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EDS Wellness to Host Integrative Physicians' Learning Conference in Conjunction with Ehlers-Danlos Awareness Month

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Bethesda, MD - EDS Wellness is teaming up with the Hypermobility Syndromes Association-U.K. and The Coalition Against Pediatric Pain to raise awareness about Hypermobility Spectrum Disorders (HSD), Ehlers-Danlos syndromes (EDS) and related conditions. May is EDS Awareness Month. A month-long observance of awareness, education, outreach, and fundraising for Ehlers-Danlos syndromes and related disorders. This year's awareness month occurs on the heels of the release of the revised diagnostic criteria for all Ehlers-Danlos syndromes (EDS) and Hypermobility Spectrum Disorders (HSD), a collaborative research publication published in the American Journal of Medical Genetics Part C: Seminars in Medical Genetics on March 15th, 2017. This is the first update in nearly 20 years.

"No other disease in the history of modern medicine, has been neglected in such a way as Ehlers-Danlos syndrome(s)" -- Dr. Rodney Graham

EDS Wellness' Physicians' Learning Conference, *'Integrative Healthcare Strategies for Patients with Chronic Pain and Multisystemic Chronic Illness'* will be held June 10-11th, 2017 in Middleburg, Va. The conference features top chronic illness specialists from the U.S. and the U.K. including Dr. Alan Hakim- Hospital of St. John and St. Elizabeth, Dr. Clair Francomano - Johns Hopkins, Dr. Lawrence Afrin - University of Minnesota, Dr. Pradeep Chopra - Brown Medical School and others. EDS Wellness' Physicians' Learning Conference strives to promote an open-minded environment — one that opens doors to understanding and facilitates

constructive conversations; thus, increasing awareness and decreasing the time to proper diagnosis.

All medical specialties and healthcare providers welcome!

<http://edswellness.org/2017-physicians-learning-conference>

Speakers' presentations and conference workshops cover the most up-to-date diagnostic criteria and evidence-based integrative strategies for successfully treating patients with complex, chronic and multisystemic illnesses. Attendees are encouraged to participate and share their experiences during round-table sessions and with the goal of creating constructive, interactive discussions, ultimately leading to improved quality of care and better patient outcomes.

Conference participants will be invited to join The Global Alliance for Hypermobility Spectrum Disorders Providers (GAHSDP). The GAHSDP was created by EDS Wellness as a professional network for healthcare providers who are committed to improving the proper diagnosis and care of all patients living with EDS, HSD and other complex, multisystemic conditions. Membership to GAHSDP, includes access to a private education, networking and referral forum integrated into EDS Wellness' website.

Much more than “just loose joints!”

‘Hypermobility is the term used to describe the ability to move joints beyond the normal range of movement. Joint hypermobility is common in the general population. It may be present in just a few joints or it may be widespread. It is most common in childhood and adolescence, in females, and Asian and Afro-Caribbean races. It tends to lessen with age. In many people joint hypermobility is of no medical consequence and commonly does not give rise to symptoms. Hypermobility can even be considered an advantage, for example athletes, gymnasts, dancers and musicians might specifically be selected because of their extra range of movement.

For a small percentage of the population, instead of being advantageous, hypermobility may be associated with joint and ligament injuries, pain, fatigue and other symptoms. Hypermobility can also be a sign of a more serious underlying condition, which are often passed down through the generations.’ (1/ Hakim A.J.).

‘Experts estimate that up to 10% of the general population may have some degree of hypermobility, with women affected about three times more often than men. Most hypermobile people do not develop any problems from their loose joints, but some suffer chronic pain and other symptoms.’ (2/ Pocinki A.) The exact cause(s) of joint hypermobility is unknown; however, “loose joints” may be caused by various mutations to one or more of the components that help

build our connective tissues. Research is suggesting that both genetic and epigenetic factors could play a role in the presentation signs and symptoms, as well as the severity of issues that are experienced by some with joint hypermobility.

When hypermobility becomes symptomatic, it can be an indication of a syndrome, such as hypermobile Ehlers-Danlos syndrome (hEDS). hEDS is one of the Ehlers-Danlos syndromes (EDS) - a group of thirteen heritable connective tissue disorders caused by mutations to either the structure or function of collagen – the most abundant protein in the body – or other components of the extracellular matrix. In others, symptomatic hypermobility can be a sign of another syndrome such as:

- Marfan syndrome
- Osteogenesis imperfecta
- Loeys-Dietz Syndrome
- An autoimmune disorder affecting the connective tissue (i.e. Lupus or Rheumatoid Arthritis)

While research is still searching to understand the complexities of hypermobility syndromes, they can cause a broad spectrum of multisystemic dysfunction. The first sign or symptom of hEDS is usually joint hypermobility, and many people do not experience issues with their loose joints until later in life, for example during puberty, if at all. On the other hand, some individuals with hEDS have multisystemic problems from birth. When an individual with symptomatic joint hypermobility does not meet the criteria for hEDS, they may be classified as having a ‘hypermobility spectrum disorder’ (HSD).

“Common features among the types include joint hypermobility, skin fragility, chronic pain, and fatigue. More severe types, such as Vascular Ehlers-Danlos syndrome, can be life-threatening, as fragile blood vessels and internal organs can spontaneously rupture.” -- [The Ehlers-Danlos Society](#)

People with HSDs or hEDS can have a broad range of symptoms in addition to hypermobile joints such as the knees, shoulders, neck, ankles, fingers, wrists, the pelvis, the jaw, and more. Because components of connective tissue can be found everywhere in our bodies, not only supporting our joints, it is possible that every system in the body can be affected. Confusion and misdiagnosis have only increased, because no two people with hypermobility present the same – hEDS is especially subjective. The updated diagnostic criteria for EDS and HSD, awareness, education, and early intervention are critical. Over-medicalization, or lack of proactive approaches to living well with joint hypermobility, can cause damage to the connective tissues, progress multisystemic dysfunction, and cause life-long and additional trauma, pain and suffering.

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EDS Wellness is a 501(c)(3) non-profit organization promoting health education, integrative healthcare, and wellness strategies for those living with Hypermobility Spectrum Disorders (HSD), such as Ehlers-Danlos syndromes (EDS), other disorders of the connective tissue, and related conditions, including Mast Cell Activation Syndromes (MCAS), Dysautonomia, and more.

EDS Wellness collaborates with other organizations and healthcare practitioners on various projects associated with the Ehlers-Danlos syndromes (EDS) and related conditions, to provide information and resources for those living with EDS & HSD and for the medical professionals who care for them. EDS Wellness focuses on helping patients live well while living with EDS, HSD and comorbid conditions.

The Coalition Against Pediatric Pain

<http://www.tcapp.org>

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The Coalition Against Pediatric Pain is a national non-profit committed to improving the quality of life of children living with chronic pain from rare diseases by: supporting and uniting families affected by pediatric pain, advocating for children in pain by increasing awareness of their needs, educating others regarding their long-term consequences of pediatric pain, funding research dedicated to pediatric pain conditions and providing resources to families and professionals.

TCAPP was founded by families of children who are affected by chronic neuropathic pain disease. All of the founding families' children suffer from RSD/CRPS (Reflex Sympathetic Dystrophy/ Complex Regional Pain Syndrome) and many suffer from multiple pain conditions, such as EDS (Ehlers-Danlos syndromes), HSD (Hypermobility Spectrum Disorders), muscle spasms, migraines, abdominal migraines, and painful GI issues.

The Hypermobility Syndromes Association

www.hypermobility.org

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The HMSA is the only charity offering both practical support and Information Standards Accredited health and care information to people who have a hypermobility syndrome, or who are involved in the care of someone with any of the hypermobility syndromes, including Hypermobility Spectrum Disorders (HSD), Ehlers-Danlos syndromes (all sub-types), Marfan syndrome, Sticklers and Osteogenesis Imperfecta.

The HMSA is a dynamic charity providing a network of support groups throughout the UK. All our Group Leaders are trained and have clear DBSs (previously called a Criminal Records Bureau check). The HMSA is proud that our groups are recommended by many hospitals and individual professionals because of our positive ethos and the dedication and professionalism of our Group Leaders.

References:

1. Hakim A.J., Wicks D., Smith C.E. 2015 - Introduction of the 'Help and Advice' section - Hypermobility Syndromes Association hypermobility.org/help-advice/
2. Pocinki A. G. 2010 - Joint Hypermobility and Joint Hypermobility Syndrome - www.dynainc.org/docs/hypermobility.pdf