

Senator Kelly, thank you for the opportunity to testify at this important hearing. My name is Judy Wilson. I am recently retired, am on Medicare, a Rotarian of 22 years, a volunteer for the National Multiple Sclerosis Society, a mentor for the Community Health Mentor Program and, most importantly, a grandmother of four wonderful grandchildren. I am also living with multiple sclerosis (MS).

MS is an unpredictable, often disabling disease of the central nervous system that disrupts the flow of information within the brain, and between the brain and body. Symptoms vary from person to person and range from numbness and tingling, to walking difficulties, fatigue, dizziness, pain, depression, blindness and paralysis. Nearly one million Americans live with this disease, and most people are diagnosed between the ages of 20 and 50, when they are in their prime working years. The progress, severity and specific symptoms of MS in any one person cannot yet be predicted, but advances in research and treatment are leading to better understanding and moving us closer to a world free of MS.

MS is a very expensive disease. The average total cost of living with multiple sclerosis is \$88,487 per yearⁱ. **The total estimated cost to the U.S. economy is \$85.4 billion per yearⁱⁱ.** Disease-modifying therapies (or DMTs) are the biggest cost of living with the disease, with individuals with MS spending an average of \$65,612 more on medical costs than individuals who don't have MS.

I was diagnosed in 2010 after experiencing tingling in my fingers, lack of balance, depression and anxiety, inability to write and incontinence. With the help of my general practitioner and many specialists, I was able to address many of my symptoms. Even still, I have lost much of my hearing, have no sense of smell, my eyesight is compromised, my gait is off, and my number of falls has increased, and I have constant nerve pain in my feet and hands.

Today, evidence shows that early and ongoing treatment with MS DMTs are the best way to manage the MS disease course, prevent accumulation of disability, and protect the brain from damage due to MS. There are now more than twenty DMTs on the market, including generic options, and these medications have transformed the treatment of MS over the last 29 years. The full range of MS DMTs represent various mechanisms of action and routes of administration with varying efficacy, side effects and safety profiles. No single DMT is 'best' for all people living with MSⁱⁱⁱ and, as MS presents differently in each person, every person's response to a DMT will vary. It is common for people with MS to move through several different DMTs throughout their life with MS, as they may "break-through" on a medication, or have disease activity, and need to try a different DMT.

After some trial and error with several DMTs, my neurologist prescribed Copaxone, a self-injection that I took three times a week. When I transitioned to Medicare, I was able to get assistance from a charitable foundation. They paid for my \$3272 copay for the first two months of the year and the \$250 per month after that, making my treatment affordable. Unfortunately, in 2021, the foundation I relied on ran out of money. I am unable to afford the over \$7,000 per year without this financial help, so I reached out to my neurologist for help.

After discussions with my doctor, I decided to go off my medications. I didn't have any other options and have so far been very lucky that I haven't had any relapses or other setbacks. But I want to emphasize that **the decision to stop my medication was based on money, not medicine**. If I could afford to go back on Copaxone, I would. MS is extremely unpredictable, and just because I have been healthy so far does not guarantee that I will not have a relapse in the future. For most living with MS, a gap in medication could mean disease progression, and that could lead to a permanent loss of mobility or cognitive function. This is a risk I take daily. No one should have to take this risk because they cannot afford medications they need.

It seems ridiculous that I needed charitable assistance to afford my medication, even though I was already paying \$2040 per year for health insurance through Medicare. I know I am not alone. A National MS Society survey found more than 70% of people with MS have received financial assistance for their DMT and 40% of people with MS alter the use of their DMTs due to cost, including stopping, skipping, or delaying treatment^{iv}.

As a volunteer self-help group leader for people living with MS in the Phoenix area, I hear firsthand how difficult it is for people to afford their medications. There are two others in my group who have discontinued use of their medications. One has recently gotten out of the hospital after a two week stay due to MS symptoms.

MS DMT prices are too high and still rising—even for DMTs that have been on the market for decades.

The price of MS DMTs has dramatically risen since the first MS disease-modifying therapy was approved in 1993. When the first MS DMT came to market, the price range was \$8,000 to \$11,000 for one year of treatment. The annual median price for MS DMTs has increased nearly \$34,000 in less than 10 years. As of February 2022 (see appendix), the median annual price of the brand-name MS DMTs is close to \$94,000.

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. This trajectory is not sustainable for people with MS or the U.S. healthcare system as a whole. Recent analysis of the MS DMTs shows that price increases of brand name drugs are largely driven by year-over-year price increases of drugs that are already in the market vs. new products.^v

When the version of Copaxone that I was prescribed came on market in 2014, it was priced at approximately \$60,000. Today it costs over \$75,000 (see appendix). This is an increase of over \$15,000 (25.6% increase) in 8 years for the same medication.

Seniors with MS Need Medicare Reform

Medicare is the single largest payer of MS-related costs in the United States, and the Medicare program consistently spends around \$5 billion on MS DMTs^{vi}. Like me, many other Medicare beneficiaries with

MS have reported significant difficulty affording their medications.

Unfortunately, recent analysis confirms our experience. Cumulative annual out-of-pocket spending for Medicare beneficiaries with MS was \$6,894 in 2019, including an average of \$352 in out-of-pocket cost per month for those already in the catastrophic coverage phase^{vii}.

Charitable foundations like the one I used exist for Medicare beneficiaries to apply to for some assistance affording their medication, but the need is far greater than supply. From 2018 to 2020, the various nonprofit programs serving Medicare beneficiaries with MS opened for applications only 16 to 20 times for just a total of 87 to 98 days out of the entire year—approximately 25 to 30% of the year. In 2021, these funds opened only four times, for just 25 days out of the year. And to date in 2022, the funds opened only once in January, for just three days.

Policy proposals that redesign Medicare Part D to better work for Medicare beneficiaries by capping out of pocket costs at \$2,000 and allowing beneficiaries to smooth costs within the plan year is important to helping seniors like me afford their medications. \$2,000 is a lot of money, but it is more affordable than the almost \$7,000 that I would have to pay now for my MS DMT.

In closing, I am one of the 85% of people with MS across the United States who want the federal government to do more to control the high cost of MS medications. I urge you and your colleagues to immediately pass legislation that

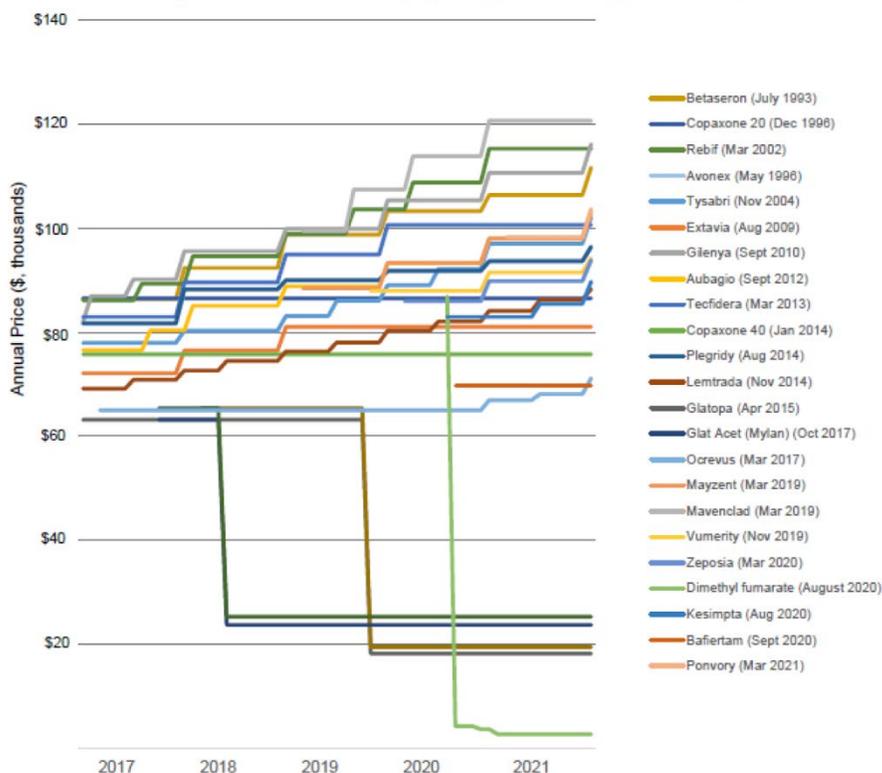
- allows Medicare to negotiate better prescription drug prices on behalf of its beneficiaries,
- establishes a \$2,000 Medicare Part D out-of-pocket cap along with a process that will allow beneficiaries to spread their cost throughout the year, and
- prevents the price of medications from increases faster than the rate of inflation.

These policies will have an immediate benefit on seniors living with MS. There is no single policy solution that will address the high cost of prescription drugs, but the policies that I discussed today are an important step in the right direction, and would immensely improve the quality of life for many seniors, including me.

Thank you for the opportunity to share with you today and I look forward to working with you to address the high price of medications.

Appendix

Trends in annual price for disease-modifying therapies for multiple sclerosis; 2017 to 2022



Notes: Annual price estimated from wholesale acquisition costs (First Databank)
Market entrance date in parenthesis
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);
*January 2017 to January 2022; **Compound annual growth rate (January 2017 to January 2022); ***lowest price dimethyl fumarate reported
Updated 2.15.2022 (Data through January 2022)

Drug (manufacturer)	5 Year Change*	5 Year CAGR**	Annual Price 2022
Self-administered Injections			
Betaseron (Bayer)	29.3%	5.2%	\$111,721
Avonex (Biogen)	18.0%	3.3%	\$96,482
Rebif (EMD Serono)	33.9%	5.9%	\$115,359
Extavia (Novartis)	12.4%	2.3%	\$81,079
Plegridy (Biogen)	18.0%	3.3%	\$96,482
Kesimpta (Novartis)		5.4%	\$89,765
Glatiramer Acetate			
Copaxone 20 (Teva)	0.0%	0.0%	\$86,554
Copaxone 40 (Teva)	0.0%	0.0%	\$75,816
Glatopa (Sandoz)	-71.1%	-21.7%	\$18,250
Glatopa 40 (Sandoz)		-26.7%	\$19,500
Glat Acet (Mylan)		-20.4%	\$23,725
Glat Acet 40 (Mylan)		-19.8%	\$25,350
S1P Receptor Modulators			
Gilenya (Novartis)	41.6%	7.1%	\$116,193
Mayzent (Novartis)		5.3%	\$102,938
Zeposia (Celgene)		4.7%	\$93,914
Ponvory (Janssen)		5.9%	\$103,660
Fumarates			
Tecfidera (Biogen)	21.3%	3.9%	\$100,690
Vumerity (Biogen)		3.1%	\$94,265
Bafiertam (Banner)		0.0%	\$69,770
Dimethyl fumarate***		-90.0%	\$2,738
Other Oral DMT			
Aubagio (Genzyme)	35.3%	6.1%	\$103,643
Mavenclad (EMD Serono)		6.9%	\$120,742
Infusions			
Tysabri (Biogen)	30.9%	5.4%	\$102,126
Lemtrada (Genzyme)	27.7%	4.9%	\$88,343
Ocrevus (Genentech)		1.9%	\$71,187



National
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ⁱ "B. Bebo et al. A Comprehensive Assessment of the total economic burden of multiple sclerosis in the United States. ECTRIMS 2021. 15, October, 2021.

<https://ectrims2021.abstractserver.com/program/#/details/presentations/557>."

ⁱⁱ "B. Bebo et al. A Comprehensive Assessment of the total economic burden of multiple sclerosis in the United States. ECTRIMS 2021. 15, October, 2021.

<https://ectrims2021.abstractserver.com/program/#/details/presentations/557>."

ⁱⁱⁱ MS Coalition. The Use of Disease Modifying Therapies in Multiple Sclerosis: Principles and Current Evidence.

[http://www.nationalmssociety.org/getmedia/5ca284d3-fc7c-4ba5-b005-](http://www.nationalmssociety.org/getmedia/5ca284d3-fc7c-4ba5-b005-ab537d495c3c/DMT_Consensus_MS_Coalition_color)

[ab537d495c3c/DMT_Consensus_MS_Coalition_color](http://www.nationalmssociety.org/getmedia/5ca284d3-fc7c-4ba5-b005-ab537d495c3c/DMT_Consensus_MS_Coalition_color). Accessed December 26, 2018.

^{iv} National MS Society. Quantifying the Effect of the High Cost of DMTs. Market Research Report. <https://www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Advocacy/NMSS-Research-Report-Full-Access-to-MS-Medications.pdf>. August 2019. Accessed March 10, 2022

^v Hernandez, Inmaculada et al. "The Contribution of New Product Entry Versus Existing Product Inflation in the Rising Cost of Drugs." Health Affairs. Vol.38, No. 1. <https://doi.org/10.1377/hlthaff.2018.05147>

^{vi} 2019 Data from Medicare Part D and Part B Spending Dashboard. (Accessed May 7, 2021).

^{vii} Daniel M Hartung, Kirbee A. Johnson, Adriane Irwin, Sheila Markwardt, and Dennis N. Bourdette, 'Trends In Coverage For Disease-Modifying Therapies For Multiple Sclerosis In Medicare Part D', Health Affairs, February 2019, Vol.38, No.2.