



National
Multiple Sclerosis
Society

People with MS want Congress to act now to lower prescription drug costs

85% of people with MS said the federal government should do more to control the high cost of MS disease-modifying treatments (DMTs).

- In a Society survey, more than half of respondents said they are very concerned about how they will afford their medications in the future.
- 40% have altered the use of their DMTs due to cost, with some skipping or delaying treatment.
- 40% experience stress or other emotional impact due to high out-of-pocket costs and are making lifestyle sacrifices to be able to pay for their DMT.
- More than 70% of people with MS have received financial assistance for their DMT and the vast majority say the financial burden of their DMT would be great without assistance.

The Society supports legislative proposals to lower prescription drug costs that:

- Address the high prices of MS medications;
- Lower out of pocket costs for people with MS;
- Improve transparency throughout the pharmaceutical supply chain;
- Require justification for significant price increases for products already on the market;
- Allow Medicare to negotiate prices for beneficiaries;
- Increase availability of and access to generic medications and biosimilars;
- Support true innovation in the development of new therapies and a cure for MS.

Innovation and Addressing Prices Can Coexist.

- Innovation transforms scientific discoveries into life-changing “best-in-class” treatments.
- Many product approvals are now “me-too” products.
 - These products simply build on previous products, do not benefit from scientific innovation nor do they demonstrate meaningful benefits for patients.
 - They may contain slight changes in the profiles of side effects or dosing of a medication.
- There may be a place for marginally improved products to provide additional options for patients, but they must be **priced appropriately** and not as “first-in-class” innovation.

What is multiple sclerosis (MS)?

- MS is an unpredictable, often disabling disease of the central nervous system.
- The progress, severity and specific symptoms of MS in any one person cannot yet be predicted.
- Nearly 1 million people in the United States live with MS.

Make MS Medications More Affordable

Jim Haslam, California

Jim Haslam spent most of his early adult years free of any major medical concerns. So in 2007, when he felt like he was “losing control” of his own body, it came as a complete shock.

“I knew there was something wrong,” Jim said. He immediately scheduled a doctor’s appointment and underwent several rounds of testing.

“It was a long, drawn out process. Working full time, having to take time off of work, it just became very stressful,” Jim recalled.

Within nine months, Jim was diagnosed with Multiple Sclerosis (MS). He began navigating the process of coordinating between doctors’ offices, insurance companies and financial assistance programs, all while trying to maintain his 40-hour per week job at a home supply distribution center.

“There’s a lot within the healthcare system that I really had no idea about, and it’s not a quick and easy process,” Jim said.

Jim quickly learned that the process was not only time consuming, but also expensive, even while on his employer’s insurance plan. After being diagnosed, Jim was prescribed a disease-modifying therapy (DMT) priced at more than \$40,000 for a year’s supply. The same prescription is now valued at nearly \$100,000 per year.

“I was making pretty good money at that point, too,” Jim said. “But the bills added up.”



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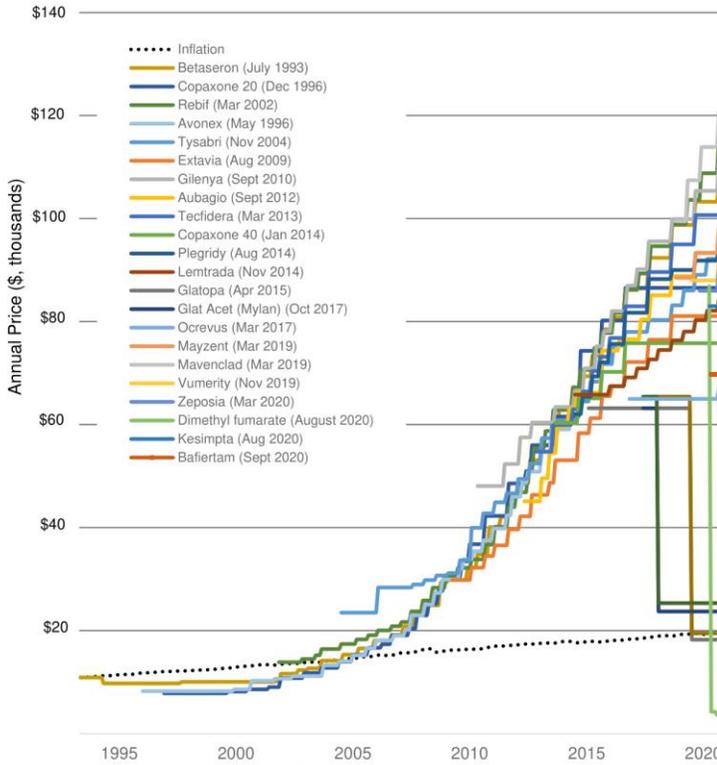
Because of the high cost, Jim began skipping his medication every other month. He now regrets this decision, as he feels it allowed the disease to progress even further, but at the time he felt like he had no other choice.

“My cognitive thinking started to become more impaired, and I noticed my mobility [declined],” Jim said. “But this was [a time of] financial hardship.”

Jim feels strongly that medications for people living with MS should become more affordable so that others don’t have to make the same tough decision he was faced with.

“[Being diagnosed with MS] wasn’t my choice, but unfortunately it happened,” Jim said. “Make it more affordable ... [and] revitalize the process for medications so that it’s a lot more simplified for a normal person.”

Trends in annual price for disease-modifying therapies for multiple sclerosis; 1997 to 2021



Notes: Annual price estimated from wholesale acquisition costs (First Databank)
 Market entrance date in parenthesis
 Dashed line is projected annual price of Betaseron assuming only inflationary increases in price (CPI)
 Lemtrada is based on four 12 mg vials (Package insert dosing: 12 mg/day (5 vials) for five consecutive days in first year; 12 mg/day (3 vials) for three days in year 2);
 *2016 to 2021 (February); **2020 to 2021 (February); ***lowest price dimethyl fumarate reported
 Updated 2.18.2021 (Data through February 2021)
 Hartung, DM- PharmD, MPH; Oregon State University/Oregon Health and Science University

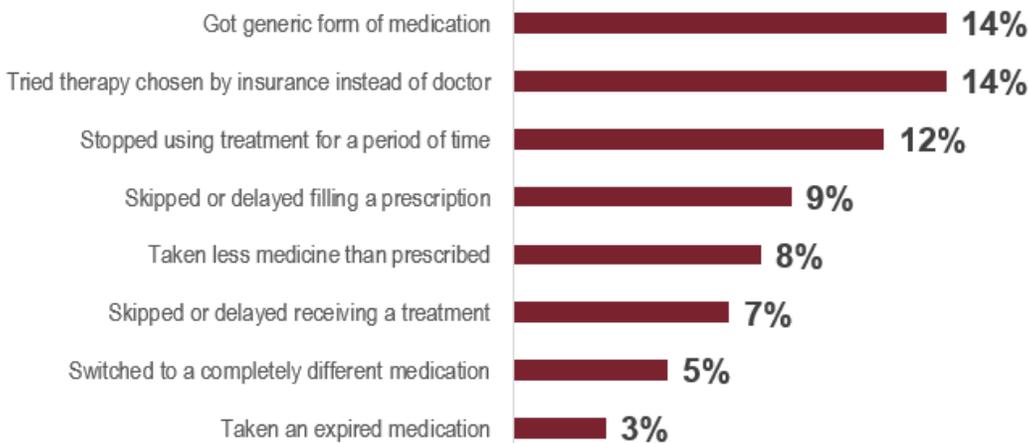
Drug	5 Year Change*	1 Year Change**	Annual Price 2021
Self-administered injections			
Betaseron	35.6%	3.0%	\$106,401
Avonex	30.0%	2.0%	\$93,672
Rebif	48.3%	11.3%	\$115,359
Extavia	23.7%	0.0%	\$81,079
Plegridy	30.0%	2.0%	\$93,672
Kesimpta			\$83,000
Glatiramer Acetate			
Copaxone 20	7.9%	0.0%	\$86,554
Copaxone 40	7.9%	0.0%	\$75,816
Glatopa	-71.1%	0.0%	\$18,250
Glatopa 40		0.0%	\$19,500
Glat Acet (Mylan)		0.0%	\$23,725
Glat Acet 40 (Mylan)		0.0%	\$25,350
Oral DMTs			
Gilenya	41.6%	5.0%	\$110,660
Aubagio	31.8%	5.1%	\$98,054
Tecfidera	37.6%	0.0%	\$100,690
Mayzent		5.0%	\$98,036
Mavenclad		12.4%	\$120,742
Vumerity		4.0%	\$91,520
Zeposia		4.5%	\$89,870
Bafiertam			\$69,770
Dimethyl fumarate***			\$3,650
Infusions			
Tysabri	35.2%	8.9%	\$97,032
Lemtrada	27.9%	4.8%	\$84,168
Ocrevus		3.0%	\$66,950



The National MS Society recently surveyed people living with MS about their use of disease-modifying therapies (DMTs). 77% of respondents reported taking one of the following six medications:

DMT	Annual Cost	5 Year Change	DMT	Annual Cost	5 Year Change
Ocrevus	\$66,950	n/a	Tysabri	\$97,032	35.2%
Tecfidera	\$100,690	37.6%	Gilenya	\$110,660	41.6%
Copaxone	\$75K - \$86K	16.5%	Aubagio	\$98,054	31.8%

How have you altered use of an MS DMT?



With the rising cost of DMTs, 40% of those living with MS are not able to stick to their treatment plan as prescribed by their provider. And more than 1 in 10 of those surveyed stopped use of their DMT entirely, which opens the door to progression of MS.