

Technology Advisory Committee B Interests Register

Ganaxolone for treating seizures caused by CDKL5 deficiency disorder in people 2 years and over [ID3988]

Publication Date: TBC

| Name | Role with NICE | Type of interest | Description of interest | Interest declared | Interest ceased | Comments |
|-------------|-----------------|------------------|---|-------------------------------------|-----------------|---|
| Dr Sam Amin | Clinical Expert | Indirect | <p>Co-authored the international study investigating ganaxolone in CDKL5.</p> <p>Co-authoring the results of the open label extension study. This study was sponsored by Marinus pharmaceuticals.</p> <p>Chief investigator on another study investigating this compound in a another neurological condition, TSC.</p> <p>Orion has given a grant to the CDKL5UK charity. CDKL5UK has purchased an online software platform, vCreate for my hospital with the grant</p> | <p>11/04/2024</p> <p>04/05/2023</p> | N/A | It was agreed that Sam's declaration would not prevent him from providing expert advice to the committee. |

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|------|----------------|------------------|---|-------------------|-----------------|----------|
| | | | <p>Sam Amin co-authored the international study investigating ganaxolone in CDKL5. He is also co-authoring the results of the open label extension study. This study was sponsored by Marinus pharmaceuticals.</p> <p>He is also chief investigator on another study investigating this compound in another neurological condition, TSC.</p> <p>Orion has given a grant to the CDKL5UK charity. CDKL5UK has purchased an online software platform, vCreate for his hospital with the grant.</p> | | | |