Omav Campaign update: Meeting with the Department of Health and Social Care

Over the past few months, Ataxia UK has been working collaboratively with families, clinicians, policymakers and parliamentarians to press for access to a licenced treatment – omaveloxolone (Omav) - for those affected by Friedreich’s ataxia (FA) aged 16 years and over.

On December 10th, an Ataxia UK delegation led by its Chief Executive Sue Millman along with Jonathan Brash MP met with Dr Zubair Ahmed MP, Parliamentary Under-Secretary of State for Health Innovation and Safety and other officials from the Department of Health and Social Care (DHSC) in London.

At the heart of the meeting were Georgia Hart, who is living with FA, and her mother Bev. Their powerful testimony during the discussion reflected the deeper realities of the condition.

Bev spoke about the urgency of the situation and the importance of sustained support, highlighting that "Jonathan's support for us has been amazing, helping to raise awareness at this crucial time provides hope that change will happen."

For Georgia, the meeting offered a vital opportunity to speak directly about her lived experience, explaining that "being able to tell my story and highlight how feelings of isolation are made worse by disparities in treatments and outcomes was really important to me."

The meeting resulted in the following agreed next steps:

Interim access: The minister agreed to instruct NHS England to initiate discussions with the manufacturer (Biogen) to explore options for an interim access pathway for Omav in England for adults with FA while the company prepares to re-submit its proposal to NICE for approval.

Prevalence and data gaps: Dr Ahmed acknowledged the lack of prevalence data for the ataxias and rare diseases more broadly and committed to looking into the matter.

Wider rare disease barriers: Dr Ahmed expressed a commitment to look at some of the barriers affecting the evaluation of medicines for rare diseases that were discussed at the meeting.

Continued dialogue: All the stakeholders agreed on continuous dialogue and sustained engagement.

This meeting is a major milestone in the Omav campaign led by the Ataxia UK community, which saw over 10,000 people sign our open letter to the Secretary of State for the Department of Health and Social Care. Many members of this community supported the campaign by sharing our letters with their constituency MPs. On November 5th Jonathan Brash MP raised the issue of access to Omav at Prime Minister’s Questions in the House of Commons and formally requested a meeting for Ataxia UK with the DHSC.

Jonathan Brash MP chaired the meeting and set out the central point: the urgent need for interim access to the only licenced treatment for those adults affected by FA in England especially in the wake of emerging disparities across the UK (*since a route for potential interim access now exists in Scotland*).

Ataxia UK stresses that this meeting does not represent a decision on access nor does it deliver an immediate result around access. It does, however, mark a major step forward for a journey that we embarked on together with our community. The realities faced by people with FA have been heard by those who have the power to act. The campaign continues. To stay up to date on the latest developments please sign up to our Omav Updates E-newsletter.