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The Rt Hon Yvette Cooper MP
Secretary of State for Health and Social Care
Department of Health and Social Care
Ministerial Correspondence and Public Enquiries Unit
39 Victoria Street
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Our Ref: MP16209 5 October 2026

Dear Secretary of State,

Access to omaveloxolone (Skyclarys) for people with Friedreich's ataxia in England

I am writing on behalf of my constituents who live with Friedreich's ataxia, or have family members who are affected. My constituents have signed and shared a petition on this issue and asked me to raise it with you directly. I am glad to do so.

Friedreich's ataxia is a rare, inherited and progressive condition. It usually starts in childhood or adolescence. Over time it takes away a person's balance, coordination, speech and mobility, and it can also affect the heart. Most people with the condition end up using a wheelchair. Until recently there was no licensed treatment at all.

That changed when omaveloxolone was approved in the United States in 2023 and in the EU in 2024. The MHRA approved it on 23 April 2025 for people aged 16 and over. It is the first and only licensed treatment for Friedreich's ataxia. It does not cure the condition, but it slows its progression. For people losing function year by year, that difference is enormous.

Seventeen months on, patients in England still cannot get it on the NHS. Biogen withdrew its NICE submission in spring 2025 after NICE indicated the appraisal would not proceed to committee. NICE terminated the appraisal in May 2025. There has been no new submission since.

The result is that England is now falling behind its neighbours. In Scotland, clinicians can apply for the drug case by case through the PACS Tier 2 route, and at least one patient has been prescribed it this way. In Wales, individual patient funding requests have been possible since February 2026. In Ireland, the HSE agreed to fund the drug in August 2026 after Biogen made an improved financial offer. In England there is no route at all.

The Irish decision shows that a deal on price is possible when there is a will on both sides. Biogen told Ataxia UK earlier this month that it remains committed to working with NICE and NHS England to secure access. The responsibility here is shared, but people with Friedreich's ataxia in England are the ones paying the price for the stalemate. Every month without treatment is a month of progression that cannot be reversed.

Families affected by the condition have made a short film about what their lives are like and what this drug could mean for them. It is a powerful and moving piece, and I would urge you or your officials to watch it.

I would be grateful if you could tell me:

1. What discussions the Department, NHS England and NICE have had with Biogen since the NICE appraisal was terminated, and whether you expect a new submission, and when.
2. Whether you will ask NHS England to open talks with Biogen on an interim access arrangement for adults in England while a new NICE appraisal takes place.
3. Whether you will look at how NICE's evaluation routes work for very rare, progressive conditions such as Friedreich's ataxia, which do not fit neatly into the current criteria.
4. Whether you or the relevant minister will meet Ataxia UK and affected families to hear their case directly.

I look forward to your reply.

Yours sincerely,



Dr Manuela Perteghella MP
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