

James Frith MP
Parliamentary Under-Secretary of State
Department of Health and Social Care
39 Victoria Street
London
SW1H 0EU

Monday 19 October 2026

Renewing the UK Rare Diseases Framework

Dear Minister,

With the UK Rare Diseases Framework set to expire in January 2027, I am writing to ask for your commitment to securing a successor UK policy for rare conditions across. Given the breadth of your portfolio, you will recognise both the vital need for, and value of, a comprehensive national policy for rare conditions. I would be grateful for the opportunity to meet with you and your officials this November to discuss how we can take this forward, and to share the findings of our enclosed *Future for Rare* report.

Over 3.5 million people across the UK live with a rare condition, yet for far too many of them, the health system simply isn't working. Across the more than 7,000 known conditions, fewer than a third have dedicated NICE guidance, over a quarter lack a specialised NHS service, and fewer than half have genetic testing available. For individuals and families, these system gaps directly compromise their ability to live well with their condition. They also carry a staggering public cost: according to recent analysis by the BioIndustry Association (BIA), delayed diagnoses and treatment shortages cost the NHS £340 million annually, alongside £4.7 billion in disability support and £14.9 billion in lost productivity.

The current Framework, published by your department in collaboration with counterparts in Scotland, Wales and Northern Ireland, has been a critical catalyst for improvement. It has underpinned national registries, the Rare Disease Research UK platform, innovative care coordination models, undiagnosed condition clinic pilots, and the NICE quality standard for rare diseases. If the Framework lapses without a successor, these vital national assets risk losing the policy structure that sustains them. We are not asking the government to start from scratch, but rather to protect and build upon what has already been achieved.

Our report, *Future for Rare: A new vision for rare conditions policy in the UK*, sets out a pragmatic, consensus-led roadmap for the future. Built on a comprehensive national survey, evidence review, and multi-stakeholder engagement programme, it delivers actionable solutions shaped by the rare community.

Together, we are urging governments to work together and take three key steps:

1. Renew the commitment to a UK rare conditions policy while establishing a National Clinical Lead for rare conditions in each nation to drive delivery.
2. Resource a national core data offer and embed robust diagnostic capabilities across the entire health system.
3. Organise care around sustainable clinical networks and track progress through an annual national patient experience survey.

No single nation has the population numbers alone to drive clinical progress or support viable registries for individual rare conditions; cross-border collaboration is therefore in the best interest of each UK nation.

A renewed UK-wide policy for rare conditions will also directly advance England's broader health priorities. Under the 10-Year Health Plan, it drives the shift from hospital to community care by linking neighborhood teams with specialist networks, embedding NICE quality standards, and enriching the single patient record with rare condition data to reinforce Core20PLUS5 commitments. Appointing National Clinical Leads, modeled on the clinical directors who transformed cancer outcomes, establishes clear accountability through ongoing NHS reform. Crucially, four-nation scale is essential to power the clinical registries, trial cohorts, Genomic Medicine Service, and MHRA frameworks needed to make England a leader in European life sciences by 2030, while offering strategic insights to embed rare conditions early into the National Care Service and Mental Health Strategy to cut costs and elevate care.

Decisions on the future of rare conditions policy for the UK must be made now to ensure a seamless transition before January 2027. I look forward to your confirmation that the government will renew this vital policy, as well as a formal response to the enclosed report.

I would be delighted to meet with you and your team in November to discuss how we can work together to deliver these goals.

Yours sincerely,



Nick Meade

Chief Executive

Genetic Alliance UK

contactus@geneticalliance.org.uk
geneticalliance.org.uk

Registered charity numbers: 1114195 and SC039299

Registered company number: 05772999