

Connecticut General Assembly – Insurance and Real Estate Committee  
Public Hearing – March 6, 2018

Testimony of Laura Hoch,  
Manager of Advocacy, National Multiple Sclerosis Society

Senator Larson, Senator Kelly, Representative Scanlon, Representative Sampson and Members of the Insurance and Real Estate Committee, thank you for the opportunity to provide testimony on House Bill 5384, An Act Concerning Prescription Drug Costs, and how the cost of prescription medication affects those who live with multiple sclerosis (MS) and their families.

The National Multiple Sclerosis Society's vision is a world free of MS. We believe that people affected by MS can live their best lives when work together to stop MS in its tracks, restore what has been lost and end MS forever.

Multiple sclerosis is an unpredictable, often disabling disease of the central nervous system that disrupts the flow of information within the brain, and between the brain and body. Symptoms range from numbness and tingling to blindness and paralysis. The progress, severity and specific symptoms of MS in any one person cannot yet be predicted, but advances in research and treatment are leading to better understanding and moving us closer to a world free of MS. When someone is diagnosed with MS, their clinician will typically prescribe a medication referred to as a disease-modifying therapy (DMT). DMT is used to modify the disease course, treat relapses, and manage symptoms. Growing evidence indicates that early and ongoing treatment with DMTs is the best way to prevent the accumulation of disability and protect the brain from permanent damage due to MS.

People living with MS face many barriers to their care. High and rapidly escalating medication prices, confusing and inconsistent formularies coupled with a complex approval process can prohibit patients getting the treatment that they need.

The cost of MS DMTs continues to rise at an alarming rate. Nearly one-third of branded medications increased 20% in price in 2015. In 2004, the average wholesale price of available MS disease-modifying therapies was approximately \$16,000. Last year, the average price was \$83,688. Despite more than a dozen DMTs (including three generic options), competition has not driven down prescription drug prices. Nearly three-quarters of MS DMTs average more than one price increase per year and DMT prices in the United States are two to three times higher than in comparable countries. Increasing challenges such as some people being required to pay a co-insurance instead of a copayment for their medication can be debilitating. Some people can face co-insurance payments up to 40%.

The US National Expenditure Growth Rate for prescription drugs is 5.4% in a calendar year and this is the benchmark we should be measuring against nation-wide. 25% in a calendar year, as is suggested in this bill, is too high and in contradiction to national trends. When we look at MS

DMTs, 25% can be devastating. If a drug costs \$65,000, a 25% increase would set the price at over \$80,000, a figure that can have crippling effects on an individual's financial well-being. The National MS Society would recommend a significantly lower figure when discussing written complaints to the Insurance Commissioner regarding wholesale acquisition cost increases.

Additionally, this bill lays out a plan for the Office of Health Strategy to "prepare a list of not more than ten prescription drugs that the office... determines are (i) provided at substantial cost to the state... or (ii) critical to public health." Similar legislation in other states has capped this figure at 20-25 medications, and for good reason. 9 of the top 25 prescription drugs in cost are related to the treatment of MS symptoms. In order to have transparency and understanding of the rising cost of prescription medications, we must have more information. We would therefore recommend increasing the cap to at least the top 20 medications.

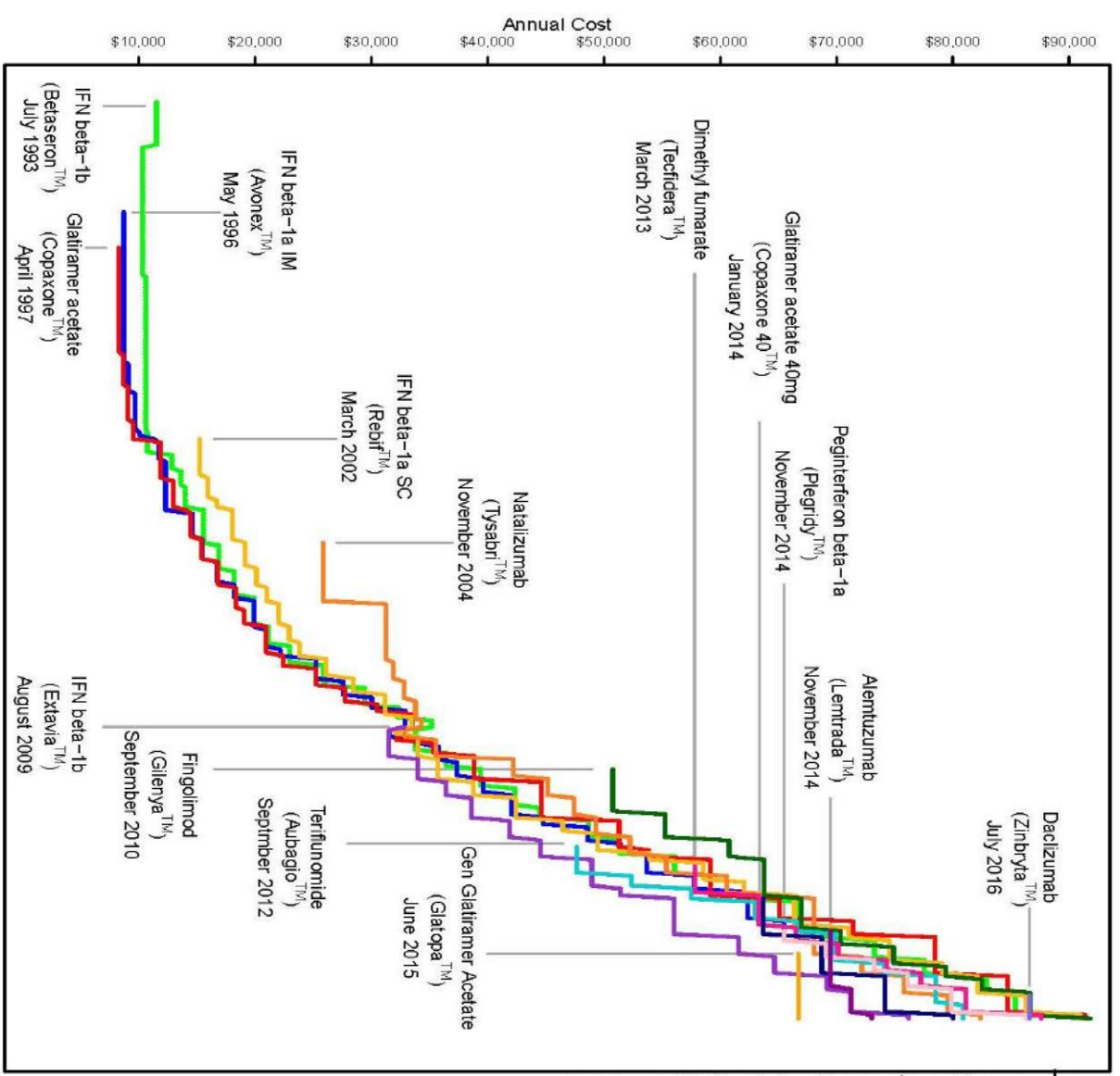
The National Multiple Sclerosis Society recently conducted a constituent survey of more than 8,500 people and the results were alarming. Nearly 40% reported that they had some or great difficulty paying for their medication. 40% of respondents get assistance from a patient assistance program and more than half of this group reported difficulty in paying. About 16% of respondents had to put their medication charges on a credit card because of a lack of funds and others have had to postpone retirement in favor of the additional income needed to afford the rising price of prescription drugs. Throughout the survey, respondents noted that cost continued to be a major concern and that managing the logistics of payment and treatment takes a substantial amount of time. One respondent even stated that they were forced to have medications prescribed based on what they can afford rather than what is actually best for treating the course of their disease.

Without transparency in drug pricing, individuals living with MS – and individuals living with any chronic health condition in general – face financial hardship as a result of treating their disease. No one should be forced to choose between medication that will improve their quality of life and retirement. No one should be forced to make the choice between life-saving medications and financial security. And no one should be forced to choose between medication that is affordable and medication that is right for them.

We appreciate any legislation that is transparent and makes medication affordable. As studies have shown, early intervention in treating the symptoms of diseases like MS makes all the difference in quality of life. While this bill aims to make positive changes to existing law, we feel it may have unintended consequences. When reporting processes are not transparent, it is much more difficult to drive good public policy. With some modifications, it can become much stronger. The National MS Society is happy to work with this committee to address these issues and ensure a strong bill that protect its residents, including those living with MS.

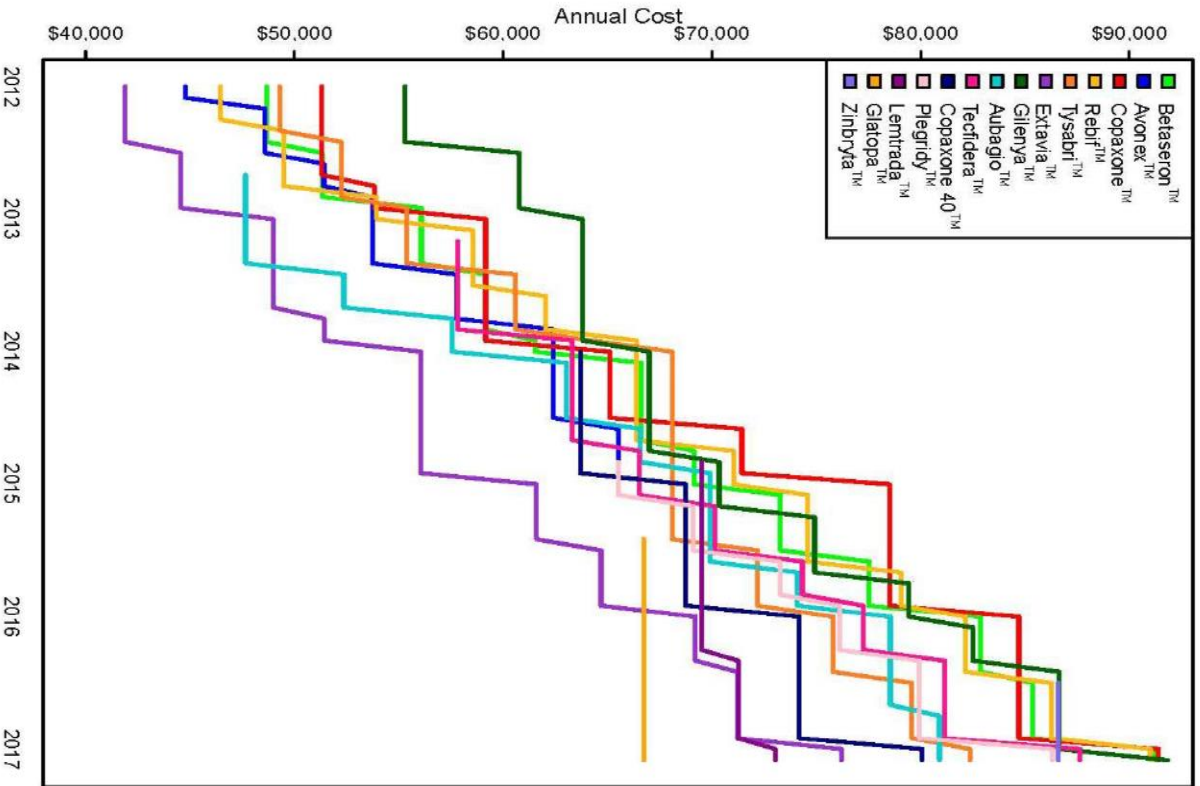
Please contact me if I can be of further assistance: [laura.hoch@nmss.org](mailto:laura.hoch@nmss.org) or (860) 913-2550 X52521.

## Trends in Annual Disease Modifying Therapy Costs 1993-2017



Drug	Approval Cost	Current Cost
Betaseron™	\$11,532	\$91,261
Avonex™	\$8,723	\$86,308
Copaxone™	\$6,292	\$91,401
Rebif™	\$15,262	\$91,005
Tysabri™	\$25,850	\$82,368
Extavia™	\$32,826	\$76,201
Gilenya™	\$50,775	\$91,836
Aubagio™	\$47,651	\$80,902
Tecfidera™	\$57,816	\$67,623
Copaxone 40™	\$63,715	\$80,062
Plegridy™	\$65,510	\$86,308
Lentrada™	\$69,520	\$73,039
Glatopa™	\$66,731	\$66,731
Zinbrya™	\$66,592	\$66,592

## Trends in Annual Disease Modifying Therapy Costs 2012–2017



Drug	2017 Cost*	2012 Cost**	Mean Annual % Increase in Cost	Mean Number of Increases per Year	Mean % Change per Increase
Betaseron™	\$91,261	\$48,676	13.4%	2.2	5.9%
Avonex™	\$86,308	\$44,781	14%	2.2	6.2%
Copaxone™	\$91,401	\$51,315	12.2%	1.4	8.6%
Rebif™	\$91,005	\$46,464	14.4%	2.2	6.3%
Tysabri™	\$82,366	\$49,294	10.8%	1.8	5.9%
Extavia™	\$76,201	\$41,883	12.7%	1.8	6.9%
Gilenya™	\$91,836	\$55,295	9.4%	1.6	5.8%
Aubagio™	\$80,902	\$47,651†	14.2%	1.6	6.8%
Tecfidera™	\$87,623	\$57,816†	11.4%	1.8	6.1%
Copaxone 40™	\$80,062	\$63,715†	7.9%	1	7.9%
Plegridy™	\$86,308	\$65,510†	9.6%	1.7	5.7%
Lemtrada™	\$73,039	\$69,520†	1.7%	0.7	2.5%
Glatopa™	\$66,731	\$66,731†	0%	0	0%
Zinbrya™	\$86,592	\$86,592†	0%	0	0%

\*February 2017

\*\*January 2012

†Market entry cost if approved after 2012

Methodology adapted from Hartung et al.<sup>1</sup> We estimated acquisition costs using average wholesale price (AWP) published by First Databank. AWP reporting was phased out in 2011 and acquisition costs were then estimated using wholesale acquisition cost (WAC) with the conversion AWP = 1.2 \* WAC. We applied a 12% discount to AWP, the median discount that state Medicaid programs reimburse pharmacies, to estimate the amount paid to pharmacies by third-party payers. Package insert for Lemtrada™ states initial dose is five consecutive daily infusions with three consecutive daily infusions in subsequent year. We estimate the annual cost for Lemtrada™ based on the use of four visits.

1. Hartung DM, Bourrette DN, Ahmed SM, Whitlam RH. The cost of multiple sclerosis drugs in the US and the pharmaceutical industry: Too big to fail? *Neurology*. 2015;84(21):2186–2192.