



Annual Report

Year ended 31st December 2020

A Charity (Charitable Incorporated Organisation) Registered in England and Wales
Registered Charity number 1177182

Our Chair's Report

2020 was a virtual year for our charity!

2020 was a difficult year for the charity sector due to the COVID-19 pandemic which negatively impacted many people, countries and sectors across the world. Even though Mind Body EDS is a small charity, we were able to survive the storm and still continue to make progress during the year. Before lockdown began, Mind Body EDS charity was able to kick-off 2020 with a terrific fundraising Quiz Night event in February to celebrate our second anniversary of our founding on 15th February 2018. We ended 2020 having raised in excess of £97,000 during these first two years. These funds have been fully invested in providing financial help for numerous EDS sufferers and in raising awareness of EDS as described further below.

We have also grown in size since the end of the reporting period by welcoming Lord and Lady Malloch-Brown as official Family Patrons; Professor Christopher Mathias as Medical Patron and Ashleigh Harley as Ambassador to provide support for 2021 and beyond. We therefore go into 2021 with great prospects for continuing our fundraising and our work.

The Charity's overarching Mission is to be **'A Gateway of Hope'** for sufferers of Ehlers-Danlos Syndromes ('EDS'). Our Mission statement includes the following goals:

"Mind Body EDS aims to be at the forefront of making a difference every day to the lives of people with Ehlers-Danlos syndromes and their families. We are committed to having a positive impact for everyone affected by Ehlers-Danlos syndromes, to ensure each individual's health outcome is neither determined nor disadvantaged by their personal means.

We confront Ehlers-Danlos syndromes on all fronts - through advocacy and awareness, together with financial and research support - to help save lives and improve individual sufferers' quality of life.

Our vision is for a world where diagnosis of Ehlers-Danlos syndromes no longer takes decades, in order to prevent the condition from causing disabling and life-threatening complications."

Thanks to the generosity of donors and of the individuals who have run, cycled and climbed for us, we have been able to continue on the road to achieving this Mission and we are proud to say that in the course of our first two years we have been able to make grants to individual applicants totalling £64,000 to enable them to travel to appointments; to fund new wheelchairs; to access diagnostic services not available on the NHS; and to receive therapy appropriate to their individual needs. Even though we were unable to open for a grant round this year, we were able to succeed in other areas of mission, specifically in advocacy and education.

Since our inaugural chair, Jacqueline Burke, stepped down as a Trustee in September 2019 and on a temporary basis, Graham Noakes, Kevin Sylvester and I have acted as Temporary Chairs to continue our charity's mission.

We are setting ourselves positive targets for 2021 to help make up for a challenging 2020 to enable us to carry on helping EDS sufferers through financial support and in reaching both the public and clinicians to build awareness of the disease and its potentially devastating effects.

John Hogan
John Hogan

Acting Chair of the Trustees

Our Founder's Story



Laura Sylvester, Founder of Mind Body EDS, featuring in her #MyEDSDiagnosis campaign helping spread awareness of EDS.

My symptoms went unrecognised for more than a decade, until five years ago when I finally was given my diagnosis of Ehlers-Danlos syndrome (Hypermobility, hEDS) along with a number of other common comorbidities. Unfortunately, my diagnosis came too late because my condition had deteriorated to a point of becoming life-threatening: essentially, not only was my neck dangerously unstable, my brain was sinking through my skull causing serious life-threatening damage.

Living without an accurate diagnosis for the majority of my life has put a tremendous strain on my whole family. With a lack of funding and expertise available on the NHS or elsewhere, my family and I were then faced with the huge financial burden and stress of having to empty our pockets to seek the limited EDS specialists in the UK and eventually we had no choice but to go abroad to the USA for life-saving treatment. To-date, at the age of twenty-six I've undergone a total of six brain and spinal surgeries in just under two years.

As a result of this life-altering experience, when I woke from my first neurosurgery in 2016, I wanted it to be put to good use to ensure that others did not suffer in the same way from a failure to diagnose EDS early. The result has been the creation of the Mind Body EDS charity.

The ongoing suffering amongst patients is real and it is a problem on a worldwide scale. Due to lack of awareness, knowledge and understanding in the medical profession and general public, patients go unbelieved for years and even decades, being told "it's just all in your head". They see doctor after doctor, getting misdiagnosis after misdiagnosis, only making their symptoms worse, causing irreversible damage to the body. When will this ignorance end?

Timely early diagnosis and the provision of appropriate care in order to manage the condition is imperative so that the proper course of treatment, therapy and lifestyle adjustments are made before the condition becomes disabling or life-threatening. Early diagnosis and treatment can

have a hugely positive impact on the lives of sufferers and their families - and it is with this aspect of care for the EDS patient that our charity is concerned.

Living with a known diagnosis is better than an undiagnosed illness. This truly determines the type of outcome and quality of life an EDS patient is faced with.

I dream of a time where it is easier for doctors to diagnose EDS. I dream of a time when a patient's condition doesn't worsen to a point of becoming critically severe, until ultimately being diagnosed.

I dream of a time when doctors have heard of this 'not-so-rare' connective tissue disease, being able to diagnose early and treat patients, giving them the best chance at life.

EDS is not a rare condition: the rarity is in the awareness and knowledge amongst the medical profession and general public. So being diagnosed correctly should not be rare.

Even though no two EDS individuals are ever the same, the one thing I have witnessed amongst patients that is similar are the characteristics of unity, resilience and hope. Without these three vital characteristics, our voices would never be heard or believed.

Invisible illness is the very definition of hell. Understanding Ehlers-Danlos syndromes is a steep learning curve, and the only way in which to climb, is to have hope for what the future could bring. Because there simply is nothing else. There is no cure.

In actively spreading education and awareness, a goal of our charity is to bring hope. By providing financial grants and support to EDS sufferers, a goal of our charity is to bring relief. Through supporting medical research, a goal of our charity is to bring resolution.

Mind Body EDS aspires to be '*a gateway of hope*', to not just those of us with Ehlers-Danlos syndromes, but also for the future generations of zebras¹ to come.

I'm a true believer and live by this famous quote by author Paul Shane, "helping one person might not change the world, but it could change the world for one person."

So, it's your turn. Help change the world for those who are impacted by EDS and contribute to their life-changing diagnosis, treatment and management of their condition by offering your kindness and support in giving today.

¹ Many people who suffer from rare diseases, such as [Ehlers-Danlos syndromes](#) are known as medical zebras. The zebra originates from the phrase doctors are taught in medical school "when you hear the sound of hooves, think horses not zebras". Doctors are taught to assume the most common and simplest diagnosis (horses) which is usually correct, to avoid misdiagnosing patients with rare illnesses (zebras). Yet sometimes, when you hear the sound of hooves, it really is a zebra.

It's time for us to be heard. It's time for us to be believed. United, we stand together and ask you to join us in this battle, making our invisible visible.

Laura Sylvestor

Report of the Trustees for year ended 31st December 2020

The Trustees of Mind Body EDS are pleased to present the third annual report and accounts for the Charity. The Charity was licensed on 15th February 2018 and the Trustees have chosen to close the accounting period end on 31st December each year. This report covers a full 12-month accounting period from 1st January 2020 to 31st December 2020.

The financial statements have been prepared on a Receipts and Payments basis using the Charities Commission model format. This charity has a turnover of less than £250,000 and in accordance with section 133 of the Charities Act 2011 has elected to prepare accounts on this basis.

In accordance with the Charities Commission guidelines, as the Charity had income of less than £25,000 for this year there is no requirement for an Independent Accountant's report this year.

Reference and Administrative Details

Our Trustees for 2020

John Hogan

Graham Noakes (Chair) – from 7th September 2019

Kevin Sylvester

John Nicholls – from 26th November 2019

Francesca Lock – from 26th November 2019

Our Founder

Laura Sylvester

Our Family Patrons

Rt Hon. Lord Mark Malloch Brown and Lady Trish Malloch-Brown

Our Medical Patron

Professor Christopher Matthias

Our Ambassador

Ashleigh Harley

Our Registered Address

11 South Street

Farnham

Surrey

GU9 7QX

Our contact details

Find us at: MindBodyEDS.org.uk

Or on Social media: [@mindbodyeds.org.uk](https://twitter.com/mindbodyeds)

Our purposes and activities

Our charitable objects as detailed in our constitution are these:

- 1) *The relief of sickness and the preservation and promotion of good health among people suffering from Ehlers Danlos Syndromes, comorbidities and related conditions in particular but not exclusively by:*
 - a) *Providing information and grants of financial assistance to those diagnosed with such conditions, and those seeking a diagnosis*
 - b) *Providing grants of financial assistance to organisations undertaking research into Ehlers Danlos Syndromes, comorbidities and related conditions, the useful results of which will be disseminated for the public benefit*
- 2) *To advance education of the public in Ehlers Danlos Syndromes, comorbidities and related conditions in particular but not exclusively by providing informative talks designed to raise awareness and further knowledge of the conditions among the medical profession*

These defined purposes translate into our key objectives as an organisation which are to provide support in three key areas:

Education:

We are about raising awareness and educating the public and medical community about the range of Ehlers-Danlos syndromes and how widespread they are, specifically advocating across the UK's medical schools. By uniquely focusing on the doctors of tomorrow we aim to provide better outcomes for EDS patients - and in this way differentiate ourselves from other charities. The earlier a patient can get a diagnosis, the earlier their life can improve and potentially mitigate disabling or life-threatening medical complications that can occur depending on the progression and severity of their EDS

Financial support:

We are about financially supporting and contributing to individuals and families who are directly impacted by EDS enabling them to have the option (NHS or private) to access the limited EDS specialists to diagnose, manage and treat their conditions in the UK. Key interventional diagnostics and treatments for some patients are only offered in specialist locations, resulting in substantial travel and accommodation costs for many families, even when treatments are available on the NHS. Fundamentally, we aim to ensure that delay through lack of affordability does not determine a worse outcome for the patient.

Research:

We support research to find causes, treatments and potential cures of the Ehlers-Danlos syndromes and improving the quality of life of patients affected by this genetic condition.

Our Structure, Governance and Management

As at 31st December 2020 the Charity has five trustees who meet on a regular basis in Trustee meetings which are the decision making forum of the Charity. The terms of office for the individuals vary and are set for 2, 3 and 4 years.

The role of Interim-Chair continues to rotate between Graham Noakes, John Hogan and Kevin Sylvester. (Jacqueline Burke, our original Chair, continues to volunteer as the Charity's bookkeeper).

During the course of 2020 there have been six full Trustee meetings. At those meetings all Trustees were present either in person or via telephone or video on all occasions.

The Trustees are not paid and volunteer their time in meetings and in other activities to further the causes of the Charity.

The Charity is supported in administrative and ambassadorial roles by the Charity's founder, Laura Sylvester. Laura also attends Trustee meetings and has been influential in defining the direction and principles of the Charity.

In addition to the formal Trustee meetings, to coincide with the closing date² of the quarterly calls for grant applications, 'Grant Application review meetings' are held. In 2020 due to the financial challenges of fundraising the Trustees were unable to make any grant awards to individuals. The Charity keeps detailed accounting records and has an agreed set of Financial Policies which set out the way in which the Charity's financial activities are carried out, covering such activities as operating the bank account, and producing monthly financial updates to Trustees.

In managing its financial resources, the Trustees from time to time consider the need to hold reserves. The Charity does not have employees, nor premises, and does not therefore incur regular expenses of this nature. However, to be prudent and to allow the Charity to meet potential expenses and commitments as they fall due (such as for professional fees) the Trustees have determined that a small sum should be set aside at all times to meet these expenses (the balance being £1800 at the end of the accounting period).

As the Charity's turnover for 2020 did not exceed £250,000 the Trustees have elected to produce Receipts and Payments accounts and these are to be seen later in this report. In

² Closing dates for grant applications are published on our website.

accordance with the Charities Commission guidelines, as the Charity had income of less than £25,000 for this year there is no requirements for an Independent Accountant's report this year.

Mind Body EDS is officially trademarked by the IPO.

How have we fulfilled our Objectives in 2020?

Fund Raising

The income of the Charity for 2020 was £10,388. Even though the pandemic impacted our usual fundraising events and donations, we were extremely fortunate to receive two donations from foundations totalling £3,000 as well as having many individuals come forward wanting to carry-out virtual fundraising challenges for us.



We hosted a Mind Body EDS Quiz Night which was a huge success, fundraising a net profit of £2,300. This included a tremendous amount of high-value raffle prizes such as a signed Chelsea FC football shirt and tour of the stadium.

In May 2020 for EDS awareness month, we created a campaign: #10forEDS. The concept was to highlight the average number of years it takes for an EDS diagnosis which is 10 years. People had to 'Do 10, Donate 10, Nominate 10'.

Other friends of the Charity who have helped us through the year included:

- Rosie, Becky and Julie ran the virtual Vitality 10k and raised £430.00
- Serena Patel ran 40 miles over the month of August, made up of 13 runs: one for each subtype of EDS and raised £670.01
- Contributions are made in many ways, including via eBay and Amazon donations, to 'dress-down' Friday contributions. We are grateful to all of our donors, whatever the method you choose to help us.

Grant Giving

Awarding grants to individuals is the core of what we do. In the course of 2020 we were unable to award grants to applicants seeking financial support for diagnostic tests, travel, treatments or equipment arising from their diagnosis – or suspected diagnosis – of Ehlers-Danlos syndromes because of difficulties with fundraising activities and donations. We are very hopeful that a grant round will open in 2021 when more funding opportunities are available.

Everything we have experienced in these first years of activity for the Charity indicates to us that there is a huge unmet need for support and we will continue to work hard to help individuals to access support and treatment to give everyone the best chance of an earlier diagnosis or the support they need to live better with EDS.

Awareness Raising

Our aim to raise awareness amongst the public and the medical community will never be complete – there will always be more that can be done. In 2020 we made an impact locally and internationally, such as our rebrand and redesign of Mind Body EDS Awareness Brochures for use at conferences, events, medical clinics etc., as well as appearing on Podcast interviews and an Oscar-winning production team film about invisible illnesses.

Our aim to reach the medical community is specifically focussed on the next generation of young doctors and GPs. By raising awareness of the symptoms and prevalence of EDS amongst trainee medics – and particularly using the 'zebra' analogy – in future, the experience of hearing about EDS may lead a clinician to pursue EDS as a diagnosis – possibly leading to achieving the ultimate goal of more timely diagnosis and appropriate, and possibly life saving, treatment.

Our aim to reach the general public has grown during 2020 with the help of fundraising events, social media and website, and film. We would like to highlight:

1. Fundraising events - our charity participated in numerous sporting events as described in the 'Fundraising' section above.
2. Podcasts - our Founder, Laura Sylvester, was invited for a podcast interview by the 'Wellrestorer's Wellness Podcast' (Season 1 Episode 8) to speak about EDS and the Charity. It was recorded and uploaded in June onto all audio platforms such as Spotify, Apple Podcasts, Google Cast etc. and is accessible worldwide here: <https://www.wellrestorer.co.uk/podcast/>
3. Film - 'The Dark Horse' - invited by our Ambassador, Ashleigh Harley, and working with Oscar-winning production team, Slick Films, along with the support from our Charity, the film documents Ashleigh Harley's 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 creation of the charity, which will be presented at film festivals and screenings around the world. This incredible spotlight opportunity enables our charity to spread education, advocacy and awareness on an international platform.

4. Social Media - our accounts on Facebook, Instagram and Twitter have been very active this year gaining around 2000 supporters/followers, thanks to the efforts and support of volunteers working with us. Our #myedsdiagnosis campaign that began in May 2018 continues to be a success with over 200 individuals from around the world sharing their diagnosis story and number of years to diagnosis to help spread awareness of our Charity's mission. Most weeks we have shared these stories, EDS Facts, Awareness Days and Grant Testimonials to reach a wider audience and have received positive feedback.

2020 was a positive year for raising awareness even though the pandemic hit the charity sector for fundraising events and donations. We would like to thank all of our supporters and volunteers for making it successful.

Funding Research

Our objective to fund research into Ehlers-Danlos syndromes is aspirational – in these early years, funds have been directed towards our more immediate priority of helping individuals to seek diagnosis and to aid them in living more comfortably with EDS. In the longer term, there will be many opportunities to contribute to the research agenda and to focus funding in areas which will support greater understanding of the origins, progress and treatments for EDS, and we are hoping that within 5 years, we will have made a start on this particular objective.

Looking ahead to 2021 and beyond

As our experience over the past few years as a Charity has shown us, there is much unmet need for EDS sufferers and much more to do.

Our focus for 2021 will be to secure longer-term sponsorship donors to enable us to re-open grant awards to individuals to help them achieve a timely diagnosis, and to provide support for medical and lifestyle requirements of those living with the disease.

We will also be stepping up our advocacy work and are planning to reach out to more of the medical community – particularly medical school students – to raise awareness of symptoms and prevalence of Ehlers-Danlos Syndromes to give new patients the best chance of an early diagnosis.

For our fundraising efforts, we are hopeful that the lifting of restrictions from COVID-19 will come hand-in-hand with more events and opportunities to connect with donors.

And we will be continuing to engage with our networks and communities to seek support for our work through a variety of sponsored and individual efforts.

This report is signed by the Chair of Trustees and was approved by the Trustees at their meeting on 11 October 2021.

Signature:

Dated: 11 October 2021

Mind Body EDS A Charitable Incorporated Organisation registered in England & Wales Charity number 1177182

Mind Body EDS		
Receipts and Payments accounts		
For the period 1st January 2020 to 31st December 2020		
Receipts and Payments		
	2020	2019
Receipts	£	£
Donations from Charitable foundations	3,000	22,500
Donations from Individuals and companies	390	12,898
Donations from Sponsors	2,763	9,663
Direct Fundraising activities	4,235	355
Sub total Receipts	10,388	45,416
Payments		
Grants to applicants	0	44,922
Bank and money transfer fees	-	2
Professional fees	2,265	2,560
Purchase of equipment	-	232
Office expenses	519	1,474
Fundraising expenses	1,705	2,791
Conference and educational events	2,500	6,926
Sub total payments	6,988	58,907
Net (payments)/receipts	3,400	(13,491)
Statement of Assets and Liabilities at 31st December 2020		
	31/12/2020	31/12/2019
Cash Funds		£
Bank Account	8,954	6,127
Pay Pal Balance	589	16
Total Cash funds	9,543	6,143
All Funds are Unrestricted		

Please see the Notes to the Accounts on the following pages

Notes to the Accounts

These 'Receipts and Payments' accounts are presented under section 133 of the Charities Act 2011, which states that charities registered in England and Wales that are not companies are allowed to complete Receipts and Payments accounts if their turnover does not exceed £250,000.

Also, In accordance with section 25 of the Charity's constitution, the trustees have kept proper accounting records and the charity is entitled to file receipts and payments accounts if the Trustees choose to do so. The Trustees confirm that none of the exceptions listed in the Charity Commission's guidelines apply to the Charity and that receipts and payments accounts are appropriate to the Charity's circumstances. The Trustees have opted to use the Charity Commission's proforma for completing the accounts.

Accounting year end

The Charity was licensed on 15th February 2018 and all payments and receipts accounted for in these accounts relate to the time period relating to that date or after. The Charity has chosen to designate 31st December as its accounting period end.

Specific disclosures for Charitable Incorporated Organisations

- The Charity has given no guarantees which would give rise to a potential liability and consequently there are no guarantees outstanding as at 31st December 2020.
- There are no debts outstanding at 31st December 2020 and consequently no debts secured by an express charge on any asset of the Charity.

Related Party Transactions

There were no related party transactions in 2020.

Trustee remuneration and expenses

During the year no Trustee received any remuneration in their role as trustees.

A total of £291 was reimbursed to trustees and volunteers in relation to travel and accommodation incurred in the course of pursuing the Charity's activities.

Accounting for separate funds – restricted and endowment funds

All receipts to the Charity have been technically unrestricted – no specific conditions attach to funds received and hence no separate accounting for reserved funds is required. The Charity holds no endowment funds.

However, in order to be prudent and to ensure that the Charity is able to meet potential expenses and commitments as they fall due (such as for professional fees) the Trustees have determined that a small sum should be set aside at all times to meet these expenses (the balance being £1800 at the end of the accounting period). These funds set aside are not restricted or reserved under the meaning of the SORP but are internally designated for specific costs or circumstances for management purposes.

End of Notes