



Neurological Disease Working Group

2023 Meeting Summary

The Alliance for Patient Access hosted its annual Neurological Disease Working Group meeting on May 12-13, 2023. Clinicians, advocates and other stakeholders convened to discuss policies affecting people living neurological diseases including Alzheimer's, dementia and movement disorders.

Utilization Management

Working Group members expressed a sense of encouragement as many new and innovative treatments have been approved in recent years for patients with neurological diseases. However, excessive utilization management practices frequently prevent patients from accessing these treatments and can lead to worsening symptoms, unneeded ER or doctor's visits and disease progression.

Step Therapy

Several clinicians expressed concerns that the current health care system focuses too much on "treating the average" rather than on individual, patient-centered care. Forcing patients to fail certain insurer-preferred therapies before approval of their provider-prescribed treatment can lead to negative outcomes and decreased quality of care.

Prior Authorization and Reauthorization

While prior authorization remains one of the most burdensome utilization management tools used by insurers, reauthorization similarly has significant negative impacts. One clinician, a headache specialist, recalls working for an extended period of time to identify a treatment that successfully treated their patients' migraines, however failing a reauthorization request, due to the patient having fewer migraine days since starting their treatment.

Cost Sharing and Specialty Tiers

Patients with neurological diseases may use copay cards to help cover their high medication costs. These cards have traditionally helped patients afford their medications, while also contributing towards a patient's out-of-pocket deductible. Some plans, however, have implemented copay accumulator programs which do not apply the card's value towards the patient's deductible. This leaves patients with unexpected costs once the assistance card runs out.

Patients also often must deal with co-insurance programs. Health plans may place innovative, but expensive, treatments in a "specialty tier" on the formulary. While the drug may still be covered, it is often accompanied by a co-insurance that can price many patients out.



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Barriers to Alzheimer's and Dementia Treatment

Working group members discussed several of the ongoing treatment barriers for patients with Alzheimer's. Last year's National Coverage Determination by the Centers for Medicare & Medicaid Services dealt a significant blow to the Alzheimer's community. This ruling effectively restricted access for disease-modifying treatments. For medications approved through the accelerated approval pathway, access is limited to only patients in CMS-approved clinical trials.

While patients, providers and advocates urged CMS to reconsider their determination, CMS has not yet revised their decision. The providers reiterated that the CMS decision severely limits access. Providers mentioned a number of barriers to clinical trials access, including transportation, issues with diverse representation, and the administrative burden, to name a few.

While CMS will allow broader coverage for disease-modifying Alzheimer's therapies receiving traditional FDA-approval, which now includes lecanemab, through a registry program, providers expressed concern about the administrative duties that this would place on clinicians and their offices.

Lastly, clinicians agreed that CMS's current coverage restrictions for amyloid PET scans are similarly repressive, limiting access to one test per lifetime for patients enrolled in clinical trials. In recent days, CMS has indicated they are revisiting this topic and will potentially allow broader access.

These barriers combine to pose significant challenges for those living with Alzheimer's disease, their families and their communities.

Continued Challenges in Long-Term Care

As many patients with Alzheimer's and dementia ultimately end up receiving care in long-term care facilities, recent changes due to the Public Health Emergency's end have emerged. As of May 11, the waiver eliminating a 3-day inpatient hospital stay to qualify for

Medicare Part A coverage went into effect. There is also continued concern regarding gradual dose reduction and access to psychotropic medications in long-term care facilities.

Clinicians expressed frustration at their difficulties gaining appropriate access to antipsychotic or other psychotropic medications for patients in long-term care facilities. Others noted that patients may have trouble accessing long-term care itself due to Medicare regulations that penalize facilities with high antipsychotic usage.

Needs Assessment

Working group members recognized that recent innovations continue to drastically change the treatment landscape. However, these groundbreaking advancements must be accessible and affordable for patients. Increasing awareness about new treatments, improving access to timely diagnostics, and ensuring continuity of care is paramount for patients in the neurological disease space.

Next Steps

Working group members discussed plans for educational materials to build on current and future advocacy efforts, as well as effective messaging for policy makers as they consider policies and legislation that prioritizes patient-centered care.

Get Involved

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



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