Ehlers-Danlos Syndromes
New Zealand

Want to hold a fundraiser?

Fill out this form or
fill out our online form at ehlers-danlos.org.nz/fundraising

Name:

Email Address:

What type of fundraiser:

Date of fundraiser:

Location of fundrasier:

Email it to contact@ehlers-danlos.org.nz and let us know!

MORE INFORMATION AND HOW TO CONTACT US ON WWW.EHLERS-DANLOS.ORG.NZ

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HOW TO FUNDRAISE FOR US

WHAT IS EHLERS-DANLOS SYNDROMES?

This is a condition that effects the connective tissue of our bodies- this is the glue that holds us together.
It can make it harder for us to do tasks such as PE, writing, sitting, and standing for long periods.
We may be extra flexible in school, sit differently, and tire easily.
(Further information on this can be found at the end.)

WHY FUNDRAISE FOR US?

Early intervention is key, and this comes from awareness in our community. The more we know about this condition in our communities, the better support we will have.
For example: If we can strengthen muscles from an early age, this can be great building blocks for the rest of our lives

WHY THE ZIWI MASCOT?

We are country of Kiwis, and Zebra is the rare disorders mascot. When we hear Hoof Beats, we automatically think we will see a horse, but it may be a Zebra! Much like the Zebra, we all have different stripes

IDEAS FOR FUNDRAISING WITH YOUR SCHOOL

PARKOUR COURSE!

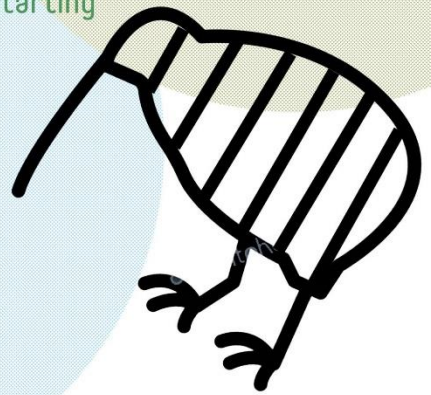
Set out your hall with gym equipment for some fun Lunchtime activities!
Gold coin entry

MUFTI DAY!

Have a gold coin donation mufti day, dressing in black in white like the zebra!

GOLD COIN COURSE!

Create a Gold coin Ziwi mural on your courts or in your hall, starting with a chalk outline



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FURTHER INFORMATION :

What is HSD/EDS?
Ehlers-Danlos Syndrome (EDS) is a group of connective tissue disorders that are generally inherited and are varied both in their genetic causes and how they affect the body. The most common characteristics are joint hypermobility (joints that move more than normal), skin hyperextensibility (skin that can be stretched more than normal), and tissue fragility (easy bruising, wounds taking longer to heal and scars that heal abnormally).

Ehlers-Danlos Syndromes are currently classified into 13 subtypes (as of 2017) but by far the most common types are Hypermobile (hEDS) and Classical (cEDS). Each subtype has a set of clinical criteria that help guide with diagnosis.

An individual's experience with EDS is personal in terms of symptoms and severity and may not necessarily be the same as another person's experience. Diagnostic criteria exist to help distinguish EDS from other connective tissue disorders, and one type of EDS from another. There are many more possible symptoms for each EDS type than are listed in the official criteria. The symptoms listed here are the most common ones.

Signs and symptoms to look out for in children.
The hallmark clinical manifestations of an Ehlers-Danlos Syndrome are most often joint and skin related and may include:

Joints
Joint hypermobility (they move beyond the joint's normal range); loose/unstable joints which are prone to frequent spraining, dislocations and/or subluxations (coming out of place but not dislocating); joint pain; early onset of osteoarthritis.

Skin
Soft velvety-like skin; stretchy skin (most associated with Classical EDS); fragile skin that tears or bruises easily (bruising may be severe); severe or unusual scarring; slow and poor wound healing.

Miscellaneous/Less Common
Chronic, debilitating musculoskeletal pain (especially associated with Hypermobile EDS); fatigue/tiredness; gastrointestinal problems (Irritable Bowel Syndrome, etc); mitral valve prolapse, and heart arrhythmia, scoliosis; hernias; poor response to local anaesthetic; arterial/intestinal/uterine fragility or rupture (life threatening and most commonly associated with Vascular EDS).

Other conditions such as POTS (Postural Orthostatic Tachycardia Syndrome – heart rate increases when standing up, often manifesting as fainting or dizziness), blood pressure changes (often related to dysautonomia issues), MCAD (Mast Cell Activation Disorder – sometimes severe and unusual allergy symptoms) are commonly associated with EDS, but are not definitive for diagnosis.

WHAT HAPPENS IF I THINK MY CHILD MAY HAVE THIS CONDITION?

Kids are generally flexible from an early age, and as they age often stiffen up. Strengthening excercises such as balance activities are great for all children. Having great tools such as comfortable well fitted shoes is always a fanstastic tool for your childs wellbeing, unhealthy habbits such as W sitting, and overstretching joints (like hyperextending elbows and knees), can ensure stronger, more stable muscles for their futures.

If this condition is having an impact on your child, the best first step you can take, is having a great GP who listens and will work with you. Using the Beighton and Brighton scoring in clinic with your GP can help identify if this is a condition that needs to be monitiored and worked on with a physiotherapist.

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