PRESS RELEASE

Ataxia UK urges action as Republic of Ireland approves access to Friedreich's ataxia treatment still unavailable to patients in Northern Ireland and the rest of the UK

London, 28 August 2026: Ataxia UK is calling again on people across the UK to add their name to the over 5,000 who have already signed our Open Letter to Andy Burnham after the Health Service Executive (HSE) in Republic of Ireland approved reimbursement for omaveloxolone, branded as Skyclarys, for eligible people living with Friedreich's ataxia.

The decision means patients over the age of 16 in the Republic of Ireland are set to gain publicly reimbursed access to the only licensed treatment for Friedreich's ataxia, while patients and families in Northern Ireland, England, Scotland and Wales still cannot access the same treatment through the NHS.

Friedreich's ataxia is a rare, degenerative, life-limiting and severely disabling neurological condition. It progressively affects the nervous system, leading to loss of balance and coordination, weakening of the heart and other complications, and significantly reduced life expectancy.

Omaveloxolone is the first and only licensed treatment for Friedreich's ataxia and it significantly slows the progression of the condition. The MHRA approved omaveloxolone in April 2025 for people aged 16 and over in the UK, but the medicine is still not routinely available to patients through the NHS in England, Scotland or Wales, or through HSC in Northern Ireland.

Ireland's decision shows that progress is possible when health services, government and the manufacturer work collaboratively to find a route to patient access. Ataxia UK believes families in Northern Ireland and across the UK should not be left behind simply because reimbursement processes have stalled.

The charity is therefore renewing its call for urgent action and asking supporters to add their names to the Open Letter to Andy Burnham, urging him to help bring NHS England, the Department of Health and Social Care, NICE and the manufacturer, Biogen, together to explore an interim access pathway to omaveloxolone for people with Friedreich's ataxia.

Sue Millman, Chief Executive of Ataxia UK, said: *"The HSE decision is welcome news for families in the Republic of Ireland, but it also makes the inequality facing families in Northern Ireland and the rest of the UK impossible to ignore. People living with Friedreich's ataxia do not have time on their side. We need urgent leadership to turn regulatory approval into real access for patients."*

The Open Letter asks Andy Burnham to use his voice and influence to help secure a practical interim access route while formal reimbursement decisions continue. Ataxia UK is encouraging patients, families, clinicians, parliamentarians and members of the public to sign and share the letter. **You can read and sign the Open Letter here.**

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Ataxia UK is the leading national charity in the UK for people affected by any type of ataxia. We fund research into finding treatments and cures, and offer advice, information and support to people affected by the condition. Ataxia UK works across the whole of the UK and is a charity registered in Scotland (no SC040607) and in England and Wales (no1102391) and a company limited by guarantee (4974832) www.ataxia.org.uk