



Minister for Public Health and Women's Health  
The Scottish Government  
St Andrew's House  
Regent Road  
Edinburgh  
EH1 3DG

10 September 2025

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

Dear Minister,

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 today's meeting of the Scottish Rare Disease Implementation Board, 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 Scottish Government to agree to this one-year extension.

The current Framework and the Scottish Rare Disease Action Plan, due to conclude in 2026, has laid a vital foundation for improving the lives of the 400,000 people in Scotland 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 Scottish Government to progress the work of Scottish Rare Disease Implementation Board (RDIB) which has been a constructive forum for key stakeholders in the rare conditions space. RDIB has contributed to delivering many initiatives that have improved care for people with rare conditions in Scotland. For example, RDIB has supported the advancement of CARDRISS initiatives, development of vital education resources for healthcare professionals and, through funding allocated by the board, is contributing to the delivery of an essential information and support service for families affected by rare conditions.

Furthermore, extension of the Framework will facilitate cooperation with the other home nations, ensuring Scotland 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 what Scotland's future 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,

Natalie Frankish

Head of Scotland and Public Affairs

Genetic Alliance UK

[contactus@geneticalliance.org.uk](mailto:contactus@geneticalliance.org.uk)

[geneticalliance.org.uk](https://geneticalliance.org.uk)

Registered charity numbers: 1114195 and SC039299

Registered company number: 05772999