



Neurological Disease Working Group

2024 Meeting Summary

The Alliance for Patient Access hosted its annual meeting for the Neurological Disease Working Group on June 7-8, 2024 in Washington, DC. Working group members convened to discuss policies impacting people living with neurological diseases like Alzheimer's, dementia and movement disorders.

Utilization Management

Meeting participants discussed the harm caused by utilization management. When health plans implement these tactics, providers and patients can experience many significant challenges, from disease progression to financial burdens. Meeting participants also noted the role that pharmacy benefit managers play in creating these barriers.

Prior Authorization

Prior authorization places a heavy administrative burden on providers and delays patient care. In some cases, treatment may even be denied. Meeting participants explained that this is particularly troublesome for people living with a neurological disease, who need timely treatment to slow disease progression.

Participants also highlighted a lack of transparency from health plans requesting prior authorization and said that peer-to-peer requests are rarely met with an appropriate peer.

Step Therapy

Another hurdle many providers experience is step therapy. Patients are forced to try alternative treatments and fail them before they can access their prescribed treatments. In some cases, one participant highlighted, a condition may have only one approved treatment, yet patients still must step through other drugs before they can access the right medication. The delays caused by step therapy are a serious hindrance to both providers and patients.

Non-Medical Switching

Non-medical switching also poses a challenge for providers and people living with neurological diseases. Insurers often make formulary decisions at the beginning of the year. But when health plans remove a treatment from a formulary, patients on that medication are switched off to a different covered medication.

These switches take decision-making power away from providers and people living with neurological diseases.



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Movement Disorders

Working group members discussed how crucial innovation is for patients with movement disorders. New treatments, however, are often out of reach for patients due to health plan restrictions.

In Parkinson's disease, for instance, patients are often restricted from accessing innovative medications due to medication exclusions and onerous utilization management protocols.

Cost Sharing

Working group members highlighted that health plans' cost-sharing efforts can place a heavy financial burden on patients. Copay accumulator programs, for instance, prevent copay cards from counting toward a patient's deductible. Patients are often left with overwhelming out-of-pocket costs.

Meanwhile, a new tactic called alternative funding programs also complicates coverage. When employers are making health plan decisions, a third-party vendor offers these programs as an alternative to coverage for specialty medications. Insured patients must go outside their health plan, taking funds from patient assistance programs meant for the uninsured and needy, to access their treatment.

Access in Alzheimer's Disease

Working group members also noted that FDA-approved disease-modifying treatments now provide hope for many patients with Alzheimer's. Accessing these treatments, however, is a challenging journey.

For instance, restrictions put into place by the Centers for Medicare and Medicaid Services require patients to enroll in a patient registry as a condition of coverage for newer therapies. The requirement can be burdensome to providers and patients.

Clinicians were, however, glad to see that Medicare has removed its burdensome requirements for accessing PET scans, an important tool in diagnosing and monitoring Alzheimer's disease.

Challenges in Long-Term Care

Meeting participants also highlighted the importance of long-term care facilities, especially for seniors living with a neurological condition.

Sometimes, however, well-intentioned CMS rules can get in the way of appropriate care. Such is the case with treatment for conditions like Parkinson's disease psychosis or Alzheimer's-related agitation. Long-term care facilities may be penalized for using medications that target these conditions, leading patients to be under treated. Clinicians noted that, due to these CMS restrictions, some long-term care facilities hesitate to accept patients who might need antipsychotics.

Needs Assessment

Meeting participants highlighted several areas where providers, patients and advocates can partner to encourage patient-centered care. Efforts should prioritize:

- Education to raise awareness of the impact of neurological diseases
- Better access to treatment through utilization management reform
- A focus on cost-sharing reform to ensure patients can afford their medications.

Next Steps

Working group members identified advocacy opportunities and discussed plans for educational materials to promote patient-centered care for people living with neurological diseases.

Get Involved

To learn more about AfPA's Neurological Disease Working Group, contact Casey McPherson at cmcpherson@allianceforpatientaccess.org.



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