

March 2026

Urgent update: SMC decision on evaluation of omaveloxolone in Scotland

On 9th March, the Scottish Medicines Consortium (SMC) announced that it has not recommended omaveloxolone for the treatment of Friedreich's ataxia (FA) in people aged 16 and over within the NHS in Scotland.

This news will be very disappointing for the FA community, as it is for us at Ataxia UK.

The SMC said that the evidence of benefits from omaveloxolone compared to current treatment was not strong enough to justify the cost of the medicine, and that the manufacturing company (Biogen) did not provide strong enough evidence of omaveloxolone's value for money.

The decision was made by considering evidence from the manufacturing company (Biogen), Ataxia UK, and healthcare professionals, about the potential benefits and impact that omaveloxolone could have on the lives of people living with and affected by FA.

As per Biogen's statement to Ataxia UK, which can be read [here](#), **it is encouraging and an important step that the SMC acknowledged both the clinical value of this treatment and the significant unmet need in FA.**

Despite this decision, as detailed in the [February policy briefing note](#), **clinicians are still able to make individual funding requests for patients to be prescribed omaveloxolone under the PACS Tier 2 process in Scotland.** This is a route that may allow access to omaveloxolone on a case-by-case basis despite a negative recommendation from the SMC. We have advised that people in Scotland can speak to their neurologist about this and that Ataxia UK can support with the process. We have been made aware of at least one person with FA in Scotland who has been prescribed omaveloxolone via this process.

To read a summary of the SMC's decision please [click here](#) to read the SMC's Decision Explained document.

For more detailed information regarding the SMC's decision please [click here](#) to read the SMC's Detailed Advice Document.

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Ataxia UK's Interim Access Campaign for FA treatment

Ataxia UK is leading an evidence-based, and community-backed campaign to secure interim equitable access to the only available treatment for Friedreich's ataxia.

Over 10,000 supporters signed our open letter to the Secretary of State for Health and Social Care to address this issue. As a result of our sustained campaign, the issue was also raised at Prime Minister's Questions as well as presented at the All-Party Parliamentary Group (APPG) for Rare Disease.

We have engaged directly with DHSC ministers, clinicians, researchers, and industry partners. On 10th December 2025, a delegation led by our Chief Executive, along with Jonathan Brash MP, met with the Parliamentary Under-Secretary of State for Health Innovation and Safety to press for interim access to Omap along with addressing structural barriers faced by the rare disease community in general.

[Our campaign continues and we invite you to work with us to ensure that people living with FA can gain access to this life-changing treatment.](#)

Important Links

[Ataxia UK Policy & Influencing documents](#)

[Ataxia UK Omaveloxolone Policy Briefing Note March 2026](#)

[Scottish Medicines Consortium omaveloxolone decision](#) (SMC website)

[Scottish Medicines Consortium omaveloxolone decision - detailed overview](#) (SMC website)

[Biogen Statement following SMC decision](#)

About Ataxia UK

Ataxia is the umbrella term for a group of neurological conditions and Ataxia UK is the UK's leading ataxia support and research-active charity. Our Services team is dedicated to supporting everyone affected by ataxia in the UK to live their best possible life. We offer a Helpline and Advocacy service that provides trusted information, tailored advice, and one-to-one support to help people access their rights. Alongside this, we deliver a range of activities, engagement opportunities, and volunteer-led initiatives designed to bring the ataxia community together and reduce feelings of isolation.

For policy enquiries, please contact Communications@ataxia.org.uk | ataxia.org.uk

Ataxia UK works across the whole of the UK and is a charity registered in Scotland (no SC040607) and in England and Wales (no 1102391) and a company limited by guarantee (4974832).