Neurological Disease Working Group

2025 MEETING SUMMARY

The Alliance for Patient Access hosted its annual meeting for the Neurological Disease Working Group on May 2-3, 2025, in Washington, DC. Working group members convened to discuss policies impacting people living with neurological diseases like Alzheimer's, dementia, Parkinson's and other movement disorders.

UTILIZATION MANAGEMENT

Meeting participants discussed how utilization management practices create roadblocks to effective and timely care for patients. Not only do these practices impact patients' health and finances, but they also create a burden on clinicians to prioritize insurers over patients.

Prior Authorization and Reauthorization

Prior authorization calls into question clinician-prescribed medications, tests and procedures. Many patients are denied access to treatments by their health plans and forced to undergo arduous appeals processes just to be properly treated. One clinician described having to ration time, energy and resources that should be going toward their patients but go toward paperwork instead.

Reauthorization can often delay or interrupt treatment because patients must go through the approval process once more, even if they are stable on their treatment. This significantly impacts people with chronic and progressive diseases because their diagnosis doesn't change, but their coverage does. A neurologist posed the question, "If patients are doing well, what is the need for reauthorization?"

Step Therapy

Clinicians expressed concern for their patients impacted by step therapy because they must try several different treatments that may or may not work—before their insurance covers the treatment that was initially prescribed. When patients' employers change their insurance plans, they often have to start at the beginning of the treatment cycle (step one) before getting back to the treatment that was working for them.

Non-medical Switching

Non-medical switching affects patients who are undergoing treatment that works for them and must switch to a different medication because it saves their insurer money. This practice impacts neurology patients on stable treatments that are switched to a medication that is not necessarily equivalent or effective. One clinician expressed that "medical literature is no longer guiding care—only cost is."

ACCESS TO TESTING AND INNOVATIVE TREATMENTS

Access to innovative treatments was a major concern for meeting participants. Current legislation in several states prevents biomarker testing in neurology patients from insurance coverage. Biomarker testing is a growing and crucial development in neurology because it can connect patients to neurologists earlier in their disease. Several clinicians emphasized the importance of early detection and how it improves health outcomes.

A meeting participant also highlighted the need for protection of people living with neurological diseases against insurance practices, so patients aren't categorized to have a "preexisting condition" based on their biomarker results.

FORMULARY EXCLUSIONS OF INNOVATIVE TREATMENTS

Increasingly, pharmacy benefit managers (PBMs) have become a taxing issue for clinicians. PBMs are using exclusion lists to limit access to neurological disease medications. These exclusion lists, which typically include hundreds of medications across disease areas, exclude treatments from coverage, fully preventing patients from accessing the therapy their clinician prescribes. PBMs and insurers also limit access through "new-to-market" exclusions, which delay or deny coverage for newly FDA-approved therapies, forcing patients to wait before accessing the appropriate treatment.

A neurologist said, "Access to innovative treatments look good on paper, but in reality, the patients can't access them without roadblocks from insurance."

MEDICARE PART D CHALLENGES

Clinicians and advocates highlighted the need for greater patient awareness regarding Medicare Part D changes. The Inflation Reduction Act instituted several changes to the Medicare Part D Program. In addition to drug price negotiation, patient cost-sharing was altered to include a $2,000 out-of-pocket cap ($2,100 in 2026), as well as the Medicare Prescription Payment Plan.

The payment plan allows Part D beneficiaries to spread their out-of-pocket expenses evenly across the year, allowing them to better manage and plan their costs.

NEXT STEPS

Meeting participants identified new opportunities to create a more patient-centered approach to care for neurological disease patients. These next steps include new educational resources, legislative engagement and using their voice as advocates and clinician-advocates.

GET INVOLVED

To learn more about AfPA's Neurological Disease Working Group, contact Payton Marvin
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