Cabinet Secretary for Health and Social Care
Welsh Parliament
Cardiff Bay
Cardiff
CF99 1SN

18 September 2025

Urgent request to support a one-year extension of the UK Rare Diseases Framework

Dear Jeremy Miles MS,

I am writing to you today on behalf of Genetic Alliance UK, an alliance of over 200 charities and support groups working together to improve the lives of people in the UK with genetic, rare and undiagnosed conditions. Following Tuesday's meeting of the Wales Rare Disease Implementation Group (RDIG), we are aware of the request from the Parliamentary Under-Secretary of State for Public Health and Prevention to extend the UK Rare Diseases Framework and are writing to strongly urge the Welsh Government to agree to this one-year extension.

The current Framework and the Welsh Rare Disease Action Plan, due to conclude in 2026, has laid a vital foundation for improving the lives of the 180,000 people in Wales living with a rare condition. It is crucial that the momentum we have built is not lost. The need for a dedicated, long-term policy for rare conditions is supported overwhelmingly by the rare conditions community, as evidenced in 'More than you can imagine: Opportunities for improving the lives of people with rare conditions', a recent report by Genetic Alliance UK.

A one-year extension will enable the Welsh Government to progress the work of the Welsh Rare Disease Implementation Group (RDIG) which has been a constructive forum for key stakeholders in the rare conditions space. RDIG has contributed to delivering many initiatives that have improved care for people with rare conditions in Wales. For example, RDIG has supported the launch of a Digital Rare Care Centre Pilot which will provide an online platform for medical, social care, and professional support for those with rare conditions in Wales. It also led the development of a rare disease dashboard and patient-reported measures to support evaluation. The success of a Syndromes Without a Name (SWAN) Clinic pilot has demonstrated improved care coordination for those affected by rare conditions. This has now been commissioned as an NHS service. At the end of the month, the launch of an inaugural meeting of the Rare Disease Research Network will take place to foster collaborations between academic institutions, the NHS, and individuals with lived experience.

Furthermore, extension of the Framework will facilitate cooperation with the other home nations, ensuring Wales not only benefits from a shared pool of expertise and resources but also contributes its own innovations and experience, building a truly reciprocal partnership that strengthens rare conditions initiatives across the UK.

This critical period should also be used to explore the future of what Wales’ rare conditions policy could look like. Future policy must be developed in close, ongoing collaboration with the rare conditions community to ensure it's effectively implemented. This will ensure that a new framework is robust and effective in meeting the complex needs of our community for years to come. Genetic Alliance UK stands ready to support this vital dialogue.

Extending the Framework will send a powerful signal to people living with rare conditions that their needs are a priority.

Thank you for your time and consideration of this urgent request.

Yours sincerely,

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Emma Hughes

Policy & Engagement Manager (Wales)

Genetic Alliance UK