



Mind Body **EDS**[®]

Supporting those impacted by Ehlers-Danlos syndromes

ANNUAL REPORT

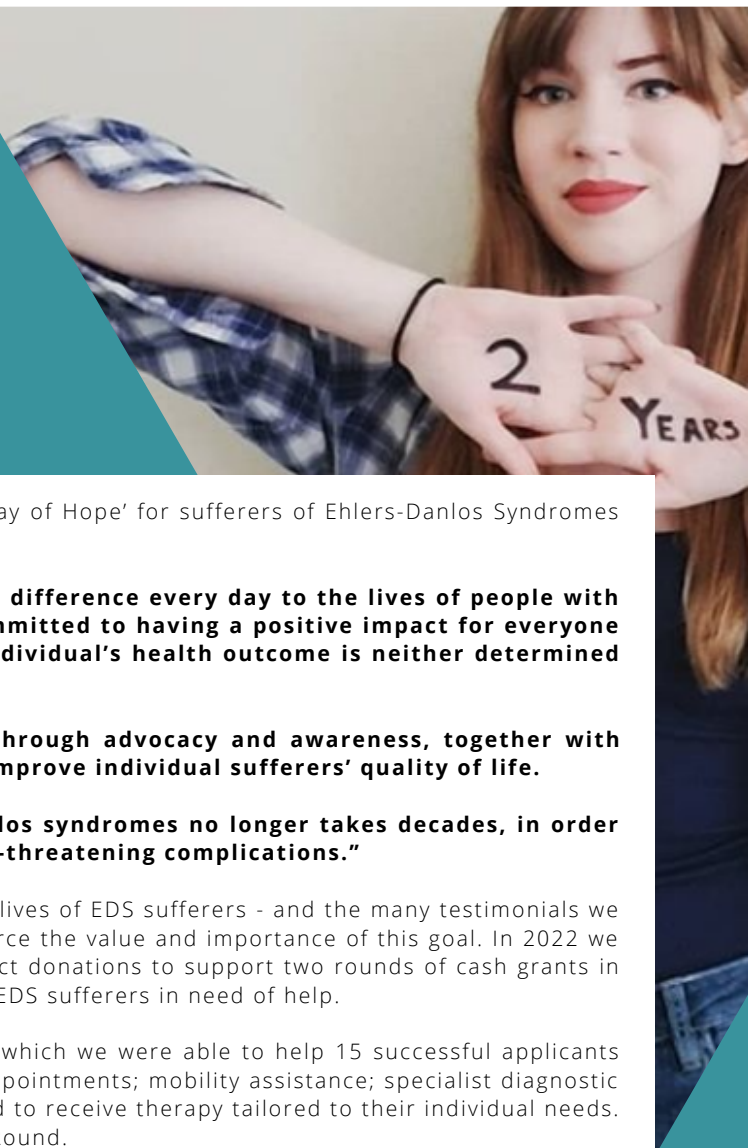
YEAR ENDED 31ST DECEMBER 2022



A GATEWAY OF HOPE FOR EHLERS-DANLOS SYNDROMES

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

OUR CHAIR'S REPORT



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."

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 2022 we raised sufficient funds through sponsored activities and direct donations to support two rounds 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 January 2022 through which we were able to help 15 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 distributed a total of £26,017 to those applicants in this Round.

A second Grant Round was opened in November 2022. This was the ninth Grant Round the Charity has been able to fund to help EDS sufferers since its foundation in 2018. In the November round the Charity helped 6 applicants with a total financial support of £16,624.55.

A summary of the financial report is that the Charity opened 2022 with £32,188 in cash; raised £31,125 through sponsored activities and direct donations; distributed £42,642 through two Grant Rounds referred to above and incurred £2,637 in expenses and 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 £32,249 as of 31st December 2022 (but with £14,214 committed as awards already promised).

As I reported in the 2021 Chair's Report, 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.

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 in 2023 we continue to take steps in broadening recognition of EDS as a unique set of disabilities.

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 2022.

The position of Chair of the Trustees rotates between the Trustees, and I have held the role since 2020.

Acting Chair of the Trustees

OUR FOUNDER'S STORY



My symptoms went unrecognised for more than a decade, until 2014 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. Between 2016 and 2019 I underwent a total of seven brain and spinal surgeries in my mid-twenties.

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 zebras[1] 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.

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.

Laura Sylvester

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REPORT OF THE TRUSTEES FOR YEAR ENDED 31ST DECEMBER 2022

The Trustees of Mind Body EDS are pleased to present this fifth 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 2022 to 31st December 2022.

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.



REFERENCE AND ADMINISTRATIVE DETAILS

OUR TRUSTEES FOR 2022

John Hogan (Acting chair)
Graham Noakes
Kevin Sylvester
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

c/o Shaw Gibbs
Wey Court West
Union Road
Farnham
Surrey
GU9 7PT

OUR INDEPENDENT ACCOUNTANTS

Shaw Gibbs (Audit) Limited
Wey Court West
Union Road
Farnham
Surrey
GU9 7PT

OUR CONTACT DETAILS

Find us at: www.mindbodyeds.org.uk
Or on Social media: @mindbodyeds.org.uk

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 2022 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. For 2022, this role has been fulfilled by John Hogan.

During the course of 2022 there have been four full Trustee meetings, all meetings being held virtually. Two trustees attended all four meetings and three trustees attended three 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 date^[2] of the calls for grant applications, 'Grant Application review meetings' are held. This year, two such grant review meetings were held in March and December 2022.

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.

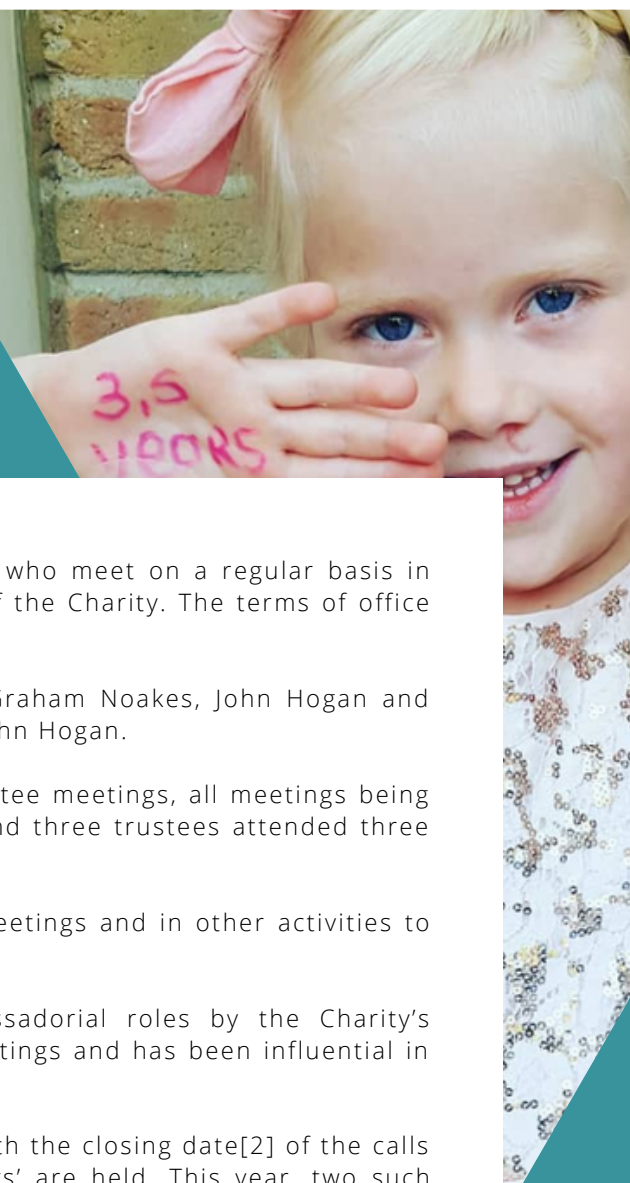
In managing its financial resources, the Trustees from time to time consider the need to hold reserves. The Charity does not have employees, nor premises, and does not therefore incur regular expenses of this nature. However, to be prudent and to allow the Charity to meet potential expenses and commitments 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 £2,370 at the end of the accounting period).

As the Charity's turnover for 2022 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 Shaw Gibbs (Audit) Limited.

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 2022?

FUND RAISING

The income of the Charity for 2022 was £31,125. Even though the pandemic impacted our usual fundraising events and donations, we were extremely fortunate to receive two donations from foundations totalling £20,000, as well as having many individuals come forward wanting to carry-out fundraising challenges for us. 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.

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

- Over £2,000 raised by our friend Dr John Thompson (our runner in the 2018 London Marathon) from a sponsored run in his home state of Texas
- £1,500 raised by Ben MacDonald for running the Great Scottish Run Half Marathon
- £1,500 raised by the Zebra 24 Hour Charity Stream in June - thank you to all who contributed
- £1,500 raised from the MMEA scout group (a geological organisation)
- In memorium contributions from family and friends who have lost loved ones
- Contributions are made in many ways, including via eBay and Amazon donations via Crowd Funder, PayPal, and the Charities Aid Foundation.

We are grateful to all of our donors, whatever the method you choose to help us.



With thanks to John Thompson



With thanks to Ben MacDonald

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 2022, we held two grant awarding rounds - one closed at the end of January and one at the end of November. In total we had 35 applications and were able to award 20 grants to a total value of over £42,000 (this figure differs from the accounts presented here as 4 awards were not paid until after the year end - please see the Notes to the Accounts for further explanation). The value of the grants awarded ranged from £300 to £6,000.

Everything we have experienced in these first five 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.

£31,125

**Fundraised by
individuals and events in
2022**

21

**EDS patients positively
impacted by financial
grants in 2022**

£43,000

**Total financial grants
awarded to EDS patients
in 2022**

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 2022 we made a virtual impact actively using Social Media (Facebook, Instagram and Twitter) gaining around 3,000 further supporters/followers this year, thanks to the efforts and support of volunteers working with us posting EDS Facts, Grant Testimonials and Awareness Days.

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 continued to grow in 2022 with the help of fundraising events, social media and website. We would like to highlight:

- Fundraising events - individuals participated for our Charity in several sporting events as described in the 'Fundraising' section above
- Carol singing at Christmas in our local town, Farnham, spreading awareness of EDS to members of the public by handing out MB-EDS awareness flyers and advocating.
- 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 2023/2024.
- Social Media - our accounts on Facebook, Instagram and Twitter have been very active this year gaining around 3,000 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, 2022 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 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 2023 AND BEYOND

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

Our focus for 2022, and continuing into 2023, 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 with COVID-19 restrictions being permanently lifted, we will have 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 13th August 2023.



Acting Chair of the Trustees

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 2022 which are set out on pages 11 to 13.

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
Shaw Gibbs (Audit) Limited
Wey Court West
Union Road
Farnham
GU9 7PT

11 September 2023

MIND BODY EDS

A CHARITABLE INCORPORATED ORGANISATION REGISTERED IN ENGLAND & WALES CHARITY NUMBER 1177182

Receipts and Payments Analysis for accounting period 1st January 2022 to 31st December 2022				
		2022		2021
		£		£
Receipts				
Donations from Charitable foundations		20,000		20,000
Donations from Individuals and companies		5,714		16,181
Donations from Sponsors		5,222		4,881
Direct Fundraising activities		190		538
		31,125		41,600
Payments				
Grants to applicants		28,428		17,429
Bank and money transfer fees		2		-
Professional fees		2,134		715
Purchase of equipment		-		130
Office expenses		176		597
Fundraising expenses		84		84
Conference and educational events		240		-
		31,065		18,954
Cash Funds				
Bank account balance		32,149		32,138
Pay Pal account balance		100		50
		32,249		32,188

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 2022 the Trustees had awarded, but not yet paid, five awards to successful applicants totalling £14,213.65 (these were all subsequently paid in early 2023).

In addition, at the year end the Trustees had approved a payment for expenses of £302.10 incurred by Kevin Sylvester for regular payments made by him personally for fees relating to the hosting of the charity's website. The payment was agreed prior to the year end but not transacted until January 2023.

- There are no debts outstanding at 31st December 2022 and consequently no debts secured by an express charge on any asset of the Charity.

RELATED PARTY TRANSACTIONS

The Charity had two related party transactions in 2022 – both to Laura Sylvester, the charity's founder, and daughter of Trustee Kevin Sylvester. The payments were for grant applications made during the competitive grant rounds under the same application criteria as apply to all applicants. The grants awarded were £1,100 in March 2022 and £2,411 in December 2022. To avoid conflict in decision making, Laura's application was considered by all Trustees excluding her father.

TRUSTEE REMUNERATION AND EXPENSES

During the year no Trustee received any remuneration in their role as a Trustee. A total of £500.40 was reimbursed to Trustees for payments made on behalf of the charity (£260.40) or in the course of carrying out the charity's business (£240).

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 £2,370 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