



Department of Health & Social Care

From Ashley Dalton MP
Parliamentary Under-Secretary of State
for Public Health and Prevention

39 Victoria Street
London
SW1H 0EU

Peter Dowd MP
By email to: peter.dowd.mp@parliament.uk

21 November 2025

Dear Peter,

Thank you for your ongoing work as Chair of the All-Party Parliamentary Group on Rare, Genetic and Undiagnosed Conditions. I welcome your continued efforts to understand the challenges facing people living with rare and genetic conditions and work constructively with your members and stakeholders to identify solutions. As you are aware rare diseases, though individually uncommon, affect about 3.5 million people in the UK and it is important that we continue to strive to address the enormous unmet need and health inequalities which exist for people living with rare conditions.

As the Minister with responsibility for rare diseases, I am pleased to be able to write to you today to confirm that Ministers from all four nations have agreed to extend the UK Rare Diseases Framework by one year. Extending the UK wide Framework demonstrates our ongoing commitment and helps coordinate efforts to better support those with rare diseases.

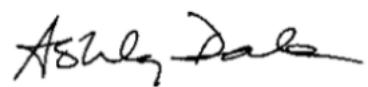
The UK Rare Diseases Framework was published following the National Conversation on Rare Diseases which received nearly 6300 responses. This helped identify the four priorities of the Framework in tackling rare diseases: helping patients get a final diagnosis faster, increasing awareness of rare diseases among healthcare professionals, better coordination of care, and improving access to specialist care, treatment and drugs. In England, we have now published four action plans setting out how we will address the priorities of the Framework. The four nations approach has been a cornerstone of our progress, ensuring that delivery of the framework by the actions plans responds to the varied challenges across our rare disease communities.

There is of course considerable interest amongst our stakeholders, and we are now actively working with the rare diseases community to help shape the next steps beyond the current Framework.

I have asked my officials to work with their counterparts in Scotland, Wales and Northern Ireland and return to me, by autumn next year, with proposals for what should follow when the one-year extension expires. I hope we can once again reach agreement on a UK wide approach.

Thank you for your continued support in improving outcomes for those living with rare diseases. Please do not hesitate to get in touch should you have any questions.

Yours sincerely,

A handwritten signature in black ink, appearing to read "Ashley Dalton".

ASHLEY DALTON