

15th March 2017

Dear Professional,

Your patient has brought this letter to you following changes published today, to the classification of Ehlers-Danlos syndromes and to the Joint Hypermobility syndrome diagnosis. Many of the people affected by these changes are understandably worried about the future impact of these changes on their care and treatment. The HMSA has updated our website on information which may be of help to you and your patient.

The diagnostic criteria for hypermobile Ehlers-Danlos syndrome (hEDS, previously known as Ehlers-Danlos hypermobility) have changed significantly, details can be found on our website. In addition 'Joint Hypermobility syndrome' is now obsolete having been replaced by the diagnostic term, Hypermobility Spectrum Disorder. You can find details of these changes, including an article called 'Hypermobility Disorders – An update for clinicians', on the HMSA website, hypermobility.org

The HMSA has been working with people with Hypermobility Spectrum Disorders for 25 years and is best placed to share its considerable experience and education opportunities. A few years ago, at the request of members, we agreed to bring all the Ehlers-Danlos syndromes, Marfan syndrome, Osteogenesis Imperfecta, Stickler syndrome and PXE under our umbrella to promote 'living well' with these conditions by providing self-management courses and information. We also offer a helpline, social media closed support groups and a patient membership.

The HMSA can offer assistance to medical, health, social and educational professionals in providing information or support to practitioners. We also offer a professional membership scheme which has proven to be very successful and run bespoke HMSA Hypermobility Masterclasses for clinicians. If you would like more information please contact us by emailing professionals@hypermobility.org

Yours sincerely,

Donna Wicks (CEO)

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Patrons

Helene Raynsford, Paralympic Gold Medallist - Mr. Norman Lamb, MP - Kaliya Franklin, Disability and Awareness - Hannah Ensor, Author & Illustrator - Kate Monaghan, Media Awareness - Sandro Forte, International Speaker - George Asprey, Actor

The Hypermobility Syndrome Association is a charity registered in England and Wales (1011063) and in Scotland (SC037916)

