

# Access to MS Medications

## **Request:** Pass legislation to lower high drug prices and out-of-pocket costs

### People with MS Want Congress to Act

- 85% of people with MS in a recent survey said the federal government should do more to control the high cost of MS disease-modifying treatments (DMT).
- Medications must be affordable and the process for getting them simple and transparent.

### Continual Price Increases for MS Medications

- Five MS DMTs are now priced at more than \$100,000 per year; almost all these treatments must be taken each year.
- Three new DMTs entered the market in 2019; two already increased prices by 5.5% and 8%.
- A recent study showed that MS medication costs per prescription doubled from 2011-2017-- meaning that higher costs are associated with price increases of medications.<sup>i</sup>
- In 2013, the average price of MS DMTs was around \$60,000 per year; in 2018 the median price of brand DMTs increased to \$80,000 and just two years later in 2020, the brand median is \$91,835.

### High Out-of-Pocket Cost Burden In Medicare Part D

- People with MS on Medicare Part D face out-of-pocket costs that are more than \$6,000 just for their MS DMT, much of which is incurred above the catastrophic limit.<sup>ii</sup> For those on a fixed income, paying more than \$6,000 can represent a serious financial burden.
- Generics are not helping. In 2019, expected annual out-of-pocket costs for MS generics were higher than for the brand. MS DMT generics are almost always on a specialty drug tier with coinsurance, requiring people with MS to pay a percentage of the cost of the drug.

### Impact on People with MS from a Recent Survey

- Four in 10 people with MS have altered their use of their MS DMT due to cost.
- Only 11% can easily afford their MS DMT without financial assistance.
- 40% have at least some stress or emotional impact due to high out-of-pocket costs and have made some type of sacrifice.
- More than half of people with MS are very concerned about affording their DMT over the coming years. People with a chronic health condition shouldn't have to face this kind of uncertainty.

<sup>i</sup> Hartung DM, Johnston KA, Geddes J, Bourdette DN. Effect of generic glatiramer acetate on spending and use of drugs for multiple sclerosis. *Neurology* 2020 Jan 15 published online.

<sup>ii</sup> Cubanski, Koma, and Neuman. The Out-of-Pocket Cost Burden for Specialty Drugs in Medicare Part D in 2019. Kaiser Family Foundation. Feb. 1, 2019.

### What is multiple sclerosis (MS)?

- MS is an unpredictable, often disabling disease of the central nervous system.
- Symptoms range from numbness and tingling to blindness and paralysis.
- Nearly 1 million people are living with MS in the United States—more than twice the previously reported number.

### MS DMTs

- 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 accumulation of disability, and protect the brain from damage due to MS.
- Despite nearly twenty disease-modifying therapies (including two generics) available to treat relapsing forms of MS, competition has not driven down prices.
- The rising costs of drugs and changing insurance coverage disproportionately affect people with MS, causing delays and disruptions in treatment.

## Make MS Medications More Affordable

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.”

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.

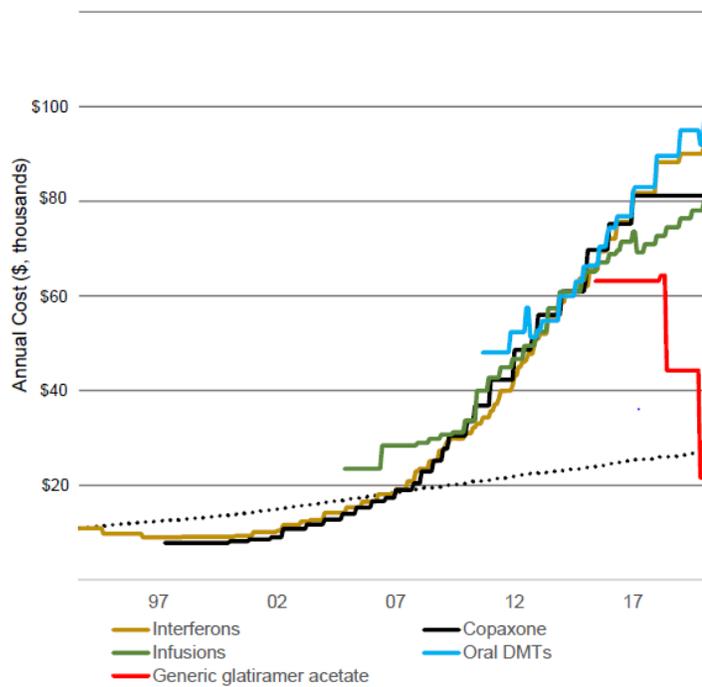
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“My cognitive thinking started to become more impaired, and I noticed my mobility [declined],” Jim said. “But this was [a time of] financial hardship.”

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 median annual price for disease-modifying therapies for multiple sclerosis by category; 1997 to 2020



Drug	5 Year Change*	1 Year Change**	Annual Cost 2020
<b>Interferons</b>			
Betaseron	48.9%	4.6%	\$103,302
Avonex	48.0%	2.0%	\$91,835
Rebif	46.7%	4.8%	\$103,647
Extavia	39.0%	0.0%	\$81,079
Plegridy	48.0%	2.0%	\$91,835
<b>Glatiramer Acetate</b>			
Copaxone 20	16.4%	0.0%	\$86,554
Copaxone 40	16.5%	0.0%	\$75,816
Glatopa 20		-71.1%	\$18,250
Glatopa 40		-70.2%	\$19,500
Glat Acet 20		0.0%	\$23,725
Glat Acet 40		0.0%	\$25,350
<b>Oral DMTs</b>			
Gilenya	58.2%	5.5%	\$105,390
Aubagio	40.9%	5.0%	\$93,296
Tecfidera	59.9%	6.0%	\$100,690
Mayzent			\$93,367
Mavenclad			\$107,460
Vumerity			\$88,000
<b>Infusions</b>			
Tysabri	38.1%	7.1%	\$89,074
Lemtrada	22.0%	5.2%	\$80,320
Ocrevus		0.0%	\$65,000

Notes:  
 Annual price estimated from wholesale acquisition costs (First Databank)  
 Dashed line is projected annual price of Betaseron assuming only inflationary increases in price (medical care)  
 The annual price for 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)  
 \*2015 to 2020 (Feb); \*\*2019 to 2020 (Feb)  
 Updated 2.20.2020

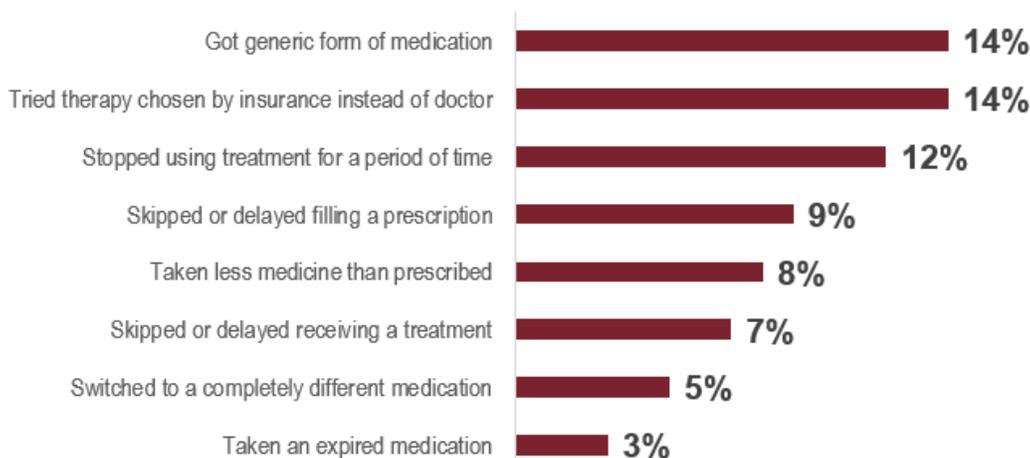
Hartung, DM- PharmD, MPH; Oregon State University/Oregon Health and Science University

**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
<b>Ocrevus</b>	\$65,000	n/a	<b>Tysabri</b>	\$89,074	38.1%
<b>Tecfidera</b>	\$100,690	59.9%	<b>Gilenya</b>	\$105,390	58.2%
<b>Copaxone</b>	\$75K - \$86K	16.5%	<b>Aubagio</b>	\$93,296	40.9%

- Only 11% of those **with MS** said they could easily afford their DMT without financial assistance
- **More than half** are very concerned about how they will afford their medication in the future
- **85%** think the federal government should do more to control the high cost of MS medications

### 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.