



22 March 2019

Media release for immediate use

Official launch of Ehlers-Danlos Society New Zealand

The Ehlers-Danlos Society New Zealand (EDSNZ) will officially launch on 18 March 2019.

The Ehlers-Danlos Syndromes (EDS) are a group of 13 sub-types of a genetic disorder that affects connective tissue, and also includes another associated disorder, Hypermobility Spectrum Disorder (HSD). Connective tissue serves as the building blocks of the body, and supports skin, bones, blood vessels, and many other organs and tissues. The most common types of EDS usually results in joint hypermobility, frequent joint dislocations, chronic pain, easy bruising, and gastrointestinal issues. The most dangerous type, Vascular EDS (vEDS), may cause spontaneous artery or organ rupture, sometimes causing premature death.

Although most types of EDS are rare or extremely rare, the most common type, Hypermobility EDS (hEDS) is currently known to occur in 1 in 2,500-5,000 people. Current research however, may soon prove it is more common than this.

Unfortunately, it is typical for it to take many years, and sometimes decades for an EDS patient to receive a proper diagnosis. Once they receive that diagnosis, it may be difficult to find proper care, management and support.

The registered charity Ehlers-Danlos Society New Zealand was created to help support patients and families who are diagnosed with EDS, or in the process of receiving a diagnosis.. Society president, Kelly McQuinlan, states, "It is crucial that we connect health professionals, employers, educators and the general public with the correct information, so that EDS patients and their families receive appropriate care and experience increased well-being".

Read here for a greater understanding of EDS http://ehlers-danlos.org.nz/?page_id=401.

Internationally, the rare diseases community uses a zebra as its mascot to represent their condition. In their medical training, doctors are taught that when they hear hoof beats to think of common horses, not the rarer zebra. However, they also need to be on the lookout for rarer diseases. As every Zebra has different stripes, each EDS patient may have a different set and severity of symptoms.

For more information, or to make a donation, visit the EDSNZ website at www.ehlers-danlos.org.nz.

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