



National
Multiple Sclerosis
Society

Access to MS Medications

Request: Pass a slate of legislation to help make medications more affordable and the process for getting them simple and transparent.

General Information

- 85% of voters said lowering prescription drug prices should be an important or top priority for Congress.ⁱ (January 2018 survey)
- From 2012 to 2016, the greatest cumulative price increase in health care spending was 24.9% in prescription drugs.ⁱⁱ

Prices and Price Increases

- Spending on specialty drugs, which accounts for nearly 41% of prescription drug costs, is up 11.3% compared to a 4.3% decrease in spending on traditional medications 2012-2016.ⁱⁱⁱ
- Anticompetitive tactics are currently keeping many needed generics from entering the market.
- Increased prescription drug spending accounted for 89% of the increase in total spending for people with MS 2012-2015.
- People with MS face co-insurance as high as 40%, which could mean a monthly cost of more than \$2,500 for their MS disease-modifying therapy alone.
- A person with MS spends 3x as much out-of-pocket than the average person in employer plans.

Step Therapy

- Common sense protections like transparent, simple exceptions processes are needed so people are not required to take a medication that doesn't work for them, before they can "step-up" to a treatment that might work.
- Step therapy processes take decision-making away from patients and their health care providers.
- The practice is growing; in 2013, 67% of employer-sponsored plans reported use of step therapy policies—an increase from just 27% in 2005.

Pharmacy Benefit Managers (PBMs)

- Investment analysts say PBMs "benefit from lack of transparency and misaligned incentives" which means they benefit from higher drug prices.^{iv}
- Patients do not directly benefit from rebates. In fact, co-insurance is usually based on the list price instead of the net (rebated price).

What is multiple sclerosis (MS)?

- MS is an unpredictable, often disabling disease of the central nervous system.
- MS interrupts the flow of information within the brain, and between the brain and body.
- Symptoms range from numbness and tingling to blindness and paralysis.
- The progress, severity and specific symptoms of MS in any one person cannot yet be predicted.

MS disease-modifying therapies

- 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.
- The average median price of MS DMTs in 2018 is \$80,000; in 2013 the average was less than \$60,000.
- The rising costs of drugs and changing insurance coverage adversely affect access to treatment for people with MS.

[nationalMSSociety.org/
MakeMedsAccessible](https://www.nationalMSSociety.org/MakeMedsAccessible)



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Pass this Slate of Legislation

Creating and Restoring Equal Access to Equivalent Samples (CREATES) Act **(S.974/H.R. 2212)**

Sponsors: Sens. Patrick Leahy (D-VT) and Chuck Grassley (R-IA) /Reps. Tom Marino (R-PA-10) and David Cicilline (D-RI-1)

Would prohibit brand pharmaceutical manufacturers from using safety programs/restricted access programs as a way to prevent generic or biosimilar manufacturers from purchasing samples to understand how the medication works (and create a generic, lower-cost product). A generic manufacturer could bring a civil action against the brand pharmaceutical company if the brand manufacturer refuses to supply samples. According to the Congressional Budget Office, this bill would save \$3.8 billion in federal spending.

Restoring the Patient's Voice Act **(H.R. 2077)**

Sponsor: Rep. Brad Wenstrup (R-OH-2nd)

Would require employer-based health plans (under ERISA) to provide an exceptions process to step therapy protocols. The patient or provider can request an exception based on reasonable criteria outlined in the bill and if the supporting documentation demonstrates the criteria is met, the request should be granted within three days or 24 hours if the patient's life is in danger. This process must be readily available on the website of the health plan and include an explanation of how to request the exception.

Fair Accountability and Innovative Research (FAIR) Drug Pricing Act **(S.1131/H.R. 2439)**

Sponsors: Sens. Tammy Baldwin (D-WI) and John McCain (R-AZ) /Rep. Janice Schakowsky (D-IL-9)

For drugs with a wholesale cost of \$100 or more per month, requires pharmaceutical manufacturers to justify drug price increases $\geq 10\%$ over one year or $\geq 25\%$ over three years. Manufacturers must submit a transparency and justification report to the U.S. Department of Health and Human Services (HHS) 30 days before they increase the price. The report must include a justification for each price increase, manufacturing, research and development costs for the qualifying drug, net profits attributable to the qualifying drug, marketing and advertising spending on the qualifying drug, and other information as deemed appropriate.

Creating Transparency to Have Drug Rebates Unlocked (C-THRU) Act **(S.637)**

Sponsor: Sen. Ron Wyden (D-OR)

Requires greater transparency of rebates and discounts negotiated by pharmacy benefit managers (PBMs) as well as a to-be-specified proportion of these rebates and discounts passed on to the health plan. This information must be posted publicly on the Centers for Medicare and Medicaid Services' (CMS) website.



Jessica, Indiana



No one is more grateful for innovation in medications for multiple sclerosis (MS) than me. Last year I was reliant on a wheelchair and Social Security Disability. Today I'm taking a newly approved medication, working and focused on my family. But with the excitement and hope comes feelings of anxiety: **how can we, people living with MS, afford these medications?**

I've been living with MS for 16 years and I am currently taking my sixth MS DMT. Before starting each, I had to obtain pre-approval through my insurance, find a pharmacy that could provide it and brace myself for the costs. When medications cost a minimum of \$5,000 per MONTH, that deductible comes fast; the start of each health insurance year is a struggle.

The first two medications weren't effective—I had breakthrough disease activity within 18-24 months. After another 18 months, the side effects of the third one were intolerable.

The fourth DMT was sort of an accidental meeting—I was involved in a clinical trial—and it was working! When you're part of a trial, the medication is provided for free. And then the medication was approved by the FDA! I was so glad it got approved, but I cried for days because **my insurance denied it even though it clearly worked for me!** It was a big fight to stay on the medication. Finally the insurance company approved my use of the medication, and I found copay assistance through the manufacturer. I was on that DMT for four-and-a-half years before it stopped working.

"No one deserves to go deep into debt for a medication they need to control their disease."

And then there was the fifth for eight months...

After that I was off DMT for two years, because there was nothing for me on the market. I couldn't work. I went on Social Security Disability with supplemental employment to keep my skills up. I was reliant on a wheelchair, but I was HOPEFUL. And then a new DMT was approved! And, right now, it is working for me.

Now I often wonder what will happen if I can't afford my medication. I worry about becoming a financial burden to my family. We've already missed out on so much over the years...

If I don't take the medication, I'll be back in a wheelchair. I'm young (only 43 years old!) and I still want to work. I will continue to be an active part of my family's life. I plan to dance at my kids' weddings someday. Someday I will have grandchildren; I want to help, to hold them, and to carry them. For that to happen, we need to make medications affordable, make sure people can get the medications they need, and have a health system that is transparent and puts the patient first.

Without access to affordable, necessary medication, I am unsure of what the future of my health will look like. MS is volatile and unpredictable. The price and accessibility of medication to treat my MS should not be.

ⁱ Patients for Affordable Drugs Now Survey conducted by GS Strategies Survey. Jan. 2018.

ⁱⁱ "2016 Health Care Cost and Utilization Report. Health Care Cost Institute. Jan. 2018.

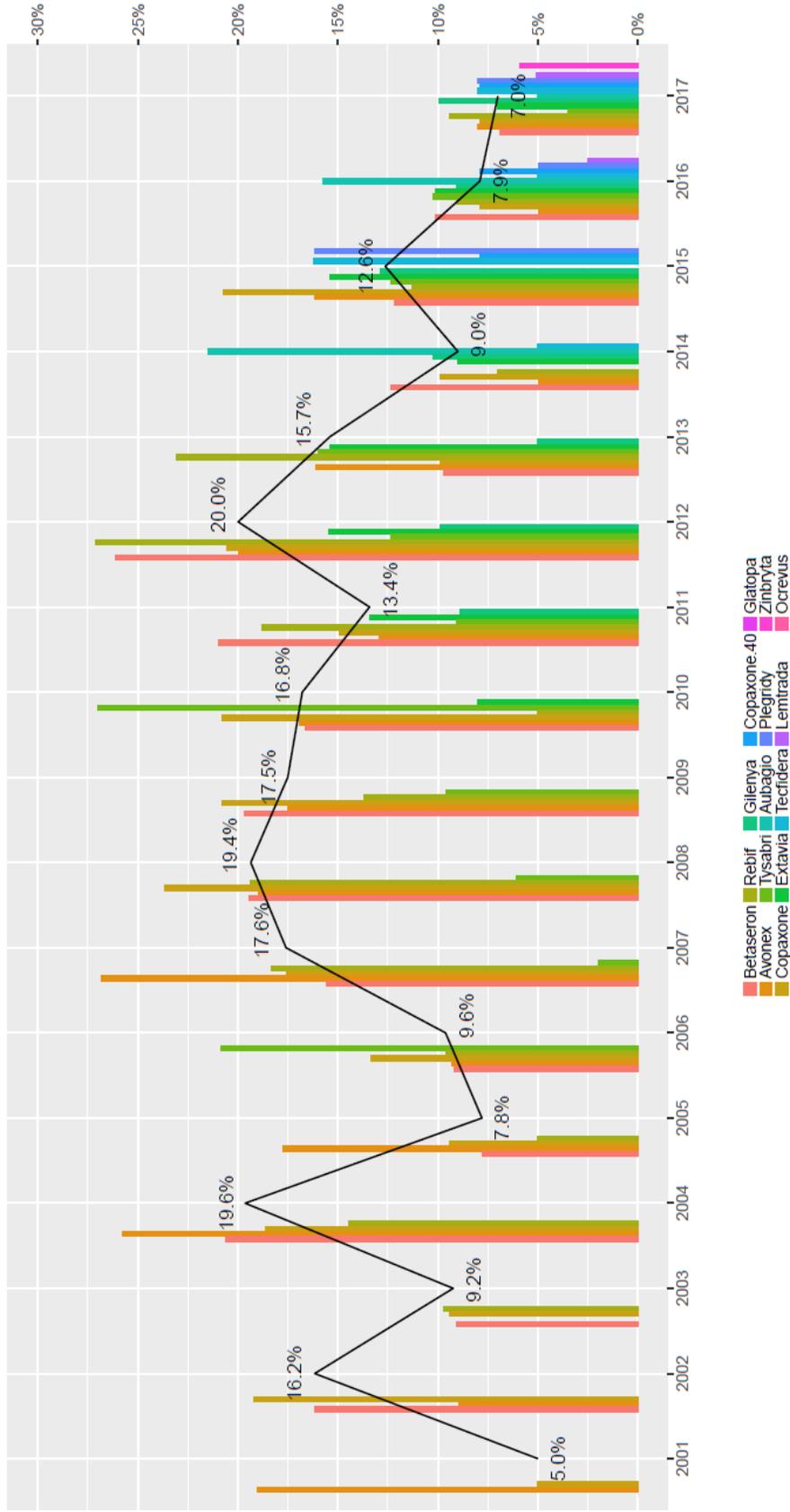
ⁱⁱⁱ 2017 Drug Trend Report. The Express Scripts Lab: Express Scripts; Feb. 2018.

^{iv} Grant, Charley. "Hidden Profits in the Prescription Drug Supply Chain". The Wall Street Journal. Feb. 24, 2018.



National Multiple Sclerosis Society

Annual Changes in Disease-Modifying Therapy Wholesale Acquisition Costs, 2001 to 2017

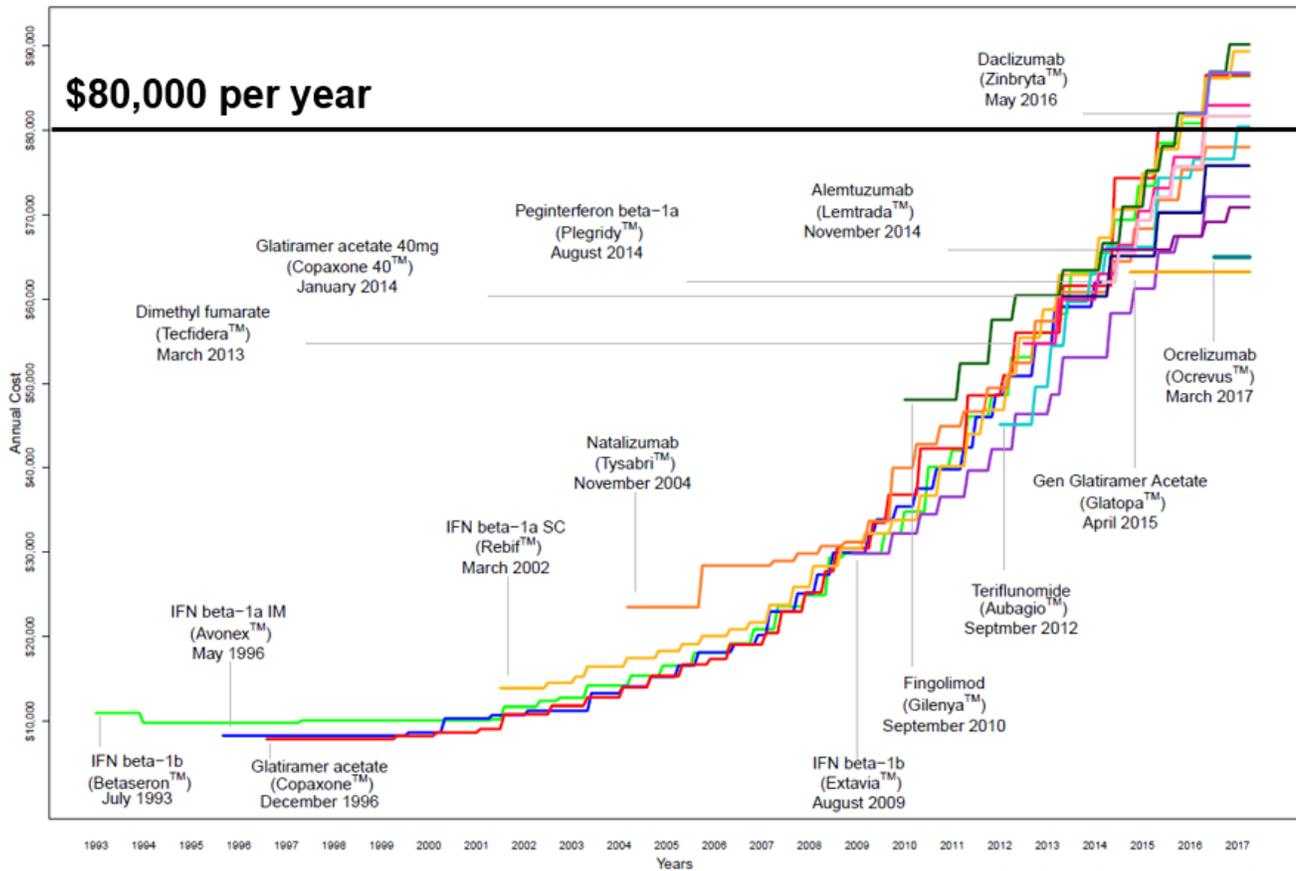


Annual changes estimated using year to year (e.g. 2017 changes are December 2016 to December 2017) percent change in wholesale acquisition costs. Solid line and numbers indicate median percent change for the year across available DMTs. Data source: First DataBank



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Annual Drug Costs*: 1993 to 2017



*estimated from undiscounted WAC

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Spending for People with ESI is On the Rise, Driven Largely by Prices



For people with ESI, total health care spending rose **15%** from 2012 to 2016, despite a decrease in utilization of most services.



For people with MS, increased prescription drug spending accounted for **89%** of the increase in their total spending from 2012 to 2015.

Spending for People with MS is Considerably Higher than the Employer-Sponsored Insurance (ESI) Population and Increasingly Attributable to Prescription Drugs

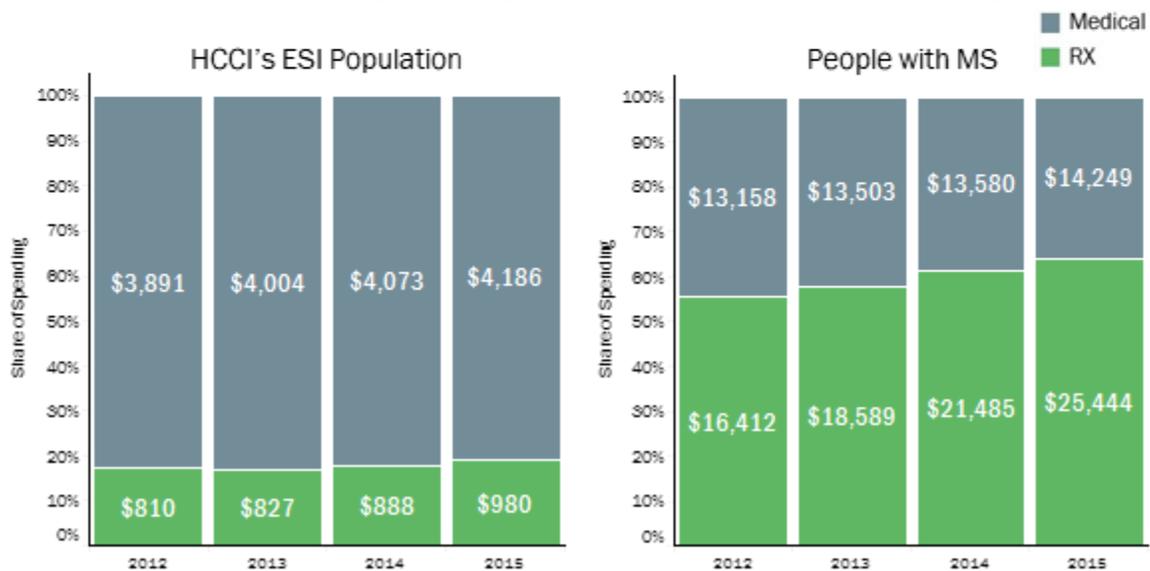
Spending per person with MS (\$39,694) is **6X higher** than spending per person with ESI (\$6,255)

OOP spending per person with MS (\$2,854) is **3X higher** than OOP spending per person with ESI (\$848)



Prescription drugs (primarily disease modifying therapies) are increasing both in terms of spending per person and share of total spending for people with MS.

Medical and Prescription Drug Spending as Share of Total Per Capita Spending, 2012-2015



HCCI HEALTH CARE COST INSTITUTE