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House Committee on Ways and Means
United States House of Representatives
The Disproportionate Impact of COVID-19 on Communities of Color
May 27, 2020

On behalf of the nearly 1 million Americans living with multiple sclerosis (MS), I appreciate the opportunity to provide a statement in response to the House Ways and Means Committee hearing on "The Disproportionate Impact of COVID-19 on Communities of Color". We appreciate that the Committee is bringing forth this vitally important issue. As Chairman Richard Neal said in his opening statement, the "health consequences of the virus are not felt evenly across our society. COVID-19 has shone a light on our country's centuries-old legacy of inequality."

According to the Centers for Disease Control and Prevention (CDC), "current data suggest a disproportionate burden of illness and death among racial and ethnic minority groups" as it relates to COVID-19. According to the CDC, this is due to a variety of factors including living conditions, work circumstances, underlying health conditions, and lower access to care.[i] In MS we have seen evidence that shows African-Americans had a 47 percent increased risk of MS compared with whites, are more likely to experience more relapses, are more likely to experience greater disability, and have a greater risk of progressing to require ambulatory assistance earlier and more likely to develop involvement of the optic nerves and spinal cord (optic-spinal MS) and inflammation of the spinal cord (transverse myelitis).[ii]

Multiple Sclerosis (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. 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.

The National MS Society is committed to creating a world where everyone, of every race, can live a life free of MS and free of injustice and inequality. We recognize the effects of COVID-19 and MS on communities of color are magnified by the inequities in our healthcare system. As Chairman Neal said "Although these groups have the highest rates of positive tests and mortality, they have less access to testing and treatment. That is simply unacceptable."

We will not be successful in finding the cure for MS until we confront and address these inequities. The disparities that keep people of color from receiving today's care must not keep them from receiving tomorrow's cure.

The MS experience with high prescription drug and out of pocket costs

A growing body of evidence indicates that early and ongoing treatment with a Food and Drug Administration (FDA) approved disease-modifying therapy (DMT) is the best way to manage the MS disease course, prevent accumulation of disability and protect the brain from damage due to MS.

Fortunately, there are now more than 17 FDA-approved DMTs for different forms of MS. 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 agent is 'best' for all people living with MS. As MS presents differently in each individual, every person's response to a DMT will be unique. In fact, it is critically important that payers, payment models, delivery systems, and the health care stakeholders at large recognize that despite similarities in their indications and usage, these medications are not therapeutically interchangeable.

The availability of MS DMTs has transformed the treatment of MS over the last 25 years. Unfortunately for people affected by MS, the cost of MS therapies has dramatically risen since the first DMT was approved in 1993. Today, people with MS report high and rapidly escalating medication prices, increasing out-of-pocket costs, confusing and inconsistent formularies and complex payer approval processes that stand in the way of getting the treatments they need.[iii]

When MS DMTs first came on the market in 1993, the price range was $8,000-$11,000 for one year of treatment. Since that time, price increases made one or more times per year for almost all DMTs have become the norm. In 2013, the average annual median price was less than $60,000. In 2018, it exceeded $80,000[iv] and in 2019, the median price for brand MS DMTs is $88,853.

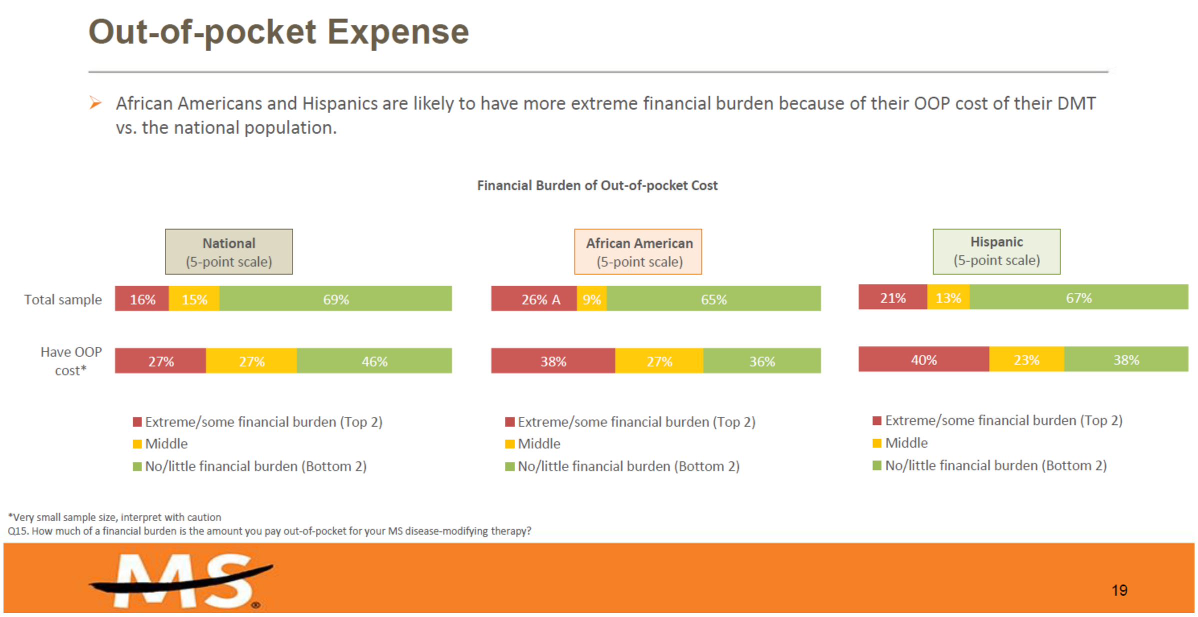
The impact of high drug costs on communities of color

In our 2019 survey, "Quantifying the Effect of the High Cost of DMTs" we found that the high costs of medications were even more acute for African Americans and Hispanics living with MS.[v] In the survey we found that African Americans and Hispanics are likely to have more extreme financial burden because of their OOP cost of their DMT (Appendix 1) They are also more likely than the overall population to receive financial assistance: 75% of African Americans and 87% of Hispanics have received financial assistance for the DMT they are currently using (vs. 71% national), the vast majority of whom say the financial burden would be great without assistance. Yet, African Americans and Hispanics are more likely to feel the process of getting financial assistance is challenging vs. the national population of people living with MS. African Americans are more likely to have to renew their assistance every year. Compared to the national population, African Americans and Hispanics are somewhat more likely to postpone paying bills.

The National MS Society applauds Chairmen Neal for their leadership in advancing policies that will result in lower drug costs for many Americans. Given the impact of high drug prices on communities of color, the Society supports the goals and many provisions of the Lowering Drug Costs Now Act of 2019 (H.R. 3) and urge you to work with your Senate colleagues to pass legislation to address drug prices this year.

We thank the Committee for your attention to this important issue and look forward to continuing to work with you to address these inequities in our healthcare system.

Appendix 1



Out-of-pocket Expense

- African Americans and Hispanics are likely to have more extreme financial burden because of their OOP cost of their DMT vs. the national population.

Financial Burden of Out-of-pocket Cost

*Very small sample size, interpret with caution
Q15. How much of a financial burden is the amount you pay out-of-pocket for your MS disease-modifying therapy?

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[i] Centers for Disease Control and Prevention. https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/racial-ethnic-minorities.html Accessed June 8, 2020.

[ii] https://www.nationalmssociety.org/What-is-MS/Who-Gets-MS/African-American-Resources

[iii] Quantifying the Effect of the High Cost of DMTs. National MS Society. https://www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Advocacy/NMSS-Research-Report-Full-Access-to-MS-Medications.pdf. August 2019.

[iv] Hartung DM. Economics and Cost-Effectiveness of Multiple Sclerosis Therapies in the USA. Neurotherapeutics. 2017 Oct;14(4):1018-1026. doi: 10.1007/s13311-017-0566-3. https://www.ncbi.nlm.nih.gov/pubmed/28812229

[v] Quantifying the Impact of the High Cost of DMTs Supplemental Market Research Report Detailing Findings Among African American and Hispanic People Living with MS. https://www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Advocacy/AA-Hispanic-NMSS-Research-Report.pdf