

We deeply regret NICE's decision to recommend that NHS England not fund ganaxolone for the treatment of seizures in children suffering from cyclin-dependent kinase-like 5 deficiency disorder (CDD).

Ganaxolone (Ztalmy) is the first anti-seizure medication in the UK approved by the MHRA for this rare and devastating genetic disorder and it is disappointing that children with CDD, their families, and their carers will not be able to address the serious unmet need that remains.

Orion remain open to finding an appropriate and sustainable path to secure access to ganaxolone for people/individuals living with CDD in the UK.

Ian Wariner, Country Manager UK

August 2024 / CORP-759(1)