# WRITTEN STATEMENT

# BY

# THE WELSH GOVERNMENT

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| **TITLE** | **Rare Disease Day – An Update** |
| **DATE** | **29 February 2024** |
| **BY** | **Eluned Morgan, Minister for Health & Social Services** |

As today is international Rare Disease Day, I would like to update on the progress being made by Welsh Government and the NHS Executive to improve the lives of people in Wales living with rare diseases.

Rare diseases can be both life-limiting and life-threatening. It is currently estimated that there are more than 7,000 rare diseases, with new conditions continually being identified as research advances. There are an estimated 170,000 people in Wales affected by a rare disease and 80% of these conditions are estimated to have a genetic component. Although rare diseases are individually rare, they are collectively common, with one in 17 people being affected by a rare disease at some point in their lifetime.

In 2023, the NHS Wales Executive was established. Within this new organisation the Rare Disease Implementation Group (RDIG) will develop into a Wales Rare Disease Implementation Network (WRDIN). The aim and purpose remains to bring together delivery partners to develop and monitor Wales's version of the new action plan.

The [Welsh Rare Disease Action Plan refresh](https://executive.nhs.wales/functions/networks-and-planning/rare-diseases/action-plan-2022-2026/) was published in January 2024 alongside a [progress report](https://executive.nhs.wales/functions/networks-and-planning/rare-diseases/rdig-documents/progress-report-jan-2024/) and a [Welsh Health Circular](https://www.gov.wales/sites/default/files/pdf-versions/2024/1/4/1704988247/refresh-rare-disease-action-plan-2022-2026-whc2023041.pdf). The plan sets out a clear framework for taking forward improvements and highlights the significant progress made within services. The plan was created in line with the 2021 UK Rare Diseases Framework which identifies the key priorities for rare disease and creates a vision for the future to address health inequalities, improve the quality and availability of care, and improve the lives of people living with rare diseases.

I am pleased to be able to agree an additional funding plan for the Syndrome Without a Name (SWAN) Clinic in Cardiff for 2024/25. The clinic has received international interest, enabling Wales to become a leader in the field of rare disease service provision. The clinic touches on every priority of the rare disease action plan: obtaining a faster diagnosis, increasing awareness of rare disease within healthcare professionals, coordinating care, and offering improved access to specialist care. I look forward to seeing the results of this important work.

I’m grateful for the continued commitment from all involved in supporting service improvements driven by the action plan, as well as the drive to advocate for those in Wales that can’t speak for themselves.

We will continue to support the rare disease implementation network on the action plan aims to help patients get a final diagnosis faster and increase awareness of rare diseases among healthcare professionals.