



## Craig Whittaker MP

CALDER VALLEY

[www.craigwhittakermp.co.uk](http://www.craigwhittakermp.co.uk)

### **Response to Rare diseases – March 2017**

Thank you for contacting me about ultra-rare diseases.

I have welcomed the Government's UK Strategy for Rare Diseases, published in November 2013, as a positive step forward to help people affected by these conditions to live full and independent lives. The Strategy contains 51 commitments set out a vision for improving the lives of all those affected with rare disease. It covers five areas including empowering those affected by rare diseases, identification and prevention, diagnosis and early intervention, coordination of care and the role of research. All four countries of the UK have signed up to implement the strategy by 2020.

I support the Government's commitment to ensuring that patients with rare diseases in England are able to access effective treatments. That is why Ministers launched the Accelerated Access Review to make recommendations to Government on speeding up access for NHS patients to innovative and cost effective new medicines, diagnostics and medical technologies. The Review was published on 24 October 2016 and the Government will respond to the review in due course.

The Government's National Institute for Health Research has established the Rare Diseases Translational Research Collaboration (TRC) with an initial investment of £20 million over four years. The Rare Disease TRC aims to increase rare disease research collaboration that will lead to improved diagnosis, treatment and care for rare disease patients and will support deep phenotyping of people with rare diseases.

Alongside this, patients with rare diseases are also currently the primary beneficiaries of the world-leading 100,000 Genomes Project. These participants are receiving diagnoses for the first time thus ending the uncertainty and distress for those affected on top of the considerable costs for the NHS budget. Over 25 rare disease groups comprising over 190 rare diseases are currently included in the project.

Unfortunately, I was unable to attend the debate on Tuesday 28<sup>th</sup> March. However, I shall continue to take interest in this issue and look forward to welcoming the updates to follow.

Thank you again for taking the time to contact me.

Kind regards,

A handwritten signature in black ink, appearing to read 'Craig Whittaker'.

Craig Whittaker MP