. Since medical spending continues to increase in the US, the ceiling for Revlimid's price has not been reached. It seems that BMS/Celgene is left unchecked to set prices in any way it likes. Additionally, the company has exploited loopholes in our system to delay the entry of others into the generic market. A generic, more affordable version of Revlimid may not make it to market until 2026. 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, the travesty continues. This is a travesty and has caused me, my family and thousands of other patients undue stress beyond what is caused by our diagnosis alone.

Representatives from the pharmaceutical industry have told me on many occasions that patients need not have cause for alarm 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 whose income 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 2018 when, for example, the Leukemia and Lymphoma Financial Assistance fund closed suddenly due to lack of donations from their pharma donors. A second problem shows up when one considers patients on Medicare who receive a grant from one of these co-pay assistance foundations. In the short run the patient may be thrilled to get the help, but 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 from it. 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. We've all heard of marrying for money, but I never thought I'd be the one who doesn't marry because of money! With the addition of long-term care in the revised version of the NY Health Act, I might just become one of the oldest brides in Westchester County!!!

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. 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.

Madeline Hunter

