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Monday 16th February 2026

Cross-sector call for the appointment of a National Clinical Director for Rare Diseases

Dear Secretary of State and Sir James,

We are writing as a diverse group of organisations and individuals representing the rare disease community – united in our ambition to improve the lives of people living with or caring for someone with a rare disease. **We believe that the appointment of a National Clinical Director (NCD) for Rare Diseases could make a real difference.**

There are 3.5 million people across the UK living with a rare disease – with 1 in 17 people affected at some point in their lives.¹ These conditions may be individually rare, but they are collectively common. We know that rare diseases place a significant physical, social and financial burden on individuals, families, the health system and the economy as a whole.² The cost of delayed diagnosis and limited treatment options is estimated at £340 million each year, with a further £4.7 billion in health-related disability costs and £14.9 billion annual loss to the economy.³

People affected by rare diseases deserve to be represented by a leading clinical voice at the highest level of Government and the NHS. As NHS England merges into the Department of Health and Social Care, and with confirmation that the *UK Rare Diseases Framework* will be extended for another year to 2027,⁴ we have an unmissable opportunity to reimagine what strong leadership looks like as we move into this new chapter of rare disease policy.

We propose the appointment of an NCD for Rare Diseases. We believe that this role would help to turn policy into practice across the following key areas:

- **Providing national clinical leadership** by: helping to guide the strategic direction of what follows the *UK Rare Diseases Framework* when it expires in 2027; aligning clinical priorities with NHS service planning and commissioning to improve quality of care and outcomes; and translating what the Government's wider reform agenda and three shifts for the NHS mean for rare diseases, such as the expansion of newborn screening as part of the shift from sickness to prevention
- **Championing the patient voice** by: regularly meeting with the patient community to understand their lived experiences and advocating for them at the national level; and encouraging the co-design of services with the patient community to meet their needs
- **Joining up the rare disease landscape** by: linking different parts of the rare disease environment, including the Government, the NHS, the National Institute for Health and Care Excellence (NICE), the National Institute for Health and Care Research (NIHR), the UK National Screening Committee

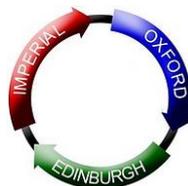
(UK NSC) and the wider life sciences sector; and helping to co-ordinate rare disease strategies across the devolved nations of the UK

NCDs have been highly successful in other areas; for example, the long-standing National Clinical Director for Cancer, Professor Peter Johnson, led the establishment of the Cancer Healthcare Goals programme, which has secured millions in funding for vital cancer research.⁵ We fully support your determination, Secretary of State, “to make sure that senior leadership in the NHS and in Government back great clinical leadership”.⁶ Extending what has been proven to work elsewhere to rare diseases would be an important step towards equity between rare and more prevalent conditions.

With the Government’s confirmation that the *UK Rare Diseases Framework* will be extended to 2027 and its future considered in 2026, we hope that the Government will use this as an opportunity to make rare diseases a national priority. The appointment of an NCD for Rare Diseases in 2026 should be part of this renewed commitment and would show that the Government and the NHS is serious about progress.

We would collectively welcome the opportunity to work with you to make this role a reality. We look forward to your response.

Yours sincerely,



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All references accessed February 2026

¹ UK Government. *England Rare Diseases Action Plan 2025: main report*. 2025. <https://www.gov.uk/government/publications/england-rare-diseases-action-plan-2025/england-rare-diseases-action-plan-2025-main-report>

² Genetic Alliance UK. *The Hidden Costs of Rare Diseases: A Feasibility Study*. 2016. <https://geneticalliance.org.uk/wp-content/uploads/2024/02/hidden-costs-2016.pdf>

³ Medicines and Healthcare products Regulatory Agency. *Major change for rare disease treatments on way, signals MHRA*. 2025. <https://www.gov.uk/government/news/major-change-for-rare-disease-treatments-on-way-signals-mhra#eel-decline>

⁴ Genetic Alliance UK. *Letter to Peter Dowd MP from Ashley Dalton MP, Parliamentary Under-Secretary of State for Public Health and Prevention*. 2025. <https://geneticalliance.org.uk/wp-content/uploads/2025/11/Min.-Dalton-to-APPG-on-Rare-Genetic-and-Undiagnosed-Conditions-21-Nov.pdf>

⁵ UK Government. *Cancer Healthcare Goals*. 2025. <https://www.gov.uk/government/publications/life-sciences-healthcare-goals/cancer-healthcare-goals>

⁶ Hansard. *Health and Adult Social Care Reform. Volume 759: debated on Monday 6 January 2025*. 2025. <https://hansard.parliament.uk/Commons/2025-01-06/debates/7725CFF7-F57D-4552-B762-374092F477C0/HealthAndAdultSocialCareReform>