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*Dear Mr Kent,*

Thank you for your letter of 10 June introducing Rare Disease UK and offering your kind words of congratulations on my appointment as Minister of State for Public Health.

I was very pleased that the EC Recommendation on Rare Diseases was formally adopted in June. We recognise the value of sharing evidence and methodologies and are looking forward to working with our European counterparts to consider how we might use the Recommendation to effect real improvements in the services for people with rare diseases in the UK.

As you know, the Recommendation set out a number of actions for Member States to take forward at national and community level. We will be scoping out how we can ensure that the Recommendation's actions are imbedded into our systems across the UK with colleagues in the devolved administrations. We will also be working closely with the National Specialised Commissioning Team, which as you know provides invaluable advice to the Department on nationally commissioned services and on ensuring high quality clinical care and equity of access for patients.

I know that you have met with officials in all UK Health Departments and we intend to continue to liaise with you in our thinking, involving other stakeholder groups such as the Specialised Health Care Alliance, Genetics Commissioning Advisory Group and Human Genetics Commission. We will also be linking up with European groups such as the Rare Disease Task Force and the European patient organisation Eurordis.

Cont.

Given that our work to scope out an appropriate implementation plan is still at an early stage, I do not think that a meeting with you would be fruitful at this stage. However, please be assured that officials and colleagues from the National Specialised Commissioning Team will be in touch later in the year to discuss how we can work with you to ensure that the Recommendation is effectively implemented across the UK.

Yours sincerely,  
Gillian

GILLIAN MERRON