

**From Director of Hospital Care
Paul Cavanagh**



By email
Chief Executives of Trusts - for cascade to:
Medical Directors
Directors of Nursing
Directors of Acute Services
Heads of Pharmacy & Medicines Management
Clinical & Social Governance Leads

Director of Primary Care, SPPG - for cascade to:
Head of Pharmacy & Medicines Management

Strategic Planning and Performance Group
12-22 Linenhall Street
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Tel: 0300 555 0115
Email: SPPG-NICEinbox@hscni.net
Date: 24 March 2025

Dear Colleague

**NICE TECHNOLOGY APPRAISAL TA1033
GANAXOLONE FOR TREATING SEIZURES CAUSED BY CDKL5 DEFICIENCY
DISORDER IN PEOPLE 2 YEARS AND OVER**

I refer to the above NICE guidance and the required arrangements to ensure compliance with the NICE decision **not to recommend** this regime for the treatment of this condition.

Background

NICE TA1033 **does not recommend** Ganaxolone for treating seizures caused by CDKL5 deficiency disorder in people 2 years and over.

This recommendation is not intended to affect treatment with Ganaxolone that was started in the NHS before this guidance was published. People having treatment outside this recommendation may continue without change to the funding arrangements in place for them before this guidance was published, until they and their NHS clinician consider it appropriate to stop.

This position has been endorsed by the DOH and represents the Department's formal policy position on this NICE guidance.

Action required

Trusts should take immediate action to ensure compliance with NICE TA1033

Trusts should ensure that within one month:

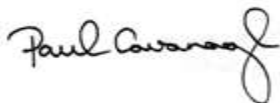
- targeted dissemination takes place;
- a clinical / management leader is in place to ensure the discharging of the Trust's responsibilities; and,
- no patients requiring treatment for treating seizures caused by CDKL5 deficiency disorder in people 2 years and over receive Ganaxolone

Assurance arrangements

The SPPG will seek direct assurances from Trusts on an ongoing basis regarding the actions outlined above.

Thank you for your attention with this matter. If you have any queries please contact SPPG-NICEinbox@hscni.net in the SPPG Hospital Care Directorate in the first instance.

Yours sincerely



Paul Cavanagh
Director of Hospital Care

Cc Chief Pharmaceutical Officer
Chief Medical Officer
Chief Executive Patient and Client Council
Chief Executive/Postgraduate Dean, NIMDTA
Chief Executive, NICPLD
Chief Executive, NIPEC
Chief Executive, NIBTS
Chief Executive, RQIA
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