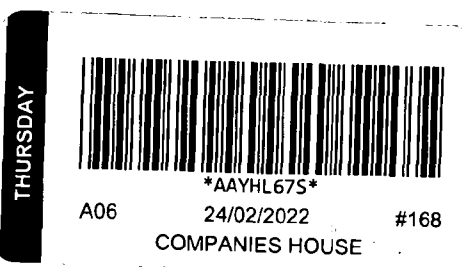


**THE EHLERS-DANLOS SOCIETY**  
**(A COMPANY LIMITED BY GUARANTEE)**

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**THE EHLERS-DANLOS SOCIETY**  
**(A COMPANY LIMITED BY GUARANTEE)**

**LEGAL AND ADMINISTRATIVE INFORMATION**

CHARITY NUMBER: 1180984

COMPANY NUMBER: 10722868

DIRECTORS AND TRUSTEES: W. Gandy, Esq  
Mrs S.Haskel  
Mrs S Hawkins  
Dr M.J. Macleod

REGISTERED OFFICE: Wayman House,  
141, Wickham Road,  
Shirley,  
CROYDON,  
Surrey, CR0 8TE.

ACCOUNTANTS: Messrs. Jeffrey Altman & Company,  
Chartered Accountants,  
Wayman House,  
141, Wickham Road,  
Shirley,  
CROYDON,  
Surrey, CR0 8TE.

BANKERS: Clydesdale Bank  
154-158 Kensington High Street  
LONDON,  
W8 7RL



**The Ehlers-Danlos Society  
Trustee Report 2020-2021**

**Charity Name:** The Ehlers-Danlos Society

**Charity Number:** 1180984

**Charity Address:** Office 7, 35-37 Ludgate Hill, London, EC4M 7JN

**Trustee Names:**

Susan Hawkins (Chair)

Dr Woodrow Gandy (Trustee)

Dr Melanie Jane MacLeod (Trustee)

Sue Haskel (Trustee)

**Report of The Directors of Trustees**

The Directors herewith present their report and the unaudited financial statements of the company for the year ended 30th April 2021.

**Structure, Governance and Management**

The Charity is organised so that the Trustees meet quarterly to review results and manage its affairs. In this way the Board gathers information needed to make decisions and plan for the future.

The UK and US organisation are two separate legal entities; however, we share a global mission, governance, financial and administrative structures, some staff, website, social media platforms, and volunteer resources; all of which ensures we are as efficient as possible and maximise the impact we can have on our UK community. Our trustees also serve on our US Board of Directors.

**Objectives and Activities**

The principal activity is that of the provision of services to the public, specifically all people and their families who either suffer or are affected by Ehlers-Danlos Syndromes and Hypermobility Spectrum Disorders. The Ehlers-Danlos Society is registered at the Charities Commission Registration Number 1180984.

Launched in 2017, The Ehlers-Danlos Society is a UK community of patients, caregivers, health care professionals, and supporters, dedicated to saving and improving the lives of those affected by the Ehlers-Danlos syndromes, hypermobility spectrum disorders, and related disorders. The Ehlers-Danlos Society supports collaborative research and education initiatives both in the UK and around the world; awareness campaigns, advocacy, community-building, and care for the EDS and HSD population.

Our charitable goals are to increase global awareness and ensure a better quality of life for all who suffer from these conditions in the UK and where appropriate globally. Research is at the centre of what we do, so that one day we will have a cure. Our strength begins with hope.

### **Achievements and Performance**

The following activities benefitting the public were done in collaboration with The Ehlers-Danlos Society in the USA:

#### **Education**

Throughout the year we have continued to work hard to connect with our community and medical professionals. The Ehlers-Danlos Society has held multiple virtual events to ensure we can reach as much of the public as possible. During this time, we have held the following conferences/events:

In response to the global COVID pandemic, The Ehlers-Danlos Society held its first ever Virtual Summer Conference in 2020. We reached over 1600 of our community through this conference, 83 from the UK. We ensured accessibility to even more of our beneficiaries by translating the entire conference into 4 languages.

For our 2021 Virtual Summer Conference, we were joined by 977 attendees (670 Community members, 145 healthcare professionals, 135 Junior Zebras, and 27 Speakers) in 39 countries, with 66 of the attendees being located in the UK. 61% of our community members and 50% of the healthcare professionals were first time attendees to an EDS Society conference. To ensure increased accessibility to all, we offered the event translated live into 4 languages from English to: French, Italian, Spanish, and Portuguese. For the health professionals who joined us, Project ECHO® designated the event a maximum of 5 AMA PRA Category 1 Credits™ available to claim for eligible sessions viewed live.

The Ehlers-Danlos Society has produced multiple webinars presented by medical professionals from around the globe, which include a Q&A portion for attendees to pose questions on the specific topic being discussed. These webinars have been viewed worldwide over 125,000 times.

#### **Research**

The Ehlers-Danlos Society continues to support enrolment and efforts with the Hypermobile Ehlers-Danlos Genetic Evaluation (HEDGE) study, a study devoted to finding the underlying genetic markers for hypermobile EDS (hEDS). To date, 1057 people are enrolled to the study, of these enrolments, 157 are based in the UK.

#### **Advocacy and Support**

Providing help and support to our community is paramount to our mission, throughout 2020 and 2021 our Helpline answered nearly 1,300 calls globally, with 5-10% of those calls from our community in the UK. Nearly 9,000 Helpline emails were received and answered, with 10-15% of emails responding to questions from the UK.

#### **Reference and Administrative Details**

As set out under the relevant sections herein.

#### **Exemptions from disclosure**

None.

### **Financial Review**

As a relatively new and expanding charity, our income from this financial year has been influenced by the COVID pandemic but has predominantly come from public donations, fundraising events in memory of those who have passed away and a grant from The Ehlers-Danlos Society (US Charitable Society). Our administrative expenditure is kept as low as possible in order to ensure maximum benefit to the beneficiaries, and as described we continue to work closely by sharing common services with The Ehlers-Danlos Society, USA.

Going forward, we aim to increase our income in the same ways and to apply for potential grant opportunities in the UK and the USA. We do not have any debts, and at this time we do not have a reserves policy but we aim to create one in the next few years as our income allows.

We currently employ eight full-time staff and two full-time consultants/contractors.

### **Statement of Directors Responsibilities for Preparing the Financial Statements**

The Directors are responsible for preparing the Director's Report and the Accounts in accordance with applicable law and regulations. Company law requires the Directors to prepare Accounts for each financial year.

Under the law, the Directors have elected to prepare the Accounts in accordance with United Kingdom Generally Accepted Accounting Practice (United Kingdom Accounting Standards and applicable law).

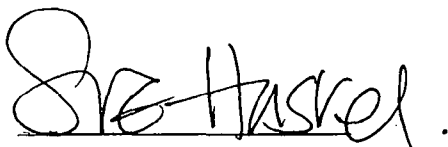
Under company law, the Directors must not approve the Accounts unless they are satisfied that they give a true and fair view of the state of affairs of the Company and of the profit or loss of the Company for that period.

In preparing these Accounts, the Directors are required to:

- select suitable accounting policies and then apply them consistently;
- make judgments and estimates that are reasonable and prudent;
- prepare the Financial Statements on the going concern basis unless it is inappropriate to presume that the Company will continue in business.

The Directors are responsible for keeping adequate accounting records that are sufficient to show and explain the Company's transactions and disclose with reasonable accuracy at any time the financial position of the Company and enable them to ensure that the Accounts comply with the Companies Act 2006. The Directors are also responsible for safeguarding the assets of the Company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

This Report has been prepared in accordance with the small companies regime of the Companies Act, 2006.



Sue Haskel

Director & Trustee

**THE EHLERS-DANLOS SOCIETY**  
**(A COMPANY LIMITED BY GUARANTEE)**

**INDEPENDENT EXAMINER'S REPORT TO THE MANAGEMENT COMMITTEE OF  
THE EHLERS-DANLOSS SOCIETY**

I report on the accounts of The Ehlers-Danlos Society for the year ended 30 April, 2021, which are set out on pages 7 to 9.

**Respective responsibilities of trustees and examiner**

The charity's trustees are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year under section 144 of the Charities Act 2011 (the Charities Act) and that an independent examination is needed.

It is my responsibility to:

- Examine the accounts under section 145 of the Charities Act;  
To follow the procedures laid down in the general directions given by the Charity
- Commission under section 145(5)(b) of the Charities Act; and
- To state whether particular matters have come to my attention.

**Basis of independent examiner's report**

My examination was carried out in accordance with the general directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently no opinion is given as to whether the accounts present a "true and fair view" and the report is limited to those matters set out below.

**Independent examiner's statements**

In connection with my examination, no matter has come to my attention:

- (1) which gives me reasonable cause to believe that in any material respect the requirements
  - to keep accounting records in accordance with section 130 of the Charities Act; and
  - to prepare accounts which accord with the accounting records and comply with thehave not been met; or
- (2) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

Name: M D Altman

Relevant professional qualification or body: FCA



JEFFREY ALTMAN & COMPANY

Chartered Accountants

Wayman House

141, Wickham Road,

Shirley

Croydon

Surrey

CR0 8TE

Date: 12th January, 2022

These unaudited financial statements have been subjected to independent examination.

**THE EHLERS-DANLOS SOCIETY**  
**(A COMPANY LIMITED BY GUARANTEE)**

STATEMENT OF FINANCIAL ACTIVITIES (INCLUDING  
INCOME AND EXPENDITURE ACCOUNT) FOR THE  
YEAR ENDED 30th APRIL, 2021

		<u>2021</u>			<u>2020</u>		
	<u>NOTE</u>	Unrestricted Funds £	Restricted Funds £	Total £	Unrestricted Funds £	Restricted Funds £	Total £
<b><u>INCOMING RESOURCES</u></b>							
Incoming and endowments from:							
Donations and legacies		375,585	62,596	438,181	108,109	166,759	274,868
<b>Charitable Activities</b>							
Conference Income		( 8,508)	-	( 8,508)	10,728	-	10,728
<b>Investments:</b>							
Bank Interest		-	-	-	-	-	-
<b>TOTAL</b>	<b>3</b>	<u>367,077</u>	<u>62,596</u>	<u>429,673</u>	<u>118,837</u>	<u>166,759</u>	<u>285,596</u>
<b><u>EXPENDITURE ON:</u></b>							
Cost of Generating Funds:							
Charitable activities	4	356,353	136,764	493,117	157,507	53,228	210,735
Other	4	6,430	-	6,430	4,298	-	4,298
<b>TOTAL EXPENDITURE</b>		<u>362,783</u>	<u>136,764</u>	<u>499,547</u>	<u>161,805</u>	<u>53,228</u>	<u>215,033</u>
<b>NET INCOME/EXPENDITURE BEFORE TAXATION</b>		4,294	( 74,168)	( 69,874)	( 42,968)	113,531	70,563
<b>TAX PAYABLE</b>		-	-	-	-	-	-
		4,294	( 74,168)	( 69,874)	( 42,968)	113,531	70,563
<b><u>NET INCOMING/(EXPENDITURE)</u></b>							
Transfers between funds		-	-	-	-	-	-
		4,294	( 74,168)	( 69,874)	( 42,968)	113,531	70,563
<b><u>NET MOVEMENT IN FUNDS</u></b>							
Reconciliation of funds:							
Fund balances at 1st May, 2020		( 32,940)	113,531	80,591	10,028	-	10,028
Fund balances at 30th April, 2021		<u>( 28,646)</u>	<u>39,363</u>	<u>10,717</u>	<u>( 32,940)</u>	<u>113,531</u>	<u>80,591</u>

**CONTINUING OPERATIONS**

None of the Charity's activities were acquired or discontinued during the above financial period.  
The statement of financial activities includes all gains and losses recognized in the year.  
The notes on pages 6 to 9 form part of these accounts.

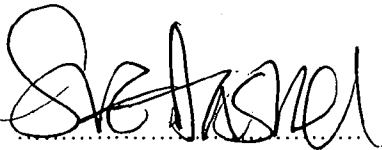
**THE EHLERS-DANLOS SOCIETY**  
**(A COMPANY LIMITED BY GUARANTEE)**

**UNAUDITED BALANCE SHEET AS AT 30TH APRIL, 2021**

	NOTES	2021	2020
		£	£
<b><u>CURRENT ASSETS</u></b>			
Debtors	7	95	1,388
Cash at Bank and in Hand		13,981	81,373
		<u>14,076</u>	<u>82,761</u>
<b><u>CURRENT LIABILITIES</u></b>			
Creditors - amounts falling due within one year	8	<u>3,359</u>	<u>2,170</u>
<b><u>NET CURRENT ASSETS</u></b>		<u>10,717</u>	<u>80,591</u>
<b><u>TOTAL ASSETS LESS CURRENT LIABILITIES</u></b>		<u>10,717</u>	<u>80,591</u>
<b><u>NET ASSETS</u></b>		<u>£ 10,717</u>	<u>£ 80,591</u>
<b><u>RESERVES</u></b>			
<b><u>Unrestricted funds</u></b>			
General funds	9	(28,646)	(32,940)
Restricted Funds	9	<u>39,363</u>	<u>113,531</u>
		<u>£ 10,717</u>	<u>£ 80,591</u>

Directors' and Trustees' responsibilities:

- For the financial period in question the company was entitled to exemption under section 477 of the Companies Act 2006 relating to small companies.
- The Directors and Trustees have not required the company to obtain an audit of its accounts for the year in accordance with section 476
- The Directors and Trustees acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and the preparation of accounts
- These accounts have been prepared in accordance with the provisions applicable to companies subject to the small companies' regime of the Companies Act 2006.
- The financial statements were approved by the board of directors and trustees on 12th January, 2022 and were signed on its behalf by:-



Mrs Susan Haskell  
 Director and Trustee

The notes on pages 7 to 9 form part of these accounts.



**THE EHLERS-DANLOS SOCIETY**  
**(A COMPANY LIMITED BY GUARANTEE)**

STATEMENT OF CASH FLOWS FOR THE  
YEAR ENDED 30th APRIL, 2021

	<u>2021</u>	<u>2020</u>
	<u>£</u>	<u>£</u>
<b><u>CASH FLOW FROM OPERATING ACTIVITIES</u></b>		
Operating (loss)/profit for the financial year	(69,874)	70,563
(Increase)/decrease in debtors	1,293	(1,388)
Increase/(decrease) in creditors	<u>1,189</u>	<u>970</u>
Cash from Operations	(67,392)	70,145
Net cash from operating activities	<u>(67,392)</u>	<u>70,145</u>
Net increase/(decrease) in cash and cash equivalents	(67,392)	70,145
Cash and cash equivalents at 1st May, 2020	<u>81,373</u>	<u>11,228</u>
Cash and cash equivalents at 30th April, 2021	<u><u>13,981</u></u>	<u><u>81,373</u></u>

**THE EHLERS-DANLOS SOCIETY**  
**(A COMPANY LIMITED BY GUARANTEE)**

**NOTES TO THE UNAUDITED ACCOUNTS FOR THE**  
**YEAR ENDED 30th APRIL, 2021**

**1. ACCOUNTING POLICIES**

The accounting policies set out below have been applied consistently by the Charity in the preparation of its Accounts.

**(a) Basis of Accounting**

The Accounts have been prepared in accordance with FRS 102 and the Charities SORP (FRS 102) (effective 1st January, 2015) and the Companies Act 2006 and under the Historical Cost Convention and on a going concern basis.

**(b) Charitable Income**

Voluntary income is received by way of donations and gifts and is included in full in the Statement of Financial Activities when receivable. The value of services provided by volunteers has not been included. Credit is taken in the Accounts for donations, legacies and grants only when they are actually received by the Charity.

**(c) Public Benefit Entity**

The Charity is a public benefit entity under FRS 102 and has been incorporated in England and Wales and is registered with The Charity Commission in England and Wales. The principal place of business being that of Office 7, 35-37 Ludgate Hill, London, EC4M 7JN.

**(d) Taxation**

As a registered Charity, the company is not liable to taxation on its income.

**(e) Funds Accounting**

Funds held by the Charity are either:

- *Unrestricted general funds* - these are funds which can be used in accordance with the charitable objects at the discretion of the Trustees.
- *Designated funds* - these are funds set aside by the Trustees out of unrestricted general funds for specific future purposes or projects.
- *Restricted funds* - these are funds that can only be used for particular restricted purposes within the objects of the Charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

**(f) Resources Expended**

Resources expended are included in the Statement of Financial Activities on an accruals basis, inclusive of any VAT which cannot be recovered.

Certain expenditure is directly attributable to specific activities and has been included in those cost categories. Certain other costs which are attributable to more than one activity, are apportioned across cost categories on the basis of an estimation of the proportion of time spent on those activities. Government costs include those incurred in the governance of the charity and its assets are primarily associated with constitutional and statutory requirements.

**THE EHLERS-DANLOS SOCIETY**  
**(A COMPANY LIMITED BY GUARANTEE)**

NOTES TO THE UNAUDITED ACCOUNTS FOR THE  
 YEAR ENDED 30th APRIL, 2021

**2. LEGAL STATUS OF THE CHARITY**

The Charity is a Company limited by guarantee and has no share capital. The liability of each member in the event of winding up is limited to £1.

**3. INCOME FROM CHARITABLE ACTIVITIES**

	<u>2021</u>			<u>2020</u>		
	Unrestricted	Restricted	Total	Unrestricted	Restricted	Total
	Funds	Funds		Funds	Funds	
	£	£	£	£	£	£
Conference Income	(8,508)	-	(8,508)	10,728	-	10,728
General Donations	369,535	-	369,535	108,109	-	108,109
Coronavirus Job Retention Scheme	6,050	-	6,050	-	-	-
Restricted Donations	-	62,596	62,596	-	166,759	166,759
Interest on Investments	-	-	-	-	-	-
	<u>367,077</u>	<u>62,596</u>	<u>429,673</u>	<u>8,580</u>	<u>166,759</u>	<u>285,596</u>

**4. ANALYSIS OF TOTAL RESOURCES EXPENDED**

	<u>2021</u>				<u>2020</u>			
	Unrestricted		Restricted		Unrestricted		Restricted	
	Funds		Funds		Funds		Funds	
	Direct	Support	Direct	Total	Direct	Support	Direct	Total
	Costs	Costs	Costs	£	Costs	Costs	Costs	£
	£	£	£	£	£	£	£	£
CHARITABLE ACTIVITIES								
Wages and salaries	176,374	-	94,094	270,468	69,228	-	30,318	99,546
National insurance	26,926	-	-	26,926	6,270	-	-	6,270
Pension costs	5,390	-	-	5,390	2,198	-	-	2,198
Staff benefits	103	-	-	103	652	-	-	652
Advertising and Promotional Expense	856	-	-	856	5,055	-	57	5,112
Charitable activities	-	-	-	-	269	-	-	269
Echo Honorarium	-	-	-	-	-	-	4,617	4,617
Hedge	-	-	-	-	-	-	599	599
Accountancy Fees	-	6,430	-	6,430	-	4,298	-	4,298
Printing, Postage and Stationery	707	-	96	803	1,798	-	827	2,625
Professional Fees	142,541	-	42,574	185,115	44,219	-	16,510	60,729
Computer costs	362	-	-	362	5,882	-	-	5,882
Conference costs	250	-	-	250	7,580	-	-	7,580
Administrative costs	-	-	-	-	40	-	-	40
Donations and subscriptions	3,210	-	-	3,210	244	-	-	244
Rent	-	-	-	-	949	-	-	949
Finance costs	389	-	-	389	135	-	-	135
Travel costs	(755)	-	-	(755)	12,988	-	300	13,288
	<u>356,353</u>	<u>6,430</u>	<u>136,764</u>	<u>499,547</u>	<u>157,507</u>	<u>4,298</u>	<u>53,228</u>	<u>215,033</u>

**THE EHLERS-DANLOS SOCIETY**  
**(A COMPANY LIMITED BY GUARANTEE)**

**NOTES TO THE UNAUDITED ACCOUNTS FOR THE**  
**YEAR ENDED 30th APRIL, 2021**

**5. STAFF COSTS AND TRUSTEES REMUNERATION**

The Trustees were not paid or reimbursed for expenses during the period.	<u>2021</u>	<u>2020</u>
The number of staff receiving a salary of over £60,000 was:		
Between £110,000-£120,000	<u>1</u>	<u>-</u>

The total remuneration of key management personnel during the year was £112,772 (2020:£24,318)

**6. STAFF NUMBERS**

Administration	<u>6</u>	<u>2</u>
----------------	----------	----------

**7. DEBTORS**

Taxation and social security	<u>95</u>	<u>1,388</u>
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**8. CREDITORS - amounts falling due within one year**

Accruals	<u>3,359</u>	<u>2,170</u>
	<u>3,359</u>	<u>2,170</u>

**9. MOVEMENT OF FUNDS IN THE YEAR**

	<u>2021</u>					<u>2020</u>		
	Unrestricted Funds		Restricted Funds			Unrestricted Funds	Restricted Funds	
	General Fund	Administrative Assistant	Echo	Hedge	Total	General Fund	Total	Total
	£	£	£	£	£	£	£	£
At 1st May, 2020	( 32,940)	42,576	77,280	( 6,325)	80,591	10,028	-	10,028
Income in the year	367,077	37,596	25,000	-	429,673	118,837	166,759	285,596
	334,137	80,172	25,000	-	510,264	128,865	166,759	295,624
Expenditure in the year	362,783	46,246	75,494	15,024	499,547	161,805	53,228	215,033
	( 28,646)	33,926	( 50,494)	(6,325)	10,717	( 32,940)	113,531	80,591
Transfers	-	-	-	-	-	-	-	-
At 30th April, 2021	<u>( 28,646)</u>	<u>33,926</u>	<u>( 50,494)</u>	<u>( 6,325)</u>	<u>10,717</u>	<u>( 32,940)</u>	<u>113,531</u>	<u>80,591</u>

**10. CONTINGENT LIABILITIES**

There were no contingent liabilities as at 30th April, 2021.