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The Honorable Mike Crapo,
Chairman
239 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Ron Wyden,
Ranking Member
221 Dirksen Senate Office Building
Washington, DC 20510

MDA Comments, Finance Full Committee Hearing: The Rising Cost of Health Care: Considering Meaningful Solutions for all Americans

Dear Chairman Crapo and Ranking Member Wyden;

In service of the neuromuscular disease (NMD) patient community, the Muscular Dystrophy Association (MDA) thanks the Senate Committee on Finance, for the opportunity to provide comments on healthcare affordability concerns for our community. While there are many affordability issues in healthcare that are of great concern to the NMD community such as PBM reform, excessive use of prior authorization, and network adequacy among many others. However, with open enrollment now begun most cogent for the community is the need to extend the Enhanced Premium Tax Credits (eAPTCs) and provide stable affordable insurance costs for community members and their families. For the neuromuscular community, time is muscle, and families cannot afford to lose any more waiting for the government to act on health insurance affordability we urge you to work in a bipartisan fashion to extend EAPTCs.

For 75 years, the Muscular Dystrophy Association has led the way in advancing basic and translational research in treatments and cures for the neuromuscular disease community. MDA is the second-largest funder of research into neuromuscular diseases after the Federal government, has founded the field of genetic neuromuscular medicine, and routinely convenes the scientific and research community to accelerate scientific breakthroughs, all in service of the neuromuscular disease community.

Due to the failure to extend eAPTCs, members of the NMD community are currently shopping for health insurance and are being met with the impossible choice of paying as much as two to three times more for health insurance than they were in 2025,[1] buying into inadequate coverage, or leaving the insurance market altogether.

An increase in healthcare costs to this degree is catastrophic for members of the NMD community, whose healthcare costs can be incredibly high already due to the rarity of their conditions, cost of therapies, and their need for a wide range of care, among many other factors. These increases are also particularly problematic in light of coming changes to Medicaid. As

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[1] https://www.kff.org/affordable-care-act/aca-marketplace-premium-payments-would-more-than-double-on-average-next-year-if-enhanced-premium-tax-credits-expire/

members of the NMD community potentially navigate off of Medicaid often due to procedural issues, not due to a change in economic status - they will likely turn to ACA marketplace plans that they will now be unable to afford.[2] Subsequently, the number of community members who are uninsured will sharply increase. Additionally, given the 75% of counties that have an MCO that provides both an ACA marketplace plan and a Medicaid plan,[3] instability in these markets will likely have consequences for both populations.

Another "option" for members of the NMD community, would be to purchase an inferior plan, but for members of the NMD community this is a false choice. Almost without exception, these "more affordable" marketplace options exclude essential services and health benefits, offer discriminatory plan design, and leave patients exposed to crushing medical bills when they need care most. Due to the lack of adequacy in these plans, it is much more likely that members of the NMD community will experience denials and delays of care that will lead to further disease progression that cannot be reclaimed. These delays also, and again, will lead them with the impossible choice of paying out of pocket for incredibly expensive care, or delaying care and having their disease progress further.

Members of the community may choose to leave the insurance market altogether. In an environment such as this, it becomes increasingly likely that "healthier" individuals may choose to leave the market place altogether. This may include those in our community whose conditions have not progressed to such a degree that they need to seek care more frequently. By contrast, those that do need to seek care more frequently are left with another layer of higher premiums because of the lack of diversity in the insurance risk pool, potentially compounding the problem. Apart from the instability that a mass exodus from the insurance market would mean for members still in the market,[4] their bills without insurance will be massive and will likely lead to a rise in uncompensated care currently estimated at 7.7 Billion which will further strain the healthcare ecosystem generally.[5]

Lastly, proposals have been floated, in addition to those already passed in the One Big Beautiful Bill Act, encouraging patients to rely more heavily on Health Savings Accounts (HSA), among other mechanisms.[6] While there are certainly benefits to these mechanisms, and we look forward to working with you on these matters, HSA's are generally not useful for those with lower

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[2] https://d3dkdvqff0zqx.cloudfront.net/groups/mda/attachments/MDA%20House%20OBBBA%20Letter%20Final%20May%2020%202025%201.pdf

[3] https://www.rwjf.org/en/insights/our-research/2024/02/marketplace-pulse-overlap-between-marketplace-and-medicaid-continues-to-increase.html

[4] https://actuary.org/risk-pooling-how-health-insurance-in-the-individual-market-works/

[5] https://www.urban.org/research/publication/changes-health-care-spending-and-uncompensated-care-under-enhanced-tax-credit

[6] https://www.commonwealthfund.org/publications/explainer/2025/jun/how-budget-bill-will-make-marketplace-coverage-less-affordable

incomes.[7] In light of the catastrophic increases to healthcare costs, we would urge the committee to focus on policy considerations that would demonstrably benefit our community.

Open enrollment has officially begun, and as we have begun to see premiums increase, it is imperative that Congress act quickly to reauthorize eAPTCs to avoid further catastrophic increases and downstream consequences.

MDA is committed to ensuring that medical research, care, and services for people with NMDs continues uninterrupted. We appreciate this opportunity to provide you with the perspectives of the NMD community. For questions regarding MDA or the above comments, please contact Joel Cartner, Director of Access Policy, at jcartner@mdausa.org.

Sincerely,

Joel Cartner

Joel Cartner, Esq
Director, Access Policy
Muscular Dystrophy Association

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[7] *Id. See also, https://chir.georgetown.edu/health-savings-accounts-robin-hood-in-reverse/*