

WRITTEN MINISTERIAL STATEMENT

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Health, Social Services and Public Safety

RARE DISEASES: UK STRATEGY

Published at 9.30 am on Friday 22 November 2013

Mr Poots (The Minister of Health, Social Services and Public Safety): I wish to make a Written Statement to the Assembly to advise Members of the publication of the United Kingdom (UK) Strategy for Rare Diseases.

In 2012, the Department of Health in London launched a UK-wide public consultation on a Plan for Rare Diseases which sought to set in motion the work to integrate all current and future initiatives at local, regional and national levels in the field of rare diseases.

I now wish to advise that the work on the UK Strategy for Rare Diseases by the Health Departments in the four UK countries is complete, and the Strategy is to be published today, 22 November 2013. Should Members wish to obtain a copy of the report, it can be found on my Department's website www.dhsspsni.gov.uk.

The UK Strategy is intended as an overarching framework document that sets out a shared vision for improving the lives of people with rare diseases, with a focus on patients and their families/carers. It includes a number of UK-wide strategic commitments for each UK nation to consider, and identifies key milestones up to 2020 for implementation of the Strategy.

While the Strategy is for the UK as a whole, its implementation in the four UK nations will be determined by each devolved administration to best meet the needs of their respective populations. The Northern Ireland implementation is being taken forward by the NI Rare Diseases Stakeholder Group led by my Department, which comprises representation from Queen's University, the University of Ulster, the Health and Social Care Board, the Public Health Agency, the Regional Genetics Centre and the Northern Ireland Rare Disease Partnership which represents patients' interests.

The Northern Ireland Rare Diseases Implementation Plan will be published in early 2014.

There are between 5,000 and 8,000 rare diseases. Each one affects less than 0.1% of the UK's population, but together they affect the lives of 3 million people. I and the other health ministers across the UK are committed to improving services for people with rare diseases, and we share the hope that, through this Strategy and the forthcoming implementation plans for each of the four UK countries, we can significantly raise the profile of rare diseases, leading to better outcomes for the many people who live with these conditions as well as their families and carers.