



# Request: The Senate must act now to advance policies to make prescription drug prices more affordable and accessible.

MS disease-modifying therapies (DMTs) are essential for many people with MS—but their prices have skyrocketed.

- The medical costs associated with living with MS are \$65,612 more each year than medical costs for individuals who do not have MS<sup>1</sup>. DMTs are the biggest cost of living with the disease.
- This year, the median annual price of the MS DMTs is close to \$94,000—up nearly \$25,000 from 2015.
- Six of the MS DMTs have increased in price more than 200% since they came on market, with nine now priced at over \$100,000.
- Many people with MS who transition to Medicare find their out-of-pocket drug costs to be impossible to afford, especially on a fixed income.

People with MS want Congress to act now to make MS medications more affordable.

- 85% of people with MS said the federal government should do more to control the high costs of MS DMTs<sup>2</sup>.
- 40% have altered the use of their DMTs due to cost, with some skipping or delaying treatment or being forced through step therapy.
- 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.
- Only 11% said they could easily afford their DMT without financial assistance.

The Society urges the Senate act by Memorial Day to:

- Implement an out-of-pocket cap on drug costs in Medicare Part D and a “smoothing mechanism” so that people in Medicare can spread their costs over the course of the year.
- Limit drug price increases by enacting rebates if prices rise faster than inflation.
- Allow the government to negotiate better drug prices for people enrolled in Medicare.

## 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.

<sup>1</sup> Economic Burden of Multiple Sclerosis in the United States: Estimate of Direct and Indirect Costs. Bruce Bebo, Inna Cintina, Nicholas LaRocca, Leslie Ritter, Bari Talente, Daniel Hartung, Surachat Ngorsuraches, Mitchell Wallin, Grace Yang. *Neurology* Apr 2022, 10.1212/WNL.000000000200150; DOI: 10.1212/WNL.000000000200150

<sup>2</sup> National Multiple Sclerosis Society. “Quantifying the Effect of the High Cost of DMTs” Market Research Report. August 2019. <https://www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Advocacy/NMSS-Research-Report-Full-Access-to-MS-Medications.pdf>.

## Stress — a six letter word that has defined Julie Belding’s journey with MS

After she was diagnosed with MS in January 2010, Julie was diagnosed with trigeminal neuralgia — a stabbing pain in the face or jaw that can impact quality of life.

Stress triggers both her MS and trigeminal neuralgia. Through the years, she found ways to manage her stress and chronic conditions, from retiring early to leaning on her husband, Ron, for support. MS medications have played an especially vital role in letting Julie live her best life.

“I started on my MS medication in May 2010. I ride my bike, I go camping with my dogs, I kayak. I feel fortunate to feel the way that I feel, and I directly tie that to the medicine and starting it so early.”

But when Ron passed away from COVID-19 last year, Julie’s life became defined by stress once again.

“Over the years, my MS treatments have made an incredible impact on slowing disease progression. But I now have to make the choice to either change treatment options or to drastically change my life even more.”

“I am now a single person trying to manage a mortgage and other expenses of daily living. In addition, the cost of MS medications and treatments continues to increase. All of that

while I now find that my out-of-pocket costs have multiplied exponentially, and Medicare Part D is just not helping enough.”

Near the end of the year, Julie pays nearly \$400 for her MS medication every 5 weeks. She also takes medication for incontinence that ballooned from \$47 a month in September 2021 to \$210 by December.

Discontinuing life-changing medications is not a choice for Julie. “I can go off the medications and then my life is not good. My quality of life would be severely impacted. Stress triggers not just the MS, but the trigeminal neuralgia, so then I’m in a world of hurt again. It’d pretty much mean me just staying home.”

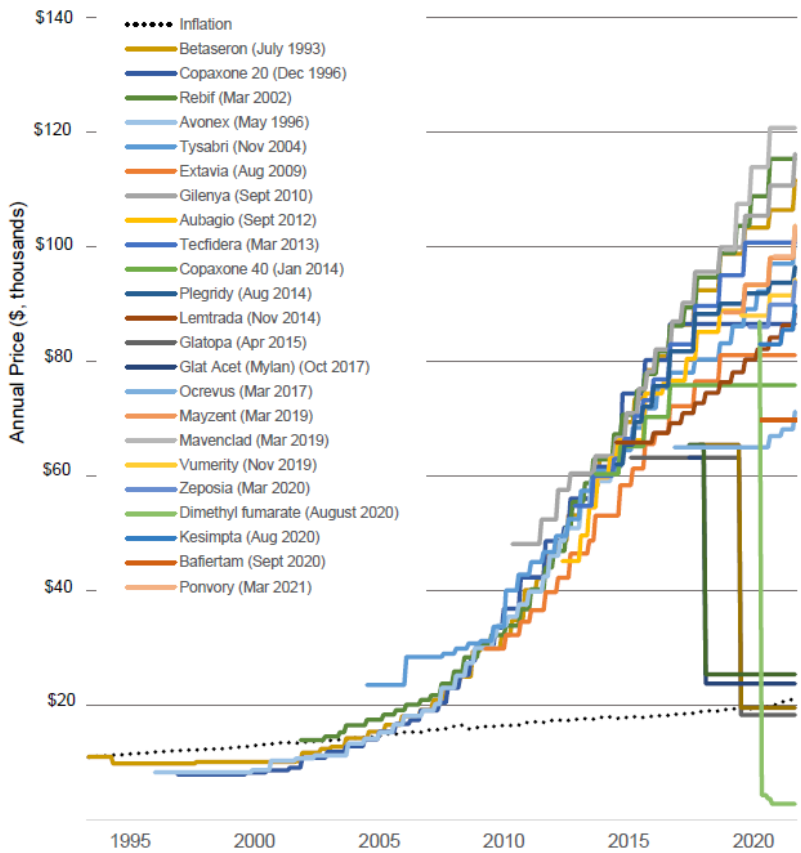
**Congress must act now to cap Medicare out-of-pocket expenses and spread costs throughout the year to accommodate for the realities of the rising cost of medications in today’s world.**

“If there were a cap on medication expenses, I wouldn’t have to watch every penny that I spend so that I have money to afford medications. It would just be a huge relief,” she says.

**“Put yourself in the shoes of someone living with a chronic disease - and then add on these additional financial problems. I am being forced to put expenses on credit cards and to make choices about what to pay first.”**



Trends in annual price for disease-modifying therapies for multiple sclerosis; 1997 to 2022



Drug (manufacturer)	1 Year Change*	Annual Price 2022
<b>Self-administered Injections</b>		
Betaseron (Bayer)	5.0%	\$111,721
Avonex (Biogen)	3.0%	\$96,487
Rebif (EMD Serono)	0.0%	\$115,351
Extavia (Novartis)	0.0%	\$81,071
Plegridy (Biogen)	3.0%	\$96,482
Kesimpta (Novartis)	8.2%	\$89,765
<b>Glatiramer Acetate</b>		
Copaxone 20 (Teva)	0.0%	\$86,554
Copaxone 40 (Teva)	0.0%	\$75,816
Glatopa (Sandoz)	0.0%	\$18,250
Glatopa 40 (Sandoz)	0.0%	\$19,500
Glat Acet (Mylan)	0.0%	\$23,725
Glat Acet 40 (Mylan)	0.0%	\$25,350
<b>S1P Receptor Modulators</b>		
Gilenya (Novartis)	5.0%	\$116,193
Mayzent (Novartis)	5.0%	\$102,938
Zeposia (Celgene)	4.5%	\$93,914
Ponvory (Janssen)	5.4%	\$103,660
<b>Fumarates</b>		
Tecfidera (Biogen)	0.0%	\$100,690
Vumerity (Biogen)	3.0%	\$94,265
Bafiertam (Banner )	0.0%	\$69,770
Dimethyl fumarate**	-25.0%	\$2,738
<b>Other Oral DMTs</b>		
Aubagio (Genzyme)	5.7%	\$103,643
Mavenclad (EMD Serono)	0.0%	\$120,742
<b>Infusions</b>		
Tysabri (Biogen)	5.2%	\$102,126
Lemtrada (Genzyme)	5.0%	\$88,343
Ocrevus (Genentech)	6.3%	\$71,187

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);  
 \*2021 to 2022 (January); \*\*lowest price dimethyl fumarate reported  
 Updated 2.15.2022 (Data through January 2022)

