



**National  
Multiple Sclerosis  
Society**

# Access to MS Medications

**Request:** Hold a hearing focused on the patient perspective on access to MS medications

## What is multiple sclerosis (MS)?

- MS is an unpredictable, often disabling disease of the central nervous system.
- MS interrupts 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.

## MS disease-modifying therapies

- A growing body of evidence indicates that early and ongoing treatment with a disease-modifying therapy (DMT) 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.
- Despite 13 disease-modifying therapies available to treat relapsing forms of MS, including one generic, competition has not driven down price.
- All MS DMTs cost approximately \$60,000-\$75,000 per year and the prices continue to rise every year.

## Access to Medications

- It is time to hear the patient voice. Congressional hearings have focused on a few specific topics: Generic drug process, new hepatitis C medication(s) and companies that buy older, existing drugs and raise prices but have not told the story from the patient perspective.
- Both innovation and affordable access are critical to ensure people receive the medication and treatments they need.
- Between 2004 and 2015, the average price of MS disease-modifying therapies (DMT) increased 300%. In 1993, the first medication cost \$11,500 per year—today it is more than \$70,000.
- DMT prices in the United States are 2 to 3 times higher than in comparable countries.
- The MS medications are all considered specialty medications, a category associated with insurance restrictions like prior authorization, step therapy, formulary tiers and co-insurance.
- In 2013, 67% of employer-sponsored plans reported use of step therapy policies - an increase from just 27% in 2005.
- Co-insurance for MS medications can be as high as 40%.
- The trend of increased out-of-pocket costs across all types of health insurance severely impacts people with MS who need an expensive medication every month for decades.
- People with MS who are new to treatment have a higher than average rate of stopping treatment; this is directly correlated to un-affordable out-of-pocket costs.
- Valuable patient care time is spent on managing insurance denials and other insurance issues; healthcare providers estimate office staff spends 20-30 hours per month addressing issues related to insurance coverage for MS medications.



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### **Impact on People Living with MS**

Nearly 39% of respondents (n=8700) to a recent survey of people with MS by the National MS Society reported that it is “very” or “somewhat difficult” to afford their MS medication.

Here are just some of the perspectives and experiences that people living with MS shared:

“Because my DMT cost continues to rise (tripled since I started medication over 10 years ago) my co-pay has more than doubled. I am concerned if my portion increases anymore I won’t be able to afford it.” Kathleen, IN

“I’ve been uninsured before and went off DMT due to cost—and my MS relapsed including six months of blindness. I fear risking that again.” Christine, NC

“I’ve gone without eating sometimes an entire day simply because I had only enough money to pay for my medication and housing/utility bills.” Kathleen, TN

“Because I’m now on Medicare, I am no longer able to use the drug co-pay assistance program from the pharmaceutical company. As a result, my new copay for my MS drug therapy is \$2900 a month. I don’t qualify for any other assistance programs because my income is too high. It isn’t high enough, however, to pay the copay amount of \$2900 a month.” Michelle, IA

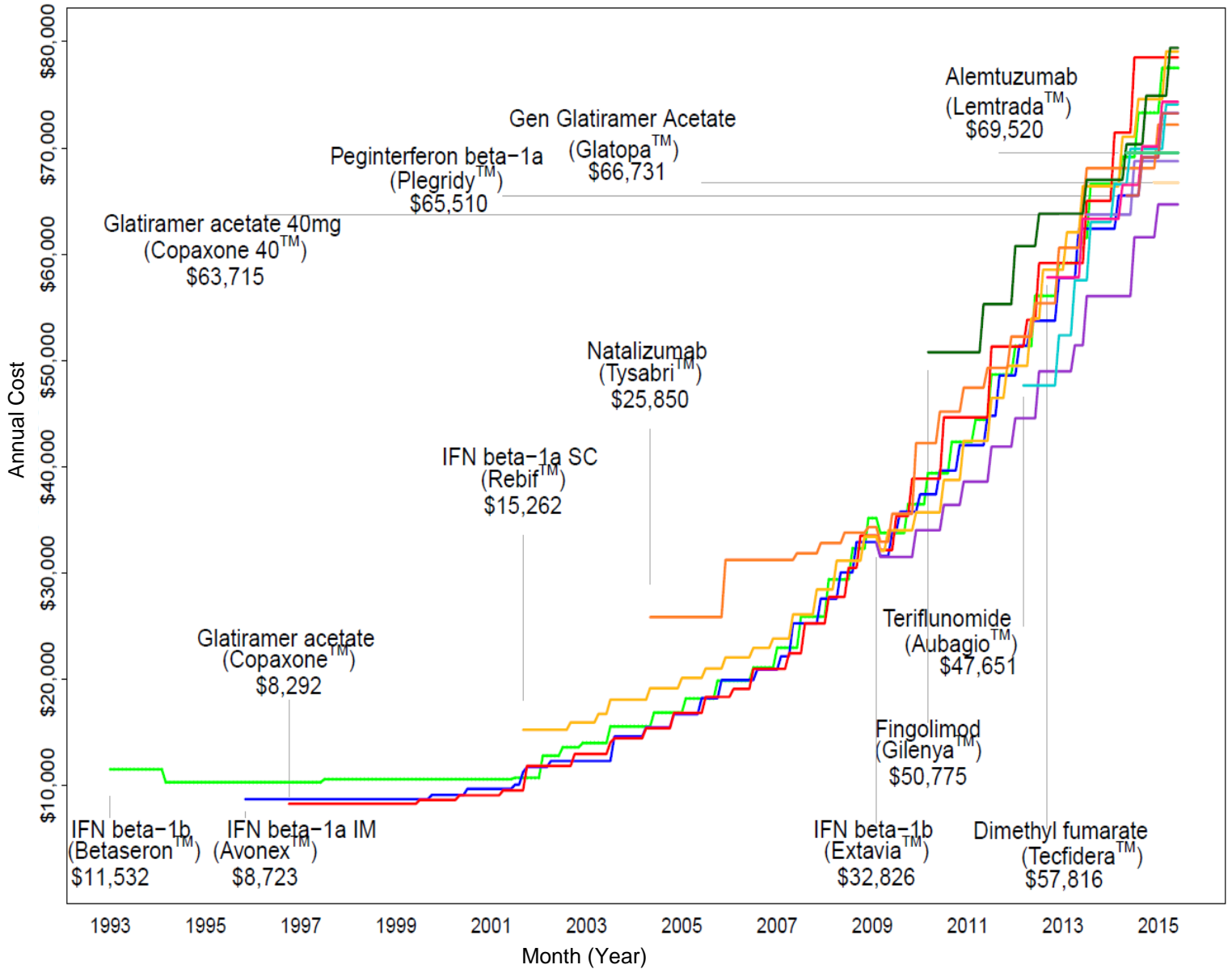
“Cost is my biggest challenge. Assistance programs do not help forever. I skip taking my 2<sup>nd</sup> pill of the day to cut back on costs.” Carol, CA

“I’m battling with insurance right now to get approval for the drug my doctor and I agreed upon. Currently in the appeals process as it falls on the non-preferred list, and therefore, is not authorized. Yet another delay in getting a treatment plan in place. Frustrated!” Mary, NY



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### MS Disease-Modifying Therapies



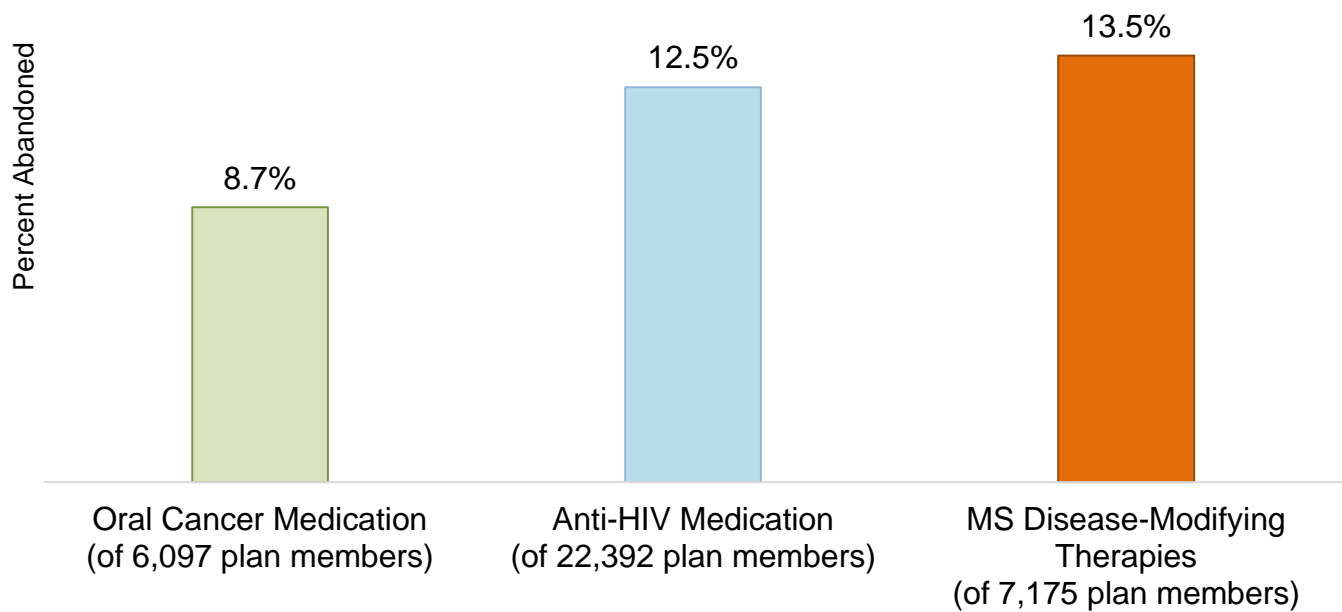
\$= Average wholesale price at market entry

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## People New to Treatment who Stopped Taking a New Specialty Drug



- Prescription abandonment was highest for MS disease-modifying therapies and lowest for oral cancer medications.
- There is a direct correlation between out-of-pocket costs and stopping treatment.
- Along with increased rates of stopping treatment, the majority of patients do not substitute their treatment with another drug in the same class.

Note: Abandonment rates are based on an Avalere retrospective analysis of pharmacy claims for commercially insured plan members who attempted to fill or filled at least one prescription for an oral oncolytic, anti-HIV agent or MS DMT anytime between January 1, 2013, and June 30, 2014 utilizing the IMS FIA database. Unit of analysis is the plan member.