Rare Diseases Working Group

EBV+ PTLD Initiative Meeting Summary

On March 24, the Alliance for Patient Access hosted a virtual meeting of its Rare Diseases Working Group. The meeting brought together providers to discuss policies that affect clinicians and patients managing Epstein Barr Virus-Positive Post-Transplant Lymphoproliferative Disorder (EBV+PTLD), an ultra-rare and aggressive form of lymphoma with a high mortality rate, and to explore the possibilities posed by a potential new treatment option.

Awareness & Consistency

As with many rare diseases, awareness is a pressing issue for EBV+ PTLD, which can develop following a hematopoietic cell (HCT) or solid organ transplant (SOT). Given the particular rarity of this disease – an estimated few hundred patients are impacted in the United States annually – these challenges are heightened. A lack of awareness on the part of providers and policymakers can lead to misdiagnosis or treatment delays, with devastating results for patients who need timely access. During the meeting, one provider highlighted the variability across institutions and their protocols for EBV+ PTLD. Hospitals' different approaches to authorizing treatment for EBV+ PTLD may make it more difficult for insurance companies to create uniform payment models and for patients to access life-saving treatment quickly.

Prior Authorization

As providers look toward a new treatment option becoming available, they also anticipate the utilization management barriers that could accompany it. One health plan barrier in particular could undermine optimal care.

Initiative members explored the encumbrance prior authorization can cause for providers, as well as the dangers it poses for EBV+ PTLD patients. "This is going to be an expensive medication no matter what," one provider said. "And that's going to be something that gives insurers an excuse to create obstacles."

The time spent waiting for approval is simply not an option for EBV+ PTLD patients, several providers emphasized. Given how time sensitive the condition is, it is crucial that restrictions do not go beyond the label. Options to address prior authorization, including federal and state legislation that would streamline the process, were discussed. Some members raised "gold card" legislation, which would allow select physicians with proven track records of prior authorization approvals to bypass prior authorization processes.

AfPA | Alliance for Patient Access

New Treatment Options

A new treatment developed specifically to treat EBV+ PTLD is undergoing review for FDA approval. Providers discussed the payment models that health plans might use to cover the new treatment, given the rarity of the disease and the small patient population it affects.

Also discussed was the need for a procedural ICD code for the administration of FDA-approved therapies, should they be approved, to ensure appropriate coding for proper and efficient reimbursement from payers.

Several providers also raised concerns that, if the drug is approved, coverage questions could delay treatment. With treatments for more common diseases, it can take several months for health plans to begin to incorporate and properly process treatment requests. But for a treatment limited to an ultra-rare condition like EBV+ PTLD, initiative members explained, it could take even longer.

It's clear that clinician engagement with health plans may be needed to guarantee insurers understand the severity and progression of EBV+ PTLD.

EBV+ PTLD experts may need to lend their expertise to health plans to convey the severe need for timely approval processes and treatment, and payers must ensure that any peer-to-peer meetings during the prior authorization process include specialists.

Timeliness

The meeting also highlighted the importance of timely care in cases of EBV+ PTLD. One working group member explained that many patients don't live very long following a diagnosis. The median survival time is 0.7 months for HCT patients and 4.1 months for SOT patients. Barriers like prior authorization will make it nearly impossible for patients to receive treatment for their condition.

Next Steps

Given the short timeframe for treating EBV+ PTLD patients, clinicians should be equipped and prepared to advocate for their patients' access. AfPA's Rare Diseases Working Group and its EBV+ PTLD initiative stands ready to engage with clinicians in support of policies that encourage optimal, patient-centered care for EBV+ PTLD patients.

AfPA | Alliance for Patient Access

allianceforpatientaccess.org