



National  
Multiple Sclerosis  
Society

Connecticut General Assembly  
Public Health Committee  
Legislative Office Building, Room 3000  
Hartford, CT 06106-1591

CC:

Senator Terry Gerratana, Co-Chair  
Legislative Office Building, Room 3002  
Hartford, CT 06106

Senator Heather Somers, Co-Chair  
Legislative Office Building, Room 3400  
Hartford, CT 06106

Representative Jonathan Steinberg, Co-Chair  
Legislative Office Building, Room 3004  
Hartford, CT 06106

Senator Ted Kennedy, Jr., Vice-Chair  
Legislative Office Building, Room 3200  
Hartford, CT 06106

Senator George Logan, Co-Chair  
Legislative Office Building, Room 3400  
Hartford, CT 06106

Rep. Prasad Srinivasan, Ranking Member  
Legislative Office Building, Room 3003  
Hartford, CT 06106

Representative Kelly Luxenberg, Vice-Chair  
Legislative Office Building, Room 4028  
Hartford, CT 06106

Re: Committee Hearing on S.B. No. 445

Multiple sclerosis (MS)—an unpredictable, often disabling disease of the central nervous system—interrupts the flow of information within the brain, and between the brain and body. In people with MS, myelin is damaged or destroyed in multiple areas, disrupting the ability of nerves to conduct electrical impulses to and from the brain and producing a variety of symptoms ranging from numbness and pain to spasticity and paralysis.

MS medications have transformed the treatment of relapsing MS over the last 20 years. Yet, many people living with MS cannot access the medications they need. Continually escalating prices are creating significant barriers to treatment, including higher costs, increased stress, and a greater burden for those who already live with a chronic, life-altering condition.

Studies show that early and ongoing treatment with a disease-modifying therapy is the best way to modify the course of the disease, prevent the accumulation of disability and protect the brain from damage due to MS. So why are these life-changing medications too often out of reach for those who need them? Please refer to the graph included at the end of this document, which illustrates how dramatically each MS medication has escalated in price following market introduction.

Over the past year, the National MS Society convened a group of diverse stakeholders to fully study the cost of MS medications and to develop policy options to improve the ability of people living

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with MS to access their medications. We applaud the Connecticut General Assembly for taking up this issue, and we offer the following thoughts as you continue to develop the language of S.B. No. 445.

There is increased pressure on all health care consumers to make good choices. Yet, people have very little information about price and cost to make these decisions. Just the term “price” can mean several different things. The prices charged for MS medications, the actual cost paid for them, and the impacting decisions between a manufacturer price and a negotiated contract with an insurer or pharmacy benefit manager, are outside of the public realm. People with MS need more information to make informed choices. We hope that, accompanied by additional reforms, increased transparency around pharmaceutical prices will lead to healthier competition in the marketplace, a reduction in the number of aggressive drug price increases, and well-informed consumers able to make wise economic decisions about their healthcare consumption.

In the healthcare marketplace, transparency can take a number of forms. Furthermore, the type of transparency needed will differ based on the type of entity that will be required to provide it.

As applied to manufacturers, the National MS Society favors the following reforms:

- Requiring transparency related to how prices are set;
- Requiring transparency related to how price increases are determined, including the frequency of such increases;
- Requiring transparency related to how prices and price increases support research and development, direct-to-consumer advertising, and marketing to healthcare providers; and
- Requiring transparency related to the number of people assisted and the amount of money spent on patient assistance programs.

As applied to insurers and pharmacy benefit managers, the National MS Society favors the following reforms:

- Requiring transparency related to formulary coverage, including the amount of patient cost-sharing required for all products and services offered;
- Requiring a significant notification period in advance of any changes in coverage in a single year and between plan years; and
- Requiring transparency related to the factors used when determining the design of a plan’s formulary.

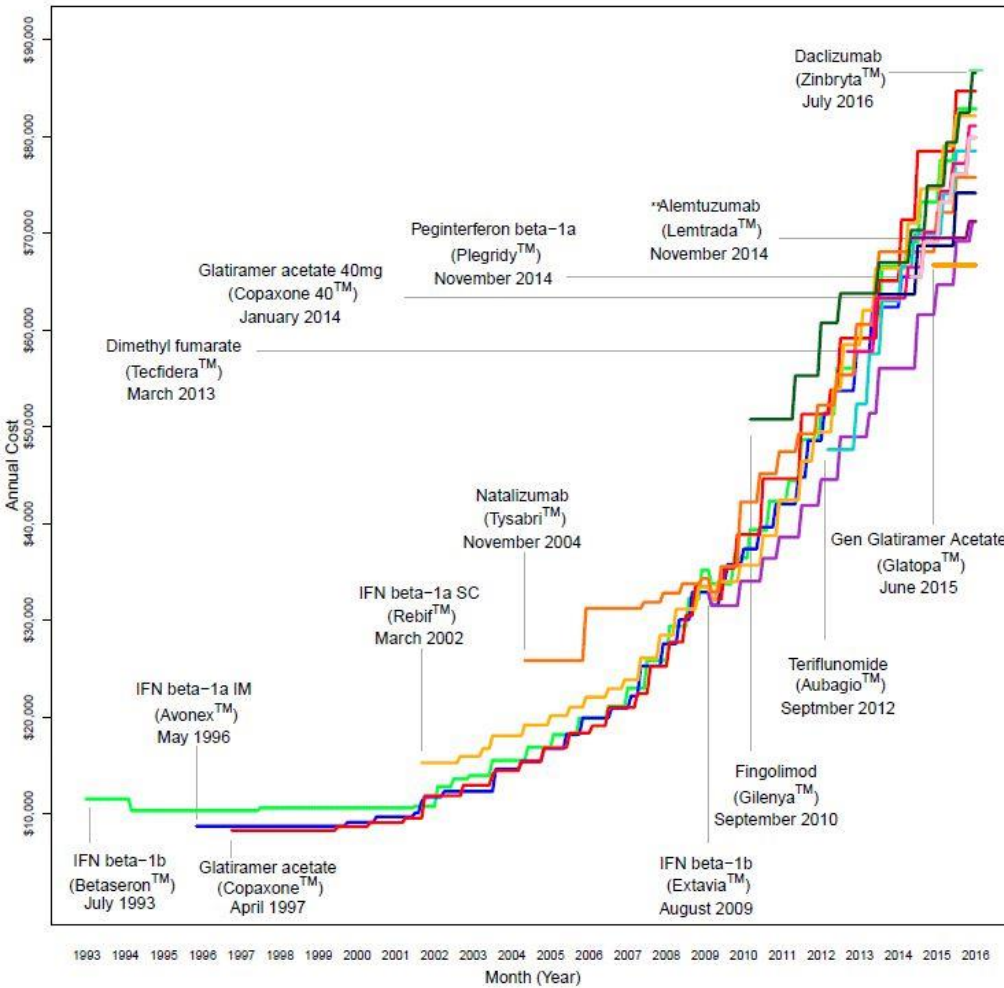
We hope to see some of these concepts incorporated into S.B. No. 445, and we look forward to working with you to develop language that will provide much-needed transparency to consumers and competitors in the healthcare marketplace.

Thank you for your time.

Should you have further questions or comments, you can contact Michelle Dickson, Senior Director of Advocacy for the Northeast, at [michelle.dickson@nmss.org](mailto:michelle.dickson@nmss.org).



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Drug	Cost at Approval	Current Cost
Betaseron™	\$11,532	\$82,884
Avonex™	\$8,723	\$79,911
Copaxone™	\$8,292	\$84,707
Rebif™	\$15,262	\$82,153
Tysabri™	\$25,850	\$75,792
Extavia™	\$32,826	\$71,216
Gilenya™	\$50,775	\$86,637
Aubagio™	\$47,651	\$78,546
Tecfidera™	\$57,816	\$81,135
Copaxone 40™	\$63,715	\$74,186
Plegridy™	\$65,510	\$79,911
Lemtrada™	\$69,520	\$71,258
Glatopa™	\$66,731	\$66,731
Zinbryta™	\$86,592	\$86,592

\$ = Average Wholesale Price at Market Entry

\*\*Price is based on average of year 1 and year 2 doses

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