



# Andrew Rosindell M.P.

*Member of Parliament for Romford*

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## **The Rt. Hon. Steve Barclay M.P.**

Secretary of State for Health and Social Care  
39 Victoria Street  
LONDON  
SW1P 3BT

Wednesday 5<sup>th</sup> July 2023

Dear Steve

### **NHS treatment and services for those with h.E.D.S. and H.S.D.**

I am writing to support the view that we should be providing those who are diagnosed with hypermobile EDS (h.E.D.S.) and hypermobility spectrum disorders (H.S.D.) with more specialised NHS treatment and services.

I have been made aware by my constituents that those affected by these disorders are in desperate need of specified assistance from the NHS, which they do not currently have.

This is because access to care for them cannot be catered for in rheumatology departments, and neither h.E.D.S. nor H.S.D. fall under the 2021 U.K. Rare Diseases Framework or the 2023 Rare Disease Action Plan, and Primary and community care, whilst generally being supportive, are not equipped with the knowledge or capacity to properly treat these conditions.

H.S.D. and h.E.D.S. both cause body-wide symptoms, which can be disabling and so affect all aspects of life. These include musculoskeletal problems, chronic pain and fatigue, gastrointestinal disturbance, pelvic and bladder problems, autonomic dysfunction and anxiety.

However, there is no single test for these disorders, which makes diagnosis of them difficult, yet together, are fairly common, said to be affecting roughly 1 in 500 people.

It would make a huge difference to my constituents, as well as people all over the U.K., if the Government devoted an area of funding into further research towards funding a diagnostic test for both diseases.



There is so much to be gained from devoting further funding into services which would be able to properly and promptly administer care and treatment for those diagnosed with h.E.D.S. and H.S.D., and so stop those affected falling through the gaps.

I look forward to your response, and hearing what more the Department for Health and Social Care can put in place to aid those diagnosed with h.E.D.S. and H.S.D.

Yours ever,

A handwritten signature in black ink that reads "Andrew Rosindell". The signature is written in a cursive style and is followed by a horizontal line.

Andrew Rosindell M.P.