



BAFTA Cymru Award winner named as first Ambassador for Mind Body EDS™

Charity links up with EDS showjumper in development of 'The Dark Horse' documentary - support for EDS sufferers "needed more than ever during COVID-19 crisis"

20 July 2020: Mind Body EDS™ (MB-EDS) has announced the appointment of young award-winning film-maker, musician and EDS sufferer, Ashleigh Harley, to be its first Ambassador as the charity continues to build support and awareness of Ehlers-Danlos Syndromes (EDS), a potentially fatal connective tissue disorder affecting huge numbers of sufferers of all ages.

Ashleigh's family first became aware that she had EDS when she was 12, but her symptoms were not officially diagnosed until several years later. She wrote her first novel, *The Messenger*, when episodically paralysed in hospital and subsequently directed a related fantasy film, *The Wall of Lyon* (www.ashleighharley.com/the-wall-of-lyon), which was showcased at the Cannes Film Festival and won over 40 awards internationally, including a BAFTA Cymru.

Working with Oscar-winning production team, Slick Films, and with support from MB-EDS, Ashleigh's latest film 'The Dark Horse' documents her journey living with EDS and her mission as a keen horsewoman to get show jumping included in the World Paralympic Games. Due for release in 2021, the film will also feature MB-EDS founder Laura Sylvester's own EDS story and, as with *The Wall of Lyon*, will be presented at film festivals and screenings around the world.

A passionate advocate in raising awareness for EDS, Ashleigh "is hugely excited to be able to collaborate with MB-EDS in this ambassadorial capacity. As a patient and a family suffering from this invisible but devastating illness," she says, "we are totally aligned with the goals of this dynamic charity. I believe this collaboration will add valuable weight and gravitas in our campaign to achieve greater public awareness of the issues around EDS across a broad range of media channels."

Bridging the funding gap

Launched in 2018, MB-EDS has undertaken a number of successful fundraising initiatives, which has enabled it to give more than £64,000 in grants to individuals desperate to speed up getting the right diagnosis and treatment for what is still a little-understood condition.

"However," says MB-EDS chairman, John Hogan, "like other charities, the more recent switch by donors to generic NHS charities has had a devastating impact on our fundraising capability, with the result that we are currently unable to continue providing financial support to those in critical need. Although the funding focus on the terrific work

being undertaken by the NHS in fighting the COVID-19 pandemic is understandable," he believes, "the almost total loss of income to charities targeted at providing practical help to those with other chronic illnesses is impacting both sufferers' physical and mental health.

"On the one hand, non-COVID-19 treatments and diagnoses are being delayed and put on hold. At the same time however, in the case of the large number of EDS sufferers for example who account for as much as 3% of the population, at a time of increased stress through enforced self-isolation the need for us to be able to connect with them and show that they are not alone becomes more important than ever," he says.

As a result, Hogan is certain that the new ambassadorial appointment is timely in furthering the charity's goals. "Ashleigh's unique drive and experience will enable us to reach important new audiences and potential donors who, like us, want to make a real difference to people's lives."

To see the video song, 'Worlds Apart', which will feature in 'The Dark Horse', visit www.facebook.com/951789524976686/posts/1721519598003671/?vh=e&d=n To-date, the video song has achieved over 200,000 plays.

- END -

FOR MORE INFORMATION PLEASE CONTACT:

Graham Noakes, Media Coordinator Trustee at Mind Body EDS™

Mobile: +44 7788 846149 Email: graham.noakes@mindbodyeds.org.uk

Mind Body EDS™ Charity Details

Address: 11 South St, Farnham, Surrey, GU9 7QX

Website:

www.mindbodyeds.org.uk

Mind Body EDS is a registered charity in England and Wales | Registered Charity No. 1177182

Social Media

Email: info@mindbodyeds.org.uk Instagram: @mindbodyeds Twitter: @mindbodyeds

NOTES TO EDITORS

About Ashleigh Harley

Ashleigh Harley is an award-winning film-maker and musician known for her films 'The Wall of Lyon' and 'The Dark Horse'. At the age of 12 she became impaired by the genetic tissue disorder Ehlers-Danlos Syndromes (EDS), which periodically impacted her ability to walk, attend school and compete in her beloved sport of show-jumping. Determined to overcome a life-changing illness, while hospitalised Ashleigh began working on her novel, 'The Messenger'. In 2017 she directed her first short, 'The Wall of Lyon', loosely based on the fantasy world of the earlier novel, which went on to win over 40 awards internationally and qualify for a BAFTA Cymru. In 2019 she got back in the saddle and began directing her second short, 'The Dark Horse', to raise awareness of invisible illnesses as she fights against perceptions of disability and get her sport included in the World Paralympic Games. Ashleigh is currently working on 'The Dark Horse' with Oscar-winning production team Slick Films for a 2021 release. For more information, visit www.ashleighharley.com

About Mind Body EDS™

Formed in 2018, Mind Body EDS™ is aimed at raising awareness amongst the public and medical community about the range of Ehlers-Danlos Syndromes (EDS). Its goals include providing financial support to individuals and families to enable effective early diagnosis and treatment, as well as towards EDS research. EDS is a group of genetic conditions affecting the body's connective tissue resulting from collagen defects. Collagen essentially acts as a 'glue' keeping the body from falling apart and is responsible for supporting the skin, tendons, muscles, ligaments, blood vessels, bones, eyes and vital organs and therefore affects the entire body. Common symptoms are: dislocations/subluxations of joints, chronic pain and fatigue, easy bruising, aortic and/or organ ruptures, palpitations, digestive disorders and other comorbidities. For more information, please visit www.mindbodyeds.org.uk

About the Mind Body EDS™ 'Thumbprint'

The choice of the 'thumbprint' logo emphasises the fact that no two patients with EDS are the same. Just as the process of diagnosis, treatment and management is always different, so the thumbprint representing each individual's EDS journey is similarly unique.

The black and white impression of a thumbprint also symbolically represents the stripes of a zebra. In medical school doctors are taught that, "when you hear the sound of hooves, think horses, not zebras" - in other words, assume that the simplest and most common diagnosis is likely to be correct (the 'horse') and avoid misdiagnosing for rare illnesses (the 'zebra'). Unfortunately, EDS sufferers can go years, even decades, without proper diagnosis, as many in the medical community forget that 'zebras', whilst less common, do exist. And, just as no two zebras have identical stripes, so no two thumbprints are the same.

With its 'thumbprint', Mind Body EDS aims to leave its mark and make a positive impression on those affected by EDS, the medical community and broader society. The earlier the diagnosis the sooner a management programme can be developed to help the EDS sufferer from spiralling into more difficult and challenging medical conditions because they have not been properly diagnosed. Saving time both saves lives and improves quality of health.

About the Founder

Laura Sylvester, 27, lives in Tilford, Surrey. Her medical symptoms went unrecognised for more than a decade until 2014, when she was diagnosed as having Ehlers-Danlos Syndrome (Hypermobility, hEDS), together with a number of other comorbidities. Over this period her condition deteriorated substantially and, with no specialist treatment available in the UK, she had to go to the USA for urgent life-saving surgery. Since then, Laura has undergone a total of seven brain and spinal operations in less than two years and treatment is ongoing.

To see a three minute video on Laura's EDS journey - 'The Invisible Illness' - visit:
www.youtube.com/watch?v=p62T1a7E9K4&t=20s

IMAGES TO BE USED IN THE RELEASE



Ashleigh Harley, Ambassador, Mind Body EDS™. Her 'Worlds Apart Concert' was viewed 28,100 times on Facebook and 56,000 times on Instagram



Laura Sylvester, Founder, Mind Body EDS™, featuring in the [#MyEDSDiagnosis](#) 2018 global campaign she initiated through Instagram aiming to help raise awareness of the length of time it can take to reach a diagnosis of Ehlers-Danlos syndromes. With over 500 responses around the world, the average time to diagnosis was 19 years!