



Annual Report

Year ended 31st December 2021

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

Our Chair's Report

2021: a tough year maybe, but certainly not a standstill year

Like other charities, irrespective of size, the on-going COVID-19 pandemic continued to present us with a huge challenge from a fundraising perspective, though the year was not without its successes in terms of our ability to boost income by attracting donations.

We ended 2021 having raised almost £140,000 since we started the charity in 2018, a result of which we are extremely proud. And the majority of the funds raised have been invested in helping numerous sufferers of Ehlers-Danlos syndromes in dire need of financial support. Grants to individual applicants totaling nearly £82,000 have enabled them to travel to appointments, access diagnostic services not available on the NHS, receive therapy appropriate to their individual needs and fund specialised new wheelchairs, for example.

Some interesting statistics are now available to show how the charity is performing. Since the first grant round in July 2018, the charity has conducted 7 grant rounds through to the end of 2021. A total of 96 grant applications were received over this period seeking financial aid to meet EDS sufferers' needs amounting to £1,169,732. The total number of successful applicants receiving full or partial financial support was 67, representing 70% of those who applied. However, the total grants awarded amounted to £81,782 for those successful 66 applicants. Of the awards given, 31 were for less than £1,000 and 36 were for greater than £1,000 (the highest award being for £3,000). For 10 of the applicants, they were seeking only a contribution to a wider and larger fundraising campaign for their needs, but when compared to the total request of £1,169,732, the charity could only fund 7.0% of the total. This emphasises the need for the charity to do more in raising revenue so it can do more to provide the financial support EDS sufferers desperately need.

However, Mind Body EDS is not just about directly helping EDS sufferers secure early accurate diagnosis and treatment, critically important though that is. The charity was also established to help address the lack of awareness and understanding of EDS amongst both the medical profession and the general public more broadly, and 2021 saw us continue to take positive steps in broadening recognition of EDS as a unique set of disabilities.

As a young charity, establishing credibility is critical as the basis for success in both fundraising and improving awareness. We were delighted therefore to be able to welcome Lord and Lady Malloch-Brown as official Family Patrons and Professor Christopher Mathias as Medical Patron. Together with Ashleigh Harley as previously-announced Ambassador, we have been able to use 2021 in part as a period in which to establish a firmer foundation to spread our message and efforts into new target areas.

As a result, despite the constraints of the past two years, as we emerge from the pandemic, we believe we are now better-placed to achieve our objectives, below:

The overarching Mission of Mind body EDS 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.”

As the mission statement states, one of our primary goals is to help make a difference to the lives of EDS sufferers - and the many testimonials we receive reinforce the value and importance of what we are aiming to achieve in meeting the original desire of our Founder, Laura Sylvester to help fellow sufferers as she emerged from life-saving surgery in 2016 and 2017.

In Laura’s case, her ability to resume something like a normal life, despite ongoing medical issues, has resulted in not only Laura graduating with an MSc with distinction, but also Imperial College London highlighting her as ‘a figure of inspiration from throughout her life and career’ as part of International Women’s Day and Women at Imperial Week. Such powerful outcomes demonstrate that ‘making a difference’ is not only desirable but achievable.

The position of Chair of the Trustees rotates on a temporary basis between the Trustees and I have acted in the role for 2021.

A handwritten signature in blue ink, appearing to read 'J. Hogan'.

John Hogan

Interim 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, but my brain was also 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.

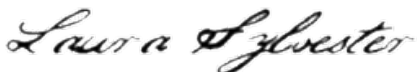
Invisible illness is the very definition of hell. Understanding Ehlers-Danlos syndromes is a steep learning curve, and the only way in which to climb, is to have hope for what the future could bring. Because there simply is nothing else. There is no cure.

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. 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.



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.

Report of the Trustees for year ended 31st December 2021

The Trustees of Mind Body EDS are pleased to present this fourth 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 the accounting period from 1st January 2021 to 31st December 2021.

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 over £25,000 for this year an Independent Accountant's examination has taken place and is included in this report.

Constitution

The charity is a charitable incorporated organization (CIO). The charity's constitution dated 1st February 2018 is the primary governing documents of the charity. Details of the trustees who served during the year, and to the date these accounts are approved are included in the Reference and Administrative Details on page 6.

In accordance with the Constitution, at section 10, new trustees are appointed having regard to the skills, knowledge and experience needed for the effective administration of the charity, and any new appointments are confirmed at a meeting of all Trustees.

Reference and Administrative Details

Our Trustees for 2021

John Hogan (Interim Chair)
Graham Noakes
Kevin Sylvester
John Nicholls – until 11th April 2021
Francesca Lock
Andrew Blair – from 14th June 2021

Our Founder

Laura Sylvester

Our Family Patrons

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

Our Medical Patron

Professor Christopher Matthias

Our Ambassador

Ashleigh Harley

Our Registered Address

Wey Court West
Union Road
Farnham
Surrey
GU9 7PT

Our Independent Accountants

Wise & Co
Wey Court West
Union Road
Farnham
Surrey
GU9 7PT

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.

Public Benefit

In setting our objectives and planning our activities the trustees have carefully considered the Charity Commission's general guidance on public benefit.

Our Structure, Governance and Management

As at 31st December 2021 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, Frankii Lock, Andy Blair and Kevin Sylvester. For 2021, this role has been fulfilled by John Hogan.

During the course of 2021 there have been three full Trustee meetings, all meetings being held virtually. Attendance by trustees at meetings was 80% or better at all meetings.

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. This year, one such grant review meeting was held in August 2021.

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 minimum amount thus held should be £500 and may be increased by the Trustees as appropriate; the balance being £2,300 at the end of the accounting period.

As the Charity's turnover for 2021 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. Also in this report is the independent examination report by accountants Wise & Co.

Mind Body EDS is officially trademarked by the IPO.

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

How have we fulfilled our Objectives in 2021?

Fund Raising

The income of the Charity for 2021 was £41,600. Even though the pandemic impacted our usual fundraising events and donations, we were extremely fortunate to receive two donations from foundations totaling £20,000, (one from the William Brake Foundation the other from a foundation preferring to remain anonymous); and a generous \$20,000 donation from JHI Associates in Toronto (who were an original supporter of our Charity when they sponsored our first London Marathon runner in 2019); as well as having many individuals come forward wanting to carry-out virtual fundraising challenges for us.

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

- Sam Williams raised over £4,000 for the London to Brighton 56km run
- Emma-Lou Smith raised £400 walking the West Highland Way
- At an equestrian event sponsored by them, X-Zony, a sporting clothing manufacture, donated prizes and support for a raffle for Mind Body EDS which raised over £500

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 – we 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. In 2020 we were unable to award any grants because of difficulties with fundraising activities, but were delighted to be able to support one grant giving round in 2021. We were able to make awards to 15 individuals totaling over £17,000

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. 2021 was another difficult year for Awareness Raising. We have been unable to attend conferences or host or contribute to events, but our objectives remain the same.

Our aim to reach the medical community is specifically focused 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 continued to grow in 2021 with the help of fundraising events, social media and website. We would like to highlight:

1. Fundraising events – individuals participated for our Charity in several sporting events as described in the ‘Fundraising’ section above.
2. Podcasts – In June 2020 our Founder, Laura Sylvester, was interviewed for the ‘Wellrestorer’s Wellness Podcast’ (Season 1 Episode 8) and spoke about EDS and the Charity. It is still available on 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’ - created 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. The film was due for release in 2021, and 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. Due to unforeseen circumstances the film has not yet been released but is scheduled for release in 2022/2023.
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.

Despite the obvious obstacles, 2021 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 2022 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, and continuing into 2022, has been to secure longer-term sponsorship donors to enable us to offer more 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 the 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 Interim Chair of Trustees and was approved by the Trustees by email on 11th April 2022.

Signature:

A handwritten signature in blue ink, appearing to read 'J Hogan'.

John Hogan – interim Chair of Trustees

Dated: 31st May 2022

Independent Accountant's Examination

Independent examiner's report to the Trustees of 'Mind Body EDS'

I report to the trustees on my examination of the accounts of Mind Body EDS (the Trust) for the period ended 31 December 2021 which are set out on pages 14 to 16.

Responsibilities and basis of report

As the charity trustees of the Trust you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the Trustee's accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

- (1) accounting records were not kept in respect of the Trust as required by section 130 of the Act; or
- (2) the accounts do not accord with those records.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.



Mark Dickinson FCA
Wise & Co
Chartered Accountants
Wey Court West
Union Road
Farnham
GU9 7PT
10 August 2022

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

Receipts and Payments Analysis for accounting period 1st January 2021 to 31st December 2021			
	2021		2020
Receipts	£		£
Donations from Charitable foundations	20,000		3,000
Donations from Individuals and companies	16,181		390
Donations from Sponsors	4,881		2,763
Direct Fundraising activities	538		4,236
	<u>41,600</u>		<u>10,388</u>
Payments			
Grants to applicants	17,429		-
Professional fees	715		2,265
Purchase of equipment	130		-
Office expenses	597		519
Fundraising expenses	84		1,705
Conference and educational events			2,500
	<u>18,954</u>		<u>6,988</u>
Movement in Cash Balances			
Cash balances brought forward	9,543		6,143
Net Receipts (payments)	22,646		3,400
Cash balances carried forward	<u>32,189</u>		<u>9,543</u>
Statement of Assets and Liabilities at 31st December 2021			
Cash Funds	31/12/2021		31/12/2020
Bank account balance	32,138		8,954
Pay Pal account balance	51		589
	<u>32,189</u>		<u>9,543</u>

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. 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 2021.
- There are no debts outstanding at 31st December 2021 and consequently no debts secured by an express charge on any asset of the Charity.
- In applying for a grant, applicants are asked for confirmation that the grant awarded will be used for the purposes stated on the application form. In one instance in 2021, an award for £2400 was made to allow an urgent diagnostic procedure to take place in a private healthcare setting. However, the applicant was able to secure an urgent NHS appointment for the procedure and therefore returned the full £2400 to the charity. This amount was received in January 2022 and is thus not recognised as income (or reduced expenditure) in this set of accounts.

Related Party Transactions

The Charity had one related party transaction in 2021 – a grant of £1,500 was awarded to Laura Sylvester, the Charity's founder (no awards were made in 2020). To avoid conflict in decision making, Laura's application was considered by all Trustees excluding her father, Kevin Sylvester.

Laura was reimbursed £130 (2020: £19) for expenses incurred on behalf of the charity.

Trustee remuneration and expenses

During the year no Trustee received any remuneration in their role as trustees. A total of £407 was reimbursed to trustees for payments made on behalf of the charity.

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 £2,300 at the end of the accounting period). These funds set aside are not restricted or reserved under the meaning of the SORP.

Pending Receipts

Income is recognized at the time it is received by the Charity. In addition, the Charity monitors pending donations collected by the PayPal Giving fund, which are transferred into the Charities Pay Pal account once per month. At 31st December 2021 there was a total of £25.00 donated to the Charity which had not yet been received in the Charity's own account.

End of Notes