

September 2020 Newsletter



The Rising Cost of MS Treatments

Disease-modifying therapies (DMTs) are treatments that can reduce the activity and progression of MS. They have been shown to reduce the frequency and severity of MS relapses. Unfortunately, continually escalating prices have created a significant barrier to obtaining these important medications for many individuals with MS.

Having an unpredictable progressive disease like MS is stressful on its own. For those living with the disease, the impact of cost on access to treatments only adds to an already taxing situation.



According to [researchers](#) at UCLA, MS is the second most expensive chronic condition (behind congestive heart failure) in terms of medical costs. In 2010, the total lifetime cost per patient with MS was estimated to be \$4.1 million. The high cost of DMTs contribute significantly to the total cost of care and the economic burden of this disease. A [2015 study](#) concluded [first-generation DMTs](#), originally costing \$8,000 to \$11,000, now cost about \$60,000 per year. Prices for these medications have increased annually at rates five to seven times higher than prescription drug inflation. They have also accelerated at rates well beyond inflation and substantially above rates observed for drugs in a similar biologic class. In addition, costs in the United States currently are two to three times higher than in

other comparable countries. Instead of driving down prices, competition has fueled the reverse. Newer DMTs have typically been introduced with a cost 25 to 60 percent higher than existing DMTs and the cost of existing DMTs has risen to meet them. A [recent study](#) suggests the cost of DMTs has increased even with the introduction of [generic drugs](#). For example, when [Glatopa](#) (the generic version of Copaxone) was introduced in 2015 the cost of the name brand drug increased by \$441 per prescription.



Last summer the National MS Society surveyed nearly 600 people with MS currently taking DMTs, then interviewed 15 of them in-depth to gain a more comprehensive understanding of their perspectives. Survey [results](#) shed light on the effects of the exorbitant cost of these drugs on people with MS.

Approximately 45 percent of respondents reported not paying anything out-of-pocket (OOP) for their DMT. The price for those who did pay was up to \$20,000 a year, with an average cost of about \$2,300. This is with 71 percent receiving financial assistance, mostly from pharmaceutical companies. The majority of participants indicated that without financial assistance the OOP cost would be a significant financial burden. One third of survey respondents indicated their OOP cost had increased over the past few years. It's important to note that the expenses associated with DMTs is only one piece of the financial picture for people living with MS. Copays for other medications, treatments and diagnostic tests, high health insurance premiums and deductibles, and lost income can also cause significant financial challenges.

Survey results suggest half of people living with MS are concerned about being able to afford their DMT over the next few years and 40 percent have altered their use of DMT because of rising prices. Only 11 percent said they could afford the medication without financial assistance. Many are going without or altering their treatment. For example, 12 percent of respondents reported stopping their medication for a time due to cost, 9 percent skipped or delayed filling a prescription and 8 percent have taken less than prescribed to stretch their drugs to last longer (to name a few). One third of respondents found the process of obtaining financial assistance to be taxing. They reported having to deal with such problems as excessive amounts of paperwork, countless hours on phone advocating for themselves or administrative delays in getting approval for treatment. Half had to go through the same stressful process to reapply/renew every year. Funding



sources are often exhausted quickly, leaving the very real possibility that these efforts might be in vain.

The NMSS survey suggests paying for DMT also affects quality of life for those living with MS. For instance, participants indicated it impacts their ability to save for college for their children or retirement for themselves and some must resort to paying these costs by using credit cards. When it comes to paying other bills, 9 percent had to put off paying some of them and 11 percent had to cut corners on groceries. A quarter said they spend less on themselves because of the money their medications cost their family, and 21 percent have cut back on entertainment or dining out.



[iConquerMS](#) is a key resource that has been used to understand the perspective of people with MS in this evolving situation. A [recent study](#) surveyed 1,200 network members about their preferences and willingness to pay (WTP) for DMTs. The majority of participants had relapsing-remitting MS. WTP was defined as the maximum amount of money subjects were willing to spend from their OOP money, based on various DMT attributes (relapse rate, disability progression, severe adverse events, route of administration, frequency of administration, and OOP cost). The WTP for DMTs varied widely. There was a strong preference for having DMTs over foregoing therapy. Participants preferred DMTs with lower relapse rate, disability progression, severe adverse event, frequency of administration, and cost. In addition, they preferred oral DMTs. The next preference was intravenous DMTs, followed by subcutaneous and intramuscular DMTs. Data showed participants were willing to pay for the attributes of their DMTs, specifically \$2,768 for every one-time decrease in the number of relapses in two years, \$289 for every one percent decrease in disability progression in two years, \$292 for every one percent decrease in severe adverse events, and \$76 a month for every one-time decrease in the frequency of administration per month. Interestingly, iConquerMS members were willing to pay between \$7,020 and \$134,934 per year for all DMTs, except [interferon beta-1a SC](#) (Rebif). This exception was due to Rebif's relatively high relapse rate and disability progression compared to other DMTs. Respondents also did not like having to administer Rebif three times per week via subcutaneous injection.

Although MS DMTs have been shown to be very effective in slowing the progression of the disease and managing its symptoms, the costs of these agents is problematic. The improved efficacy and safety profiles of newer treatments may provide an invaluable benefit to people with MS, however there is evidence that their high price tag is driving up the cost of older DMTs. The introduction of generics into the market has not offered those living with MS lower priced options. These escalating prices are creating barriers to people with MS getting these important medications and affecting their quality of life.

Change is needed to make these treatments affordable and accessible so people living with MS no longer have to make financial and personal sacrifices in order to obtain their medications. In the meantime, please [read on](#) for more information on financial assistance programs that may help.

