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November 22, 2021

The Honorable Nancy Pelosi
Speaker of the House
US House of Representatives
Washington, DC 20515

The Honorable Chuck Schumer
Majority Leader
US Senate
Washington, DC 20510

The Honorable Frank Pallone
Chair
Energy and Commerce Committee
US House of Representatives
Washington, DC 20515

The Honorable Richie Neal
Chair
Ways and Means Committee
US House of Representatives
Washington, DC 20515

The Honorable Ron Wyden
Chair
Senate Committee on Finance
US Senate
Washington, DC 20510

The Honorable Patty Murray
Chair
Senate HELP Committee
US Senate
Washington, DC 20510

Dear Speaker Pelosi, Leader Schumer, and Chairs Pallone, Neal, Wyden, and Murray,

The American Academy of Neurology (AAN), the world's largest association of neurologists representing 36,000 professionals, is strongly committed to improving the care and outcomes of persons with neurologic illness in a cost-effective manner. We write today to express our support for specific provisions of the Build Back Better Act (BBBA), which we believe will make prescription drug prices more sustainable, improve our health care workforce, provide affordable insurance coverage to more Americans, and help address critical health care inequities.

Lowering Prices Through Drug Price Negotiation (Sec. 139001—139003)

Action must be taken to lower the costs of prescription medications to the government, patients, and families who are all burdened by unstainable prices for lifesaving medications. Many neurologic disorders require ongoing therapies that are increasingly expensive, which adds uncertainty and stress for these individuals.

The AAN supports the new updated policy that would require the direct negotiation of the price of prescription drug prices in Medicare for the first time since its creation. We believe that your legislation, after much debate and compromise, strikes an appropriate balance between lowering the costs while preserving innovation. It would significantly lower the costs of prescription medications, but only for those that have been on the market for many years, protecting the financial incentives that drive new innovations. The program is also limited in size and scope with a phased-in approach that escalates over time. While the impact of this new language will not be as dramatic as others have proposed, we believe empowering Medicare to directly negotiate prices for the first time would be a significant achievement that many

stakeholders including the AAN have prioritized for years.

Part B Reimbursements Should be Held Harmless

While we support the direct negotiation provisions in the BBBA as currently drafted, we strongly urge Congress to make a technical correction, so that access to Part B drugs is not harmed due to pricing negotiations between the government and drug manufacturers. Drug pricing provisions in the current draft of the BBBA are implemented in such a way that it risks a death spiral of reimbursement to unsustainable levels.

The AAN believes that any pricing concessions resulting from negotiation or the maximum fair price (MFP) must be exempt from calculation of Average Sales Price (ASP)+6% reimbursement methodology, so provider payment rates are not artificially reduced. The current reimbursement system for in-office administered drugs is not perfect, but reforms should be addressed separately to ensure access to life-saving therapies is not disrupted. Reimbursement changes to realign incentives away from higher-priced medications are needed, but doing so will likely simultaneously require revisions in how drugs are acquired, administered, and more. Additionally, previous proposals to alter the current system have failed because they only aimed to reduce reimbursements, rather than realign incentives while preserving patient access to care. These complicated policy choices are better evaluated separately through regular order.

Prescription Drug Inflation Rebates (Sec. 139101, 139102)

The AAN supports establishing inflation rebates for drugs under Medicare Part B and Part D. Patients have long faced excessive annual increases in drug prices that outpace inflation, putting medications that have been on the market for decades out of reach. This has resulted in unsafe practices such as drug rationing or only filling one of many prescriptions to save money. For example, the cost of multiple sclerosis (MS) therapies has dramatically risen since the first MS disease-modifying therapy (DMT) was approved in 1993. This trend has mostly continued unabated, even after the first generic was approved and launched in 2015. Today, the annual median price for brand MS DMTs nearly approaches $100,000, rising from a relatively modest $8,000/year in 1993. This provision has the potential to help blunt the impacts of rising drug costs going forward.

Part D Out-Of-Pocket Cap for Medicare Beneficiaries (Sec. 139201, 139202)

The AAN supports a redesign of the Part D program to create an out-of-pocket spending maximum of $2,000 for the first time. Increasingly, patients are required to absorb more and more of the cost for their drugs. As a result, medication adherence, medication rationing, and treatment compliance issues are increasingly problematic for people living with neurologic diseases. Research shows that a $50 increase in out-of-pocket costs for prescriptions was associated with lower medication adherence of between 9-18% for dementia, Parkinson's, and neuropathy patients.[1] Neurologists work hard to provide high quality care for their patients, but the complexities of the prescription drug pricing system can make it difficult for patients to access necessary treatments. An estimated 1.2 million Medicare enrollees would be impacted by the proposed policy[2], including roughly 25,000 beneficiaries who have MS based on an internal analysis.

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[1] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7274913/

[2] https://www.kff.org/medicare/issue-brief/potential-savings-for-medicare-part-d-enrollees-under-proposals-to-add-a-hard-cap-on-out-of-pocket-spending/

Pathway to Practice Training Program and Funding to Research at Minority Serving Institutions (Sec. 31060, 137402)

The AAN is committed to intentional action to be a fully inclusive, deliberately diverse, and anti-racist organization that respects and values our membership, our staff, and the communities we serve. To that end, the AAN recognizes the importance of having a physician workforce and researchers who more accurately reflect the demographics of the patients they serve.

It is for this reason that the AAN supports the proposal to create the new Pathway to Practice Training Program, which would help promote diversity and strengthen the physician pipeline by providing scholarships to underrepresented and economically disadvantaged students, and fund 1,000 new graduate medical education (GME) slots for these students beginning in FY 2027. The AAN has worked diligently to promote and strengthen diversity in the neurology workforce, but any individual specialty can only do so much towards advancing this goal. The Pathways to Practice Training Program will help enhance opportunities for underrepresented populations across the house of medicine, while expanding access to medical care in underserved and rural areas.

Similarly, for these reasons the AAN also supports the proposed $75 million in funding for the National Institutes of Health (NIH) to increase research capacity at minority serving institutions, including Historically Black Colleges and Universities. More deliberate actions are needed to recruit and retain individuals from underrepresented groups in biomedical research – and this program would help with that effort.

Additional Graduate Medical Education Positions (Sec. 137405)

The AAN strongly supports the proposed funding of 4,000 new Medicare-supported GME slots, which builds upon the 1,000 additional slots that were authorized in 2020 – the first expansion in 25 years. These slots are critical as the United States faces a shortage of between 37,800 and 124,000 physicians by 2034 that will likely be exacerbated by rising rates of physician burnout and early retirement due to the COVID-19 pandemic.

Additionally, as the significant impacts of Long COVID for millions of Americans are emerging, having a sufficient workforce to address the additional demand for neurologic care is critical. According to a recent study, one-third of patients diagnosed with COVID-19 may develop psychiatric or neurologic disorders within six months, including depression, anxiety, strokes, and dementia. That same study found that among COVID-19 patients admitted to an intensive care unit (ICU), the incidence of developing a psychiatric or neurologic disorder increased to 46%. Given the magnitude of COVID-19 cases across the US, the impact from neurologic symptoms is likely enormous. The population of the United States is also expected to grow by 10.6% by 2034, with a 42.4% increase of individuals aged 65 years and older, and a 74% increase of individuals aged 75 years and older. As life expectancy continues to rise, more Americans will develop chronic neurologic conditions such as Parkinson's disease, dementia, and Alzheimer's disease which require specialized care.

Ensuring Affordability of Health Insurance Coverage (Sec. 30601, 30602, 137301)

The AAN has long been a supporter of ensuring quality health care access for all. The health care uninsured rate has been steady at 11% throughout the pandemic, due in large part to the current subsidies in place.[3] Thus, providing health care insurance to millions uninsured Americans for those who live in states that have not expanded Medicaid coverage will enable more individuals to be covered and provide them with high quality neurologic care. Additionally, around 60% of people in

[3] rwjf.org/en/library/research/2021/08/the-uninsurance-rate-held-steady-during-the-pandemic-as-public-coverage-increased.html

the Medicaid gap are people of color, providing an opportunity to help address long-standing racial and ethnic disparities in health care access.[4]

The AAN also supports continuing the improved affordability and reduced premium costs as established in the American Rescue Plan through 2025. The evidence is clear that these enhanced subsidies are already having a significant impact, including reducing marketplace premiums for 8 million existing Healthcare.gov enrollees by $67 per month, on average.[5] Similarly, the AAN supports funding for states to establish reinsurance and affordability programs, which would allow experimentation with different approaches to lowering individual market premiums while protecting access to essential health benefits.

Permanent Reauthorization of CHIP (Section 30801)

The Children's Health Insurance Program (CHIP) has been an essential source of children's coverage, ensuring access to high-quality, affordable, health care for children – approximately 8 million children are covered through the program. Still, as many as 4.3 million children in the US were uninsured in 2020, and the number of uninsured children has been increasing in recent years, growing by 0.7% or over 450,000 children from 2016 to 2020.[6] Hispanic children make up the largest share (43.0%) of uninsured children, while children of color, together, make up nearly two-thirds of all uninsured children.[7] The permanent extension of CHIP will help ensure that children of low-income households will always have access to high quality, affordable health insurance, even if more needs to be done to reach the two-thirds of uninsured children who are eligible for Medicaid/CHIP coverage.

Thank you for taking a leadership role on this critical issue. If you have any questions or require additional information, please do not hesitate to contact Derek Brandt, Director of Congressional Affairs at *dbrandt@aan.com* or Fred Essis, Congressional Affairs Manager at *fessis@aan.com*.

Sincerely,

Orly Avitzur, MD, MBA, FAAN
President, American Academy of Neurology

[4] https://www.cbpp.org/research/health/closing-medicaid-coverage-gap-would-help-diverse-group-and-narrow-racial
[5] https://www.kff.org/policy-watch/how-marketplace-costs-premiums-will-change-if-rescue-plan-subsidies-expire/
[6] https://www.kff.org/medicaid/issue-brief/how-could-the-build-back-better-act-affect-uninsured-children/
[7] Ibid