AMERICAN ACADEMY OF NEUROLOGY®

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September 16, 2021

The Honorable Nancy Pelosi
Speaker
U.S. House of Representatives
Washington, DC 20515

The Honorable Charles Schumer
Majority Leader
U.S. Senate
Washington, DC 20510

The Honorable Kevin McCarthy
Minority Leader
U.S. House of Representatives
Washington, DC 20515

The Honorable Mitch McConnell
Minority Leader
U.S. Senate
Washington, DC 20510

Dear Speaker Pelosi, Majority Leader Schumer, Leader McConnell, and Leader McCarthy:

The American Academy of Neurology (AAN) is the world's largest association of neurologists and neuroscience professionals, with 36,000 members. A neurologist is a doctor with specialized training in diagnosing, treating and managing disorders of the brain and nervous system such as Alzheimer's disease, stroke, migraine, multiple sclerosis, concussion, Parkinson's disease, and epilepsy.

During this unprecedented time, our country faces many critical issues that require imminent action. On behalf of our membership, I write to share several priorities that we believe are essential to include as part of the budget reconciliation process or in another health care legislative package prior to the end of the year.

**AAN Priorities:**

- **Extending COVID-19 Relief and Ensuring Medicare Program Sustainability**
- **Ensuring Continued Access to Telehealth** by enacting comprehensive reform, or at a minimum, continuing current telehealth flexibilities for the short term
- **Strengthening the Health Care Workforce** by increasing federally funded graduate medical education positions and reauthorizing and strengthening the Conrad 30 visa waiver program
- **Streamlining Prior Authorization** by enacting H.R. 3173, one of the most broadly supported bipartisan pieces of health care legislation in the 117th Congress
- **Increasing Diversity in Clinical Trials** by advancing the Equity in Neuroscience and Alzheimer's Clinical Trials (ENACT) Act (S. 1548/ H.R. 3085)
- **Lowering Prescription Drug Prices and Reducing Costs to Patients**
- **Investing in Medical Research** by creating the Advanced Research Projects Agency for Health (ARPA-H) and providing supplemental funding for federally funded research that has been stalled or delayed as a result of the pandemic

**Extending COVID-19 Relief and Ensuring Medicare Program Sustainability**

The economic impact of COVID-19 continues to affect neurology practices across the country. From January through September 2020, physician practices experienced a -16% reduction in Medicare spending. While we are grateful for the emergency relief Congress has provided for the medical provider community, physician practices are still struggling to recover. While neurology practices work to rebuild their capacity to provide patient care in their communities, several Medicare policies are scheduled to take effect on January 1, 2022, that together would severely threaten their progress.

- Medicare Sequestration – a 2% across-the-board reduction to Medicare payments created by the Budget Control Act of 2011, which Congress has been temporarily postponed multiple times during the pandemic but will go back into effect in 2022.
- Statutory Pay-As-You-Go (PAYGO) Act of 2010 – requires sequestration if new legislation increases the deficit. The recent COVID-19 relief bill, the American Rescue Plan Act, triggered this reduction, leading to a 4% cut in Medicare payments beginning in 2022.
- Medicare Fee Schedule Relief – Congress provided a 3.75% temporary increase for Medicare payments that will expire in 2022.
- No Inflation Update – No inflation update is scheduled for Medicare providers in 2022-2025 under the Merit-based Incentive Payment System (MIPS), compounding the unsustainability of this Medicare Cliff.

Congressional action is needed to fully address this nearly 10% Medicare Cliff, which is clearly unsustainable, and would no doubt impact patient access to care if allowed to go into effect. We also support calls from American Medical Association (AMA) for Congress to convene hearings on the alarming state of the Medicare physician payment system, not only from a financial perspective but also related to many fundamental operational aspects. Serious discernment through committee hearings and stakeholder input must be exercised to ensure that a critical and fundamental component of the Medicare program's infrastructure—physician practices—can be sustained under the current program and to determine what structural changes are needed to protect patient access to care.

**Ensuring Continued Access to Telehealth**

The COVID-19 pandemic has forced neurology practices around the country to dramatically reshape their delivery of care for the vulnerable populations they treat. Telehealth has become an essential method of delivering care for most neurologists, which has only been possible due to the policy flexibilities enacted by Congress, along with the broad interpretation of these provisions by the Centers for Medicare and Medicaid Services (CMS).

Neurology is one of the top specialties benefitting from telehealth flexibilities, with an increase from 1% of neurology providers delivering telemedicine in the pre-COVID period to a high of 56.3% of neurology providers delivering telemedicine from March through June 2020.[1] While virtual visits in many areas dropped after their early peak, 40% of neurology appointments remained virtual in January 2021.[2] Neurologic providers and patients have reported high levels of satisfaction with telehealth, with one study showing headache patients have a 99% level of satisfaction. Telehealth has also benefited children with neurologic disease, with 86% of patients/caregivers in a large pediatric neurology care network indicating interest in telemedicine for future care after the onset of the pandemic.[3]

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[1] https://doi.org/10.1377/hlthaff.2020.01786
[2] https://doi.org/10.1212/WNL.0000000000008708
[3] https://doi.org/10.1212/WNL.0000000000010010

Access to audio-only telephone-based services is important for Medicare beneficiaries of limited means and is also vital for Medicare patients who live in communities that lack sufficient broadband cellular service and internet connectivity. As much as 7% of the US population does not use the internet, including 25% of adults aged 65 or older, according to a recent Pew Research Center study.[4]

The ability for neurologic patients to access telehealth services will be severely threatened when the public health emergency ends. We urge you to enact the Telehealth Modernization Act (S. 368/ H.R. 1332) or the CONNECT for Health Act (S. 1512 / H.R. 2903) to maintain access to telehealth for neurologic patients following the public health emergency, or at a minimum continuing current telehealth flexibilities for another year or two, as proposed in the MedPAC's recent report.[5] Permanent policy changes should consider the following:

- Removing restrictions on the site of service of the patient to ensure that all patients can access care at home and other appropriate locations.
- Ensuring patients maintain access to virtual care without restrictions based on geography.
- Continuing coverage of audio-only services, which are essential to provide health equity for patients lacking high speed internet access or are otherwise unable to operate the necessary technology.
- Ensuring equitable access to telehealth services through the development of universal access to broadband and resources to increase digital literacy to reduce disparities for patients from underrepresented racial, ethnic, and socioeconomic populations.
- Supporting sustainable and reasonable reimbursement for audio-visual and audio-only telehealth services.
- Funding data collection and more research of telehealth to better understand impact on neurologic patient care. More research is essential to help improve both the patient and provider experience in using telehealth and to develop evidence-based policies.
- Maintaining and enhancing federal authority to determine appropriate providers and services for telehealth.
- Making permanent federal temporary waiver authority for future emergencies.

**Strengthening the Health Care Workforce**

The United States is facing 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 of 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

[4] https://www.pewresearch.org/fact-tank/2021/04/02/7-of-americans-dont-use-the-internet-who-are-they/
[5] http://www.medpac.gov/docs/default-source/reports/mar21_medpac_report_ch14_sec.pdf?sfvrsn=0

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.

Expand Graduate Medical Education

Congress increased the number of Medicare-supported graduate medical education (GME) positions by 1,000 in 2021, the first increase in nearly 25 years. Building on these new positions, the Resident Physician Shortage Reduction Act of 2021 (S. 834/H.R. 2256) would increase the number of Medicare-supported direct graduate medical education (DGME) and indirect medical education (IME) medical resident training positions by 14,000 over seven years.

Reauthorize and Strengthen the Conrad 30 Program

International medical graduates (IMGs) are an important part of the US neurology workforce, with 31.5% of active neurologists being IMGs. However non-US IMG resident physicians training in the US on J-1 visas are required to return to their home country for two years after their residency has ended before they can apply for a work visa or green card. The Conrad 30 program provides 30 waivers per state to allow these physicians to remain in the US without having to return home for two years if they agree to practice in a medically underserved area for three years. With communities across the country facing physician shortages, the Conrad 30 program helps physicians who are educated and trained in the US continue to care for patients. The Conrad State 30 and Physician Access Reauthorization Act (S. 1810/ H.R. 3541) would reauthorize the Conrad 30 program for an additional three years, as well as make several key improvements to the program, including creating a process to gradually increase the number of waivers and requiring additional employment protections.

**Streamlining Prior Authorization**

Prior authorization (PA) is a health plan cost-control process that requires physicians and other health care professionals to qualify for payment by obtaining approval before performing a service. According to the AMA's 2020 PA physician survey, more than nine in 10 physicians (94%) reported care delays while waiting for health insurers to authorize necessary care; nearly four in five physicians (79%) said patients abandon treatment due to authorization struggles with health insurers; and 85% of physicians describe the burden associated with PA as high or extremely high. Most alarmingly, nearly one-third (30%) of surveyed physicians reported that PA has led to a serious adverse event (e.g., hospitalization, disability, or even death) for a patient in their care.[6] Patients—especially the vulnerable Medicare Advantage (MA) population—deserve PA reforms that will protect them from these harms associated with PA requirements

The Improving Seniors' Timely Access to Care Act (H.R. 3173), addresses prior authorization and is one of the most broadly supported bipartisan pieces of health care legislation in the 117th Congress. Introduced by Reps. Suzan DelBene (D-CA), Mike Kelly (R-PA), Ami Bera, MD (D-CA) and Larry Bucshon (R-IN), this legislation would help protect patients from unnecessary delays in care by streamlining and standardizing prior authorization under the Medicare Advantage program, providing much-needed oversight and transparency of health insurance for America's seniors. H.R. 3173 has 202 cosponsors and is supported by nearly 300 organizations representing patients, providers, IT groups, and companies across the country.[7]

[6] https://www.ama-assn.org/system/files/2021-04/prior-authorization-survey.pdf
[7] https://www.regrelief.org/wp-content/uploads/2021/09/H.R.-3173-Endorsement-List.pdf

**Increasing Diversity in Clinical Trials**

The AAN is committed to intentional action to be a fully inclusive, deliberately diverse, and antiracist organization that respects and values our membership, our staff, and the communities we serve. We actively promote equity and social justice in neurology and the neurosciences.

One action that can be taken to improve health care equity is making a deliberate effort to foster the inclusion of diversity in clinical trials. The AAN urges you to consider enacting the Equity in Neuroscience and Alzheimer's Clinical Trials (ENACT) Act (S. 1548/ H.R. 3085). The ENACT Act would increase the participation of underrepresented populations in dementia clinical trials by expanding education and outreach, encouraging the diversity of clinical trial staff, and reducing participation burden, among other priorities.

**Investing in Medical Research**

The AAN supports the creation of an Advanced Research Projects Administration – Health (ARPA-H) that has been proposed by President Biden to pursue transformational breakthroughs in medicine. As highlighted by the administration, ARPA-H would have the potential to fund high-risk, high-reward research, such as new approaches to accelerate discovery of brain imaging and blood biomarkers. ARPA-H could help contribute to the rapidly growing need to better understand the brain and nervous system.

The AAN also supports the bipartisan, bicameral Research Investment to Spark the Economy (RISE) Act (S. 289/ H.R. 869), which we believe would provide crucial funding to support NIH-funded research—to continue federally-funded research that has been stalled, delayed, or even stopped as a result of the pandemic. Long-term consequences of the COVID-19 pandemic on the country's biomedical research enterprise include: funds being diverted from existing NIH research projects to support COVID-19 related research; the new COVID-19 related expenses required to conduct research are reducing the buying power of existing grants; and the negative impact on early-career investigators who are particularly vulnerable to career disruptions. The bill authorizes funding for research grants from multiple agencies that support scientific researchers and institutions, covering the costs of research disruptions related to the COVID-19 pandemic.

**Lowering Prescription Drug Prices and Reducing Costs to Patients**

Many neurologic disorders require ongoing medication treatment that are increasingly expensive. For example, the cost of 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. New innovative medications, such as those for Spinal Muscular Atrophy (SMA), have revolutionized treatment options for an often-fatal condition, but at a tremendous price tag. For example, Zolgensma is the most expensive medication in America at a cost of $2,125,000.[8] Most recently in June, the approval of Aduhelm and subsequent announcement that this medication would cost $56,000/year, once again brought the high cost of neurologic medications into the spotlight.

Action must be taken to lower the costs of prescription medications to the government, patients, and families who are all burdened by unrealistic and unstainable prices for lifesaving medications.

[8] https://www.goodrx.com/blog/most-expensive-drugs-period/

Permitting Medicare Negotiation of Prescription Drug Prices

The AAN supports efforts to eliminate prohibitions on the negotiation of prescription drug prices within the Medicare program. However, we agree with the AMA that it is critical to maintain access to all necessary treatments for Medicare patients. Policies that allow for Medicare prescription drug price negotiation must ensure that they are not accompanied by overly restrictive drug formularies.

Additionally, the AAN agrees with the AMA that any proposal should include safeguards to ensure that if international index pricing strategies are used, they are utilized as a part of drug price negotiations in a way that upholds market-based principles and preserves patient access to necessary medications. Further, the burden of negotiation and index pricing must be borne by the Medicare program and cannot be placed on physicians, as was proposed by the International Pricing Index model policies created by the previous administration.

Price Transparency

The AAN supports proposals to promote transparency in prescription drug pricing. Broad disclosure of pricing information, including how drugs are priced, the prices paid by insurers, and the prices paid by consumers, would provide information critical to lowering costs for patients and the entire health care system. The costs of existing prescription drugs for many neurologic conditions continue to increase and these reporting requirements would provide valuable information to patients and physicians as well as important documentation of price changes over time.

The AAN also supports the requiring public justifications of price increases of greater than 10% in one year and 25% over three years, such as those in Fair Accountability and Innovative Research Drug Pricing Act of 2021 (S. 898). The disclosure requirements in this legislation include: the total manufacturer research and development spending on the drug; total revenue and net profit from the drug each year since approval; total costs for marketing and advertising the drug; and the percentage of total research and development spending for the drug that came from federal funds.

Capping Out of Pocket Costs for Medicare Beneficiaries

The AAN supports proposals to advance a sweeping Part D program redesign to reduce the total out-of-pocket spending threshold to $3,100 or lower for covered Part D drugs. 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. 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.

In 2019, the AAN conducted a data analysis to estimate the impact of Medicare Part D out-of-pocket spending caps on people living with MS. The total sample for this study was 25,262 MS patients, which represents about 20% of the Part D population. Within this population we found that:

- 5,012 Medicare patients reach a $2,000 out-of-pocket cap
- 4,391 Medicare patients reach a $3,100 out-of-pocket cap
- 2,976 Medicare patients reach a $5,100 out-of-pocket cap

More recent research found that overall 1.2 million Medicare enrollees would be impacted by a $2,000 cap, but only around 300,000 would be impacted by a cap of $3,100.[9] Based on this, a $2,000 cap would

[9] 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/

be preferable due to it protecting 300% more Medicare enrollees compared to a $3,100 cap.

Inflation Rebates

The AAN supports proposals to establish inflation rebates for drugs under Medicare Part B and Part D. Patients have long faced annual increases in drug prices, putting medications that have been on the market for decades out of reach, resulting in unsafe practices such as drug rationing or only filling one of many prescriptions to save money. We encourage Congress to base any inflationary rebates on medical inflation rates rather than relying on the consumer price index, which is an unrealistic measure in the context of health care spending.

In conclusion, thank you for your consideration of these critical issues that require immediate action. 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*. We look forward to working with you as we all strive to improve care for all Americans with neurologic conditions.

Sincerely,

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

cc: U.S. Senate Committee on Finance
U.S. Senate Committee on Health, Education, Labor & Pensions
U.S. Senate Judiciary Committee
U.S. House Committee on Energy & Commerce
U.S. House Committee on Ways and Means
U.S. House Judiciary Committee