



Annual Report

Year ended 31st December 2023

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

Registered Charity number 1177182

Our Chair's Report

One of our primary goals is to help make a difference to the lives of EDS sufferers - and the many testimonials we receive from people the Charity has been able to help reinforce the value and importance of this goal. In 2023 we raised sufficient funds through sponsored activities and direct donations to support one round of cash grants in which the Charity was able to provide financial assistance to EDS sufferers in need of help.

The Charity opened a Grant Round in November 2023 through which we were able to help 9 successful applicants meet the costs of services ranging from travelling costs to appointments; mobility assistance; specialist diagnostic services not otherwise available to them through the NHS and to receive therapy tailored to their individual needs. We awarded a total of £20,286 to those applicants in this Round.

A summary of the financial report is that the Charity opened 2023 with £32,188 in cash; raised £23,109 through sponsored activities and direct donations; distributed £20,286 through the Grant Round referred to above, and incurred £2,524 in expenses and the costs of promotional materials. None of the Trustees or the Founder are remunerated and donate their time for free. The Charity closed the year with a cash balance of £38,619 as of 31st December 2023 (but with £20,286 committed as awards already promised).

The level of financial support being requested exceeds the Charity's capacity to support all applicants and in each Grant Round the Trustees face the unenviable task of determining how to allocate a limited cash resource amongst the many worthy applicants. Your support of the Charity either through helping raise money or making donations directly is important in allowing us to help as many EDS sufferers as possible and is most welcome.

I would like to take this opportunity to acknowledge and thank those colleagues who help run the Charity and to thank all who have contributed to its activities in whatever way during 2023.

Kevin Sylvester
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."

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.

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.

Laura Sylvestre

Report of the Trustees for year ended 31st December 2023

The Trustees of Mind Body EDS are pleased to present this sixth 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 of 31st December each year. This report covers the accounting period from 1st January 2023 to 31st December 2023.

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 under £25,000 for this year an Independent Accountant's examination was not required.

Reference and Administrative Details

Our Trustees for 2023

John Hogan (Interim Chair until November 2023)
Graham Noakes
Kevin Sylvester (Interim Chair from November 2023)
Francesca Lock
Andrew Blair

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

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.

Our Structure, Governance and Management

As at 31st December 2023 the Charity has four 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 the Trustees and until November 2023 this role was filled by John Hogan. John retired as a Trustee in November 2023, since which time the role of interim Chair has been filled by Kevin Sylvester.

During the course of 2023 there have were two full Trustee meetings, held both virtually and in person according to Trustees' other commitments. Additionally there was one Grant Allocation meeting, to coincide with the closing date² of the calls for grant applications, and one Strategy afternoon for Trustees and volunteers.

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.

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. The Charity is supported in maintaining its financial records and preparing the Annual Accounts and returns by volunteer bookkeeper Jacqueline Burke, the original Chair of the Charity, now retired as a Trustee.

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 £2,750 at the end of the accounting period).

As the Charity's turnover for 2023 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. As the income for 2023 did not exceed £25,000 the Charity is not required to have an independent examination report of the accounts and the Trustees have elected to not do so.

Mind Body EDS is officially trademarked by the IPO.

How have we fulfilled our Objectives in 2023?

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

Fund Raising

The income of the Charity for 2023 was £23,108. We are again grateful to two foundations which continue to support us – Alta Advisers and the Brake Foundation and to all who support us with donations and events. The wide variety of donors and methods of support shows us that we are raising awareness of the charity and our causes far and wide.

Grant Giving

Awarding grants to individuals is a key part 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 2023 we held one grant awarding rounds closing at the end of November. In total we had 23 applications and were able to award 10 grants to a total value of over £20,800. The value of the grants awarded ranged from £350 to £5,500. (Note that the figures shown in the accounts differ from these figures as some of the payments for 2022 were actually made in 2023 and all of the awards for 2023 will be paid in 2024.)

Everything we have experienced in these first six 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.

This report is signed by the Interim Chair of Trustees and was approved by the Trustees at its meeting on 21st May 2024

Signature: ***Kevin Sylvester***

Dated: 22nd May 2024

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

Receipts and Payments Analysis for accounting period 1st January 2023 to 31st December 2023				
		2023		2022
	Receipts	£		£
	Donations from Charitable foundations	18,000		20,000
	Donations from Individuals and companies	1,605		5,714
	Donations from Sponsors	2,234		5,222
	Direct Fundraising activities	1,270		190
		23,109		31,125
	Payments			
	Grants to applicants	14,214		28,428
	Bank and money transfer fees	-		2
	Professional fees	2,222		2,134
	Purchase of equipment	-		-
	Office expenses	302		176
	Fundraising expenses	-		84
	Conference and educational events	-		240
		16,738		31,065
	Cash Funds			
	Bank account balance	36,578		32,149
	Cash in Hand	850		
	Pay Pal account balance	1,191		100
		38,619		32,249

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 is required to disclose any guarantees which it has given and which could give rise to a potential liability. As at the end of December 2023 the Trustees had awarded, but not yet paid, ten awards to successful applicants totaling £20,808.92 (these were all subsequently paid in early 2024).
- There are no debts outstanding at 31st December 2023 and consequently no debts secured by an express charge on any asset of the Charity.

Related Party Transactions

In 2023 a sum of £302.01 was paid to Kevin Sylvester, interim Chair of the Charity, for expenses incurred on behalf of the Charity.

Trustee remuneration and expenses

During the year no Trustee received any remuneration in their role as a Trustee. A total of £302.01 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 £2,750 at the end of the accounting period). These funds set aside are not restricted or reserved under the meaning of the SORP.

End of Notes



CHARITY COMMISSION
FOR ENGLAND AND WALES

Mind Body EDS

1177182

Receipts and payments accounts

CC16a

For the period
from

1st January 2023

To

31st December 2023

Section A Receipts and payments

	Unrestricted funds	Restricted funds	Endowment funds	Total funds	Last year
	to the nearest £	to the nearest £	to the nearest £	to the nearest £	to the nearest £
A1 Receipts					
Donations from Charitable foundations	18,000	-	-	18,000	20,000
Donations from Individuals and companies	1,605	-	-	1,605	5,714
Donations from Sponsors	2,234	-	-	2,234	5,222
Direct Fundraising activities	1,270	-	-	1,270	190
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	23,109	-	-	23,109	31,125
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	23,109	-	-	23,109	31,125
A3 Payments					
Grants to applicants	14,214	-	-	14,214	28,428
Bank and money transfer fees	-	-	-	-	2
Professional fees	2,222	-	-	2,222	2,134
Purchase of equipment	-	-	-	-	-
Office expenses	302	-	-	302	176
Fundraising expenses	-	-	-	-	84
Conference and educational events	-	-	-	-	240
	-	-	-	-	-
	-	-	-	-	-
Sub total	16,738	-	-	16,738	31,065
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	16,738	-	-	16,738	31,065
Net of receipts/(payments)	6,371	-	-	6,371	60
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	32,248	-	-	32,248	32,188
Cash funds this year end	38,619	-	-	38,619	32,248

Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds	Bank account balance	36,578	-	-
	Pay Pal account balance	1,191	-	-
	Cash in Hand	850	-	-
	Total cash funds	38,619	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK

	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			-	-
			-	-
			-	-
			-	-
			-	-

	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B4 Assets retained for the charity's own use			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-

	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities			-	
			-	
			-	
			-	
			-	

Signed by one or two trustees on behalf of all the trustees

Signature	Print Name	Date of approval
Kevin Sylvester	Kevin Sylvester	5/21/2024
Graham Noakes	Graham Noakes	5/21/2024