DIRECTORATE FOR CHIEF OPERATING OFFICER, NHS SCOTLAND
DCOO : HEALTHCARE QUALITY AND IMPROVEMENT

Scottish Government
Riaghaltas na h-Alba
gov.scot

Natalie Frankish
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Our Reference: 202500484269

23 September 2025

Dear Natalie Frankish ,

Thank you for your letter of 10 September and for setting out so clearly the case for a one-year extension to the UK Rare Diseases Framework. I really appreciate the constructive way Genetic Alliance UK continues to highlight the voice of the rare conditions community and the progress being made in Scotland.

The examples you shared – from CARDRISS initiatives, to education resources for healthcare professionals, and the development of a new information and support service for families – demonstrate the value of the Scottish Rare Disease Implementation Board and the difference it has made in bringing stakeholders together around shared priorities.

Following careful consideration, the Scottish Government is supportive of a one-year extension to the current Framework. We agree that this provides the best opportunity to maintain four-nations collaboration, protect continuity, and create the space needed for meaningful consultation with people living with rare conditions before the next iteration of the Framework is developed.

In Scotland, our focus will remain on delivering the commitments set out in the Rare Disease Action Plan. While we are not in a position to expand the scope of this work during the extension period, we are committed to maintaining strong coordination and contributing actively to four-nations discussions on the successor Framework.

I want to thank you and Genetic Alliance UK for your continued leadership and partnership. Your work is vital in ensuring that future policy reflects the needs and priorities of people with rare conditions, and we look forward to continuing to work closely with you as we move through this transition period.

Yours sincerely

Tom Cranston
HQI : GENOMICS, DIAGNOSTICS AND PARTICIPATION