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April 21, 2022

The Honorable Lina M. Khan  
Chair of the Federal Trade Commission  
Federal Trade Commission  
600 Pennsylvania Avenue, NW  
Washington, DC 20580

**RE: Solicitation for Public Comments on the Business Practices of  
Pharmacy Benefit Managers and Their Impact on Independent  
Pharmacies and Consumers [FTC-2022-0015-0001]**

Dear Commissioner Khan,

The American Academy of Neurology (AAN) is the world's largest neurology specialty society representing more than 38,000 neurologists and clinical neuroscience professionals. The AAN is dedicated to promoting the highest quality patient-centered neurologic care. A neurologist is a physician with specialized training in diagnosing, treating, and managing disorders of the brain and nervous system. These disorders affect one in six people and include conditions such as multiple sclerosis (MS), Alzheimer's disease, Parkinson's disease, stroke, migraine, epilepsy, traumatic brain injury, ALS, and spinal muscular atrophy.

Addressing the high burden of drug costs for neurology patients is a key priority for the AAN. High drug costs pose numerous challenges for neurology patients, primarily by potentially limiting access to treatment. The annual cost of treating neurologic disease in the United States exceeds \$500 billion, and prescription drugs for neurologic conditions are some of the most expensive on the market.<sup>1</sup> Recent data also indicates that out-of-pocket costs for neurologic drugs have increased considerably in recent years.<sup>2</sup> Drugs that treat complex, chronic conditions like Parkinson's disease, epilepsy, and migraine, and specialty drugs that may require special handling or administration, such as those used for multiple sclerosis, are particularly expensive. The newest therapies that can cure rare neurogenetic diseases can cost two million dollars for a single, albeit potentially curative treatment. Spending on specialty medications has increased by \$54 billion since 2011 and now accounts for more than 70 percent of all prescription

<sup>1</sup> Callaghan, Brian, et al. Position Statement: Prescription Drug Prices. American Academy of Neurology, [https://www.aan.com/siteassets/home-page/policy-and-guidelines/policy/position-statements/18\\_prescriptionpricesps\\_v304.pdf](https://www.aan.com/siteassets/home-page/policy-and-guidelines/policy/position-statements/18_prescriptionpricesps_v304.pdf).

<sup>2</sup> Callaghan, Brian C, et al. "Out-of-Pocket Costs Are on the Rise for Commonly Prescribed Neurologic Medications." *Neurology*, Lippincott Williams & Wilkins, 28 May 2019, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6556089/>.

spending growth.<sup>3</sup> These prices directly impact patients and their treating providers as they work together to treat neurologic illness. The AAN appreciates that the Federal Trade Commission (FTC) is examining the practices of pharmacy benefit managers (PBMs) and their impact on stakeholders across the healthcare system and believes that action is urgently needed to promote transparency and address cost burden.

The AAN believes that the use of rebates artificially drives up the list price of medication, rarely lowers the cost to consumers, and often masks efforts from payers and PBMs to promote certain therapies for reasons other than the desire to provide the best available therapy. PBMs are an integral element of the rebate system that has allowed for the exorbitant cost of many medications used to treat neurological diseases. The current drug pricing and rebate process is intentionally opaque and creates a system in which manufacturers, payers, and third-parties are incentivized to keep drug prices high even if it means that some patients are unable to afford their medications. The AAN urges policymakers to carefully consider opportunities to reign in practices that are driving continuous increases in medication costs.

A consistent theme that concerns our members has been a lack of transparency providers, patients, and regulators face relating to the acquisition and distribution costs for medications. The AAN believes that transparency is needed so that stakeholders are informed regarding the share of savings from rebates that are shared between the PBM, payers, and patients. The AAN strongly believes that rebates should be passed through to patients at the pharmacy counter. The impact of these rebates on drug selection and costs is exceedingly opaque but has been found to represent 18 percent of total spending for brand name and specialty drugs combined, according to a recent study.<sup>4</sup>

Transparency is also needed in the formulary development processes as it relates to the specific tiers each drug is placed in, and the relationship between tiering to a specific medication's costs and effectiveness. The AAN is concerned that patients can be directed to higher-cost prescriptions via that medication's preferred status when a lower cost medication is equally or more effective, so that the PBM may receive a larger rebate from the manufacturer. The practice of using "gag orders" to restrict pharmacists from informing patients of lower cost medications or alternative purchasing options is an illustrative example of the urgent need to promote transparency within the rebate system. These "gag orders" have been shown to cost patients up to \$135 million in one year alone.<sup>5</sup>

Certain PBM business practices also impose substantial costs on providers. The AAN is highly concerned regarding the impact that formulary design practices may have on neurology practices due to the administrative burdens that stem from excessive utilization management. Additionally, the practice of "white bagging", an arrangement between payers and pharmacies that has become increasingly common, has created significant additional

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<sup>3</sup> IMS Institute for Healthcare Informatics. Medicines Use and Spending in the U.S. – A Review of 2015 and Outlook to 2020. Accessed January 18, 2017. <http://www.imshealth.com/en/thought-leadership/quintilesims-institute/reports/medicines-use-and-spending-in-the-us-a-review-of-2015-and-outlookto-2020>

<sup>4</sup> Center for Improving Value in Health Care. Prescription Drug Rebates in Colorado 2017-2019. Accessed April 4, 2022 <http://www.civhc.org/get-data/public-data/focus-areas/prescription-drug-rebates/>

<sup>5</sup> Van Nuys K, Joyce G, Ribero R, Goldman DP. Frequency and Magnitude of Co-payments Exceeding Prescription Drug Costs. JAMA. 2018;319(10):1045–1047. doi:10.1001/jama.2018.0102

burden for providers, and can cause difficulty in care coordination that can lead to substantial delays in care for urgent treatments or changes in therapy.

Each of these issues should be considered on their own and the Commission should investigate policies to address them. However, a common source and amplifier of all of these issues is the trend towards consolidation in the health care system writ large, and among PBMs specifically. As of 2019 just three PBMs, Express Scripts, CVS Caremark, and Optum, controlled 71 percent of Medicare Part D membership and 86 percent of the private payer market.<sup>6</sup> The AAN believes that the FTC should examine the appropriateness of action to promote competitiveness in the market, given ongoing consolidation. Furthermore, the AAN agrees with Commissioner Khan that study of PBM's business practices is vital and that the Federal Trade Commission should do all in its power to, "tackle the sky-high drug prices and decline of independent pharmacies."

The AAN is grateful for the opportunity to comment on this incredibly important issue and is eager to continue to engage with the FTC and other stakeholders on how to promote competition and deliver lower drug prices to patients to expand access to high quality care. If you have any questions regarding these comments or seek further input, please contact Matt Kerschner, Director, Regulatory Affairs at [mkerschner@aan.com](mailto:mkerschner@aan.com) or Max Linder, Government Relations Manager at [mlinder@aan.com](mailto:mlinder@aan.com).

Sincerely,

A handwritten signature in cursive script that reads "Orly Avitzur MD".

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

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<sup>6</sup> "Drug Pricing in America: A Prescription for Change, Part III." April 9, 2019, p. 14.