

Jeremy Miles AS/MS
Ysgrifennydd y Cabinet dros Iechyd a Gofal Cymdeithasol
Cabinet Secretary for Health and Social Care



Llywodraeth Cymru
Welsh Government

Ein cyf/Our ref: PO/JMHSC/0600/25

Peter Fox MS
Chair, Health and Social Care Committee
Welsh Parliament
Cardiff
CF99 1SN

SeneddHealth@senedd.wales

21 November 2025

Dear Peter,

You may be aware that rare disease policy is aligned across the United Kingdom through the [UK Rare Diseases Framework](#) (2021-2026). The Framework is structured around four priorities: (i) helping patients get a final diagnosis faster; (ii) increasing awareness of rare diseases amongst healthcare professionals; (iii) better coordination of care; and (iv) improving access to specialist care, treatment and drugs. This is underpinned by national action plans outlining the steps each nation will take in pursuit of these priorities, such as Wales' [Rare Disease Action Plan](#).

The Framework has brought increased attention to rare diseases, enabled four-nation information sharing about service development, and permitted structured third sector input. There have been clear benefits to this approach given the limited prevalence of individual rare diseases. The Framework is due to expire in January 2026 and officials from across the four nations have been exploring the future of UK-wide rare disease policy collaboration.

Following these official-level discussions, the UK Government's Parliamentary Under-Secretary of State for Public Health and Prevention wrote to Ministers of the Devolved Governments on 26 August proposing a one-year extension to the Framework. This proposal reflected a four-nation desire to provide sufficient time for engagement with the rare disease community about the future policy direction. It also recognised the forthcoming 2026 parliamentary elections in Wales and Scotland and the ongoing structural reorganisation of NHS England.

Bae Caerdydd • Cardiff Bay
Caerdydd • Cardiff
CF99 1SN

Canolfan Cyswllt Cyntaf / First Point of Contact Centre:
0300 0604400

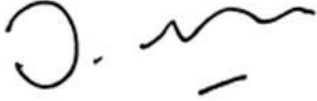
Gohebiaeth.Jeremy.Miles@llyw.cymru
Correspondence.Jeremy.Miles@gov.wales

Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

I have responded confirming my support for a one-year extension, as have my counterparts in Scotland and Northern Ireland. Our collective agreement means the Framework and the Wales Action Plan will continue until January 2027. I am writing to you as Chair of the Health and Social Care Committee to notify you of this extension.

Yours sincerely,

A handwritten signature in black ink, consisting of a large 'J' followed by a series of wavy lines and a short horizontal stroke at the end.

Jeremy Miles AS/MS

Ysgrifennydd y Cabinet dros Iechyd a Gofal Cymdeithasol
Cabinet Secretary for Health and Social Care