



National
Multiple Sclerosis
Society

October 9, 2018

To: Members of the Senate Health and Human Services Committee
Re: Informational Meeting on the Role Pharmacy Benefit Managers

The National Multiple Sclerosis Society is grateful for the opportunity to submit comments on the role of Pharmacy Benefit Managers (PBMs) in Pennsylvania. We thank Chairwoman Baker for holding this important hearing. Multiple sclerosis 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 range from numbness and tingling to 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. Preliminary results of a recent update on the prevalence of MS in the US suggests as many as one million individuals in the United States are diagnosed with the disease, including at least 23,000 people in Pennsylvania.

Research shows that early and ongoing treatment with a disease-modifying therapy is the best way to modify the course of relapsing forms of MS, prevent the accumulation of disability, and protect the brain from damage. Yet, many people living with MS cannot access the medications they need to live their best lives. Continually escalating prices are creating significant barriers to treatment, including higher costs, increased stress, and a greater burden for those who already live with a chronic, life-altering condition. This is in addition to confusing and inconsistent formularies and complex approval processes. These challenges led to the National MS Society releasing comprehensive recommendations about how to make medications more affordable and the process for getting them simpler and more transparent. These recommendations can be accessed at www.nationalmssociety.org/makemedsassessible.

There are currently 14 brand-name and 3 generic disease-modifying therapies on the market to treat MS. In 2018, the median price of these therapies is \$80,442 a year. The three generics are for the same brand product and cost between \$63,000 and \$65,000 per year. Of the eight products that cost more than the median price, more than half have been on the market for eight years or longer, some as long as 25 years. Despite longevity on the market, since 2012, annual price increases for MS disease-modifying therapies have ranged from 3.5% to 27%. In addition to disease-modifying therapies, people with MS typically take 1 to 3 symptom management drugs to help manage depression, bladder problems, fatigue and many other issues associated with the disease.

Drug pricing is complex and there is dire need for increased transparency across the system. Determining the role that PBMs play in prescription drug pricing, consumer access, and quality is currently difficult to assess given the lack of information that is publicly available. The system is driven by rebates, which are negotiations between some parties involved in the supply chain but not all parties. Rebate benefits may or may not be directly passed on to the person taking that particular medication. Greater understanding and transparency of how prices are set across the system is needed, particularly for consumers.

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In recent years it has been uncovered that consumers may be paying more than the actual cost of their medication (the price negotiated by the Pharmacy Benefit Manager) at the pharmacy. This can happen if the consumer has not yet met their deductible and pays the co-pay or co-insurance required by their insurer, even though their copay or coinsurance is more than the actual cost of the drug or the Pharmacy Benefit Manager (PBM)'s negotiated price. Compounding this issue is the fact that many PBMs have a non-disclosure or "gag clause" in the PBM/pharmacy contract which prohibits pharmacists from informing the consumer that they could save money by paying for their medication outright. Pharmacists who violate the contract may be penalized with fees or be pulled from the network. When a person pays more than what their medication costs, the profit is returned to the PBM. This profit is an unregulated stream of money: the PBM does not have a responsibility to tell the insurer or plan enrollees that they are "clawing back" this money and keeping it as profit.

There is increased pressure on all health care consumers to make good choices. Yet, people have very little information about price and cost to make these decisions. Just the term "price" can mean several different things. The prices charged for MS medications, the actual cost paid for them, and the impacting decisions between a manufacturer price and a negotiated contract with an insurer or pharmacy benefit manager, are outside of the public realm. People with MS need more information to make more informed choices. One way to ensure that information is provided fairly and consistently is to protect pharmacies and pharmacists who inform their customers that they could be paying less for their medication. Eliminating "gag clauses" in PBM contracts with pharmacies and limiting the amount of unregulated profit that PBMs are "clawing back" at the expense of consumers is one useful step towards reforming PBMs' business practices and increasing access to medications. Congress recently addressed this issue by passing The Patient Right to Know Drug Prices Act, S. 2554, and the Know the Lowest Price Act, S. 2553. These bills would prohibit the use of gag-clauses in contracts with Medicare plans and federally-regulated plans. In order to ensure all Pennsylvanians, have these protections, we encourage the General Assembly to pass similar legislation to prohibit gag-clauses for Medicaid plans and state-regulated plans.

Medications must be affordable, and the process for getting them simple and transparent. We applaud the committee for holding this hearing to learn more about the role PBMs play in this process. We encourage the state to take steps to address soaring drug prices by passing prohibiting the use of PBM gag-clauses in Pennsylvania. Thank you for your time, please let us know if we can be of assistance to you and your work in the future. Please contact me at (267) 765-5104 or mara.brough@nmss.org with any questions.

Sincerely,

Mara Brough
Senior Advocacy Manager
National MS Society

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