

Charity Registration No. 1175427

PSC SUPPORT
TRUSTEES' REPORT AND ACCOUNTS
FOR THE YEAR ENDED 5 APRIL 2023



PSC SUPPORT

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FOR THE YEAR ENDED 5 APRIL 2023

REFERENCE AND ADMINISTRATIVE DETAILS

Name	PSC SUPPORT
Charity registration no.	1175427
Address	Unit 23056, Uk Postbox PO Box 4336 MANCHESTER M61 0BW
Independent Examiner	Wenn Townsend Chartered Accountants Victoria House 10 Broad Street Abingdon Oxon OX14 3LH

Trustees serving on the date the report was approved

Tim Waterson	(Chair)
Harrison James Douglas Moller	(Appointed 8 February 2023)
Mark William Dean	(Appointed 8 February 2023)
Helen Elder	(Appointed 10 January 2023)
Rick Dallaway	
Nicholas Kane	
James Brown	
David Harvey Adams	
Roger Chapman	(Resigned 18 January 2023)
Martine Walmsley	(Resigned 16 May 2022)
James Gosney	(Resigned 22 April 2022)
Shelley Spence	(Resigned 20 March 2023)

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PSC SUPPORT

TRUSTEES' REPORT

FOR THE YEAR ENDED 5 APRIL 2023

The Trustees present their report and financial statements for the year ended 5 April 2023. The accounts have been prepared in accordance with applicable accounting standards, SORP 2015 (FRS 102) Accounting and Reporting by Charities and the Charities Act 2011.

Structure, governance and management governing document

The charity uses a **constitution** as its governing document.

PSC Support is a **Charitable Incorporated Organisation (CIO)**

Trustees use the Charity Governance code as a framework to build and improve governance standards.

Recruitment and appointment of trustees

Trustees are interviewed and then appointed by existing trustees.

Public benefit statement

The Trustees confirm that they have referred to the information contained in the Charity Commission's general guidance on public benefit when reviewing the charity's aims and objectives and in planning future activities. As a matter of course, reference is made to our agreed objectives to aid decision-making.

Our prioritised short-term goals are as follows:

- 1 Research
We will establish a pathway towards finding a cure or effective treatment for PSC
- 2 Information and Support
We will provide support and information to improve the quality of life and wellbeing of people affected by PSC
- 3 Improving Care
We will advocate for the highest standards of care for people living with PSC

OBJECTIVES AND ACTIVITIES

Our charitable objects are:

- 1 The relief of those suffering from liver diseases or disorders (in particular but without limitation PSC), and related disorders
- 2 The advancement of public awareness of PSC, other liver disease and related disorders
- 3 The advancement of both the treatment and prevention of PSC and other liver disease and related disorders.

Our related activities include (but are not limited to) the following:

1. Funding high quality research, helping to shape clinical and other research trials and being funding co-applicants for PSC research
2. Providing high-quality, medically checked information on our website, social media, newsletters and at PSC Support events

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TRUSTEES' REPORT

FOR THE YEAR ENDED 5 APRIL 2023

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3. Providing support for those affected by PSC via our Helpline service and our moderated, private PSC Support Facebook group
 4. Advocating for those affected by PSC both in the UK and internationally.

ACHIEVEMENTS AND PERFORMANCE

Fundraising/ Income

The charity received a total of £263,687 in fundraising, donations and other income (including merchandise sales) for the year ending 5th April 2023. This remarkable 42% increase in a difficult economic year was testament to our supporters who are driven by the charity's aims and objectives, especially our commitment to funding high quality research. £32,260 of the total was restricted for PSC research and £550 for education purposes.

Expenditure

PSC Support trustees place the utmost importance on spending the charities money in the best possible way for our beneficiaries. 2022 - 23 was a year of planning for a step change in subsequent years, putting the building blocks in place. Our expenditure in this FY was £127,077 an increase of 199% on the previous year.

New CEO

The charity recruited its first CEO in order to take the charity from a very small, volunteer-led charity to one that has a sustainable structure and capacity to meet the needs of people affected by PSC. The new CEO has a solid background in senior management positions in large national and small charities. Her successful income generation experience was particularly attractive to the charity. The CEO took up her new role in May 2022 so nearly had a full year in post during the FY2022/3.

Volunteers

Our volunteers make a significant contribution to the charity. Trustees recognise their pivotal role in the charity.

In particular they would like to recognise the following; Keith Anderson is the charity's long standing Treasurer and Facebook moderator Lorraine Failes another long-standing volunteer for the charity.

They are also very grateful to long term Facebook moderators Vicki and Gareth Weeks, Josie and Malcolm Eddy who manage merchandise and assist with fundraising. Trustees would also like to recognise the contribution made by our webmaster Iain McClenaghan and Noelle Srivastava for her graphic design services. They would also like to recognise all patients and their families who have provided different perspectives in this year's support, advocacy and research initiatives. As well as being a Facebook moderator Gareth Weeks also sits alongside Chris Forde, Jenny Nelson and Gary Taylor as patient representatives on our Expert Panel; they all play a crucial role in this capacity. PSC Support works with dedicated medical professionals, who give their time and expertise to PSC Support at no cost. This year, we are grateful for support from:

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TRUSTEES' REPORT

FOR THE YEAR ENDED 5 APRIL 2023

Professor David Adams
Professor Doug Thorburn
Professor Annika Bergquist
Professor Graeme Alexander
Professor Angsar Lohse
Professor Michael Heneghan
Dr Palak Trivedi
Dr Roger Chapman
Dr Deepak Joshi
Dr Simon Rushbrook
Dr Emma Culver
Dr Luke Boulter
Dr Richard Aspinall
Dr James Ferguson
Dr Jess Dyson
Dr Nabil Quraishi
Dr Andrew Yeoman
Dr Kate Lynch
Dr Elena Marcus
Dr Mike Williams
Dr Kathy McKay
Dr Mussarat Rahim
Dr Fotis Sampaziotis
Dr Francesca Saffioti
Dr Christoph Schramm
Dr Brijesh Srivastava
Dr Veronica Ranieri
Dr Dermot Gleeson
Dr Nora Cazzagon
Dr Norma Junge

Staff

An additional member of staff was recruited to provide organisational support to the CEO and the charity. The other, existing member of staff moved into a new job role managing events and fundraising.

Fundraising Tools and Products

New fundraising tools and products were launched to ensure the sustainability of the charity's fundraising capabilities. A new and secure customer relationship management system was purchased and implemented, helping to ensure supporter engagement is managed in the best possible way.

Running events were identified as a major source of income generation for the charity and the decision was made to capitalise on this opportunity by developing a partnership with Run for Charity and over 750 racing events are now offered to our supporters via the PSC Support website.

The way we interact and thank our supporters was bolstered and a volunteer was taken on to help with this.

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TRUSTEES' REPORT

FOR THE YEAR ENDED 5 APRIL 2023

Information and Support

Social media - the charity posts daily on social media channels to increase the information we give and to increase our engagement with those affected by PSC. Additionally we run a well-moderated private Facebook group to offer peer support. Huge thanks again goes to our volunteer moderators and staff moderator, Martine Walmsley, who work tirelessly to make sure the private support group is moderated extremely well even during holiday periods.

Ask the Experts - these were scheduled as monthly events in the second half of the financial year to give those affected by PSC more access to expert clinicians; to find out the latest developments and ask questions about PSC and related conditions.

Information Days - were restarted post Covid with an event in an area of the country that had never before hosted these events, Manchester. This allowed those in the north of the country easy access to the event. In reality over 100 people attended from all over the country. Great feedback was received from this event, which has led to the decision to produce these events twice a year.

Helpline - Special thanks to Martine Walmsley who is a warm listening ear, also providing her expert knowledge on the disease.

Research (including publications)

PSC research remains a priority for the charity. We launched a new research campaign called **Mission 2030** to dramatically increase the charity's research funding.

PSC Support has committed to fund £1 million worth of research by 2030. We need to urgently find, at least, effective treatments for this disease and the charity is committed to playing its part. Funding will include research projects and a Research Training Fellowship.

This is broken down as follows:

- Annual research project funding of minimum of £80,000 per annum
- Research Training Fellowship funding for three years for 2024-27; total funding of £300,000

The charity also continued to dedicate time to support clinical trial development by working with pharmaceutical companies to ensure trial protocols and patient information were fit for purpose and appropriate for our UK community.

Additional research activities included:

1. Being a co-applicant on national and international PSC research study funding applications
2. Representing people with PSC on trial steering committees and trial management groups for national research projects, studies and trials.
3. Running focus groups of 8-10 people living with PSC each to provide patient and public involvement to inform academic research studies. We are very grateful to the people with PSC who joined our research panels to provide feedback to researchers.
4. Representing PSC patients in the European Reference Network (ERN RARE-LIVER) as the Co-Lead of the PSC Working Group (MW).

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TRUSTEES' REPORT

FOR THE YEAR ENDED 5 APRIL 2023

Publications:

1. Kowdley K, Safer R, Gomel R, Hatchett J, Walmsley M, Burman J, Weinbaum S, Goldsmith K, Kim M, Garner W, McKibben A, Chien E. **Impact of pruritus in primary sclerosing cholangitis (PSC): a multinational survey.** Journal of Hepatology. 2022 vol. 77(S1): S119–S388
2. Marcus E, Stone P, Thorburn D, Walmsley M, Vivat B. **Quality of life (QoL) for people with primary sclerosing cholangitis (PSC): a pragmatic strategy for identifying relevant QoL issues for rare disease.** Journal of Patient-Reported Outcomes. 2022 Dec;6(1):1-2.
<https://doi.org/10.1186/s41687-022-00484-5>
3. Gleeson D, Walmsley M, Trivedi PJ, Joshi D, Rea B. **Surveillance for cholangiocarcinoma in patients with primary sclerosing cholangitis: Can we be more proactive?** Frontline Gastroenterology. 2022 Aug 4. <http://dx.doi.org/10.1136/flgastro-2022-102172>

Advocacy

PSC Support continued to provide strong advocacy for those affected by PSC both at a national and international level.

Organisational Risk, Limitations and Stability

PSC Support Trustees continued to hold quarterly meetings and kept in close contact with the CEO during the year.

All Trustees receive copies of income and expenditure figures for the financial year to date every month from the PSC Support Treasurer. The Board also receives a full Financial Report every quarter, which takes into account the forecast, expenditure, income and any designated funds to ensure they are fully aware of the charity's current and expected financial position as an ongoing concern.

The staff base increased with the appointment of the first CEO in May 2022 and the appointment of an Executive Assistant to the CEO in July 2022.

Following the Trustees' strategic decision in the previous financial year to increase the charity's capacity by appointing a Chief Executive, recruitment began in 3Q2021. The successful candidate was appointed in February 2022, commencing work with PSC Support in May 2022.

Following her return from maternity leave in August 2022 the Programme Development Officer took up a new role as Fundraising and Events Officer.

Change in accounting policy

During the financial year 2022-23 PSC Support crossed the threshold of £250,000 and have moved from Receipts and Payments Accounting to Accruals Accounting as outlined by the Charity Commission.

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TRUSTEES' REPORT

FOR THE YEAR ENDED 5 APRIL 2023

FINANCIAL REVIEW

The detailed accounts for the year ended 5 April 2023 are shown on pages 10-18. The accounts show that at the end of the financial year PSC Support held £542,174 in funds. This was broken down as total unrestricted £508,652 and total restricted £33,522.

At the end of the financial year the charity held £53,000 of committed funds for research.

No funds were materially in deficit.

Policy on reserves

In 2022-23 reserves contingency was twelve months operating costs. These reserves would enable normal operating activities to continue over a period of 12 months should a shortfall in income occur. It also takes into account any potential risks and contingencies that may arise from time to time. (Please note that in 2023-4 reserves have since been reduced to 9 months operating costs).

In order to establish the reserve, the Trustees consider the financial circumstances and risks annually (expenditure and unrestricted income).

The Trustees review the charity accounts monthly and the forecast on a quarterly basis.

The Trustees regularly reviewed funds/reserves levels throughout 2022/23, focusing funds on the most important priorities.

The reserves value held by the charity (which equals 12 months of running costs), stands at £138,756. This includes the increased pay expenditure allocated to new staff.

Future plans

These include the following:

- The funding of high-quality research as part of the Mission 2030 campaign. This will result in annual funding of at least £80,000 for research projects and, from 2024-27, the funding of a PhD Fellow at a total cost of £300,000.
- Increasing the staff base in 2023-4 to include an Administration Manager to fill a skills gap in the organisation. The Administration Manager will also take on the day-to-day finance work when the current Treasurer resigns.
- Moving to an automated accountancy system to help manage the charity's finances.
- Updating our app to include more reporting facilities, clinical trials information and to make it available in other English-speaking countries.
- Producing two in person Information Days a year in different parts of the country to ensure PSC experts are accessible to those affected by PSC who want to hear from them.

Independent Examiner

A resolution will be proposed at the Trustee Meeting that Wenn Townsend be re-appointed as Independent Examiner to the charity for the ensuing year.

PSC SUPPORT

TRUSTEES' REPORT *FOR THE YEAR ENDED 5 APRIL 2023*

Approved by the Trustees and signed on their behalf on 10th January 2024 by:

Tim Waterson
(Trustee)

PSC SUPPORT

STATEMENT OF TRUSTEES' RESPONSIBILITIES

The trustees are responsible for preparing the Trustees' Report and the accounts in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

The law applicable to charities in England and Wales requires the trustees to prepare accounts for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources of the charity for that year.

In preparing these accounts, the trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the accounts; and
- prepare the accounts on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The trustees are responsible for keeping sufficient accounting records that disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the accounts comply with the Charities Act 2011, the Charity (Accounts and Reports) Regulations 2008 and the provisions of the trust deed. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

PSC SUPPORT

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF PSC SUPPORT

I report to the charity trustees on my examination of the accounts of the charity for the year ended 5 April 2023 which are set out on pages 10 to 18.

Responsibilities and basis of report

As the charity's trustees 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 charity's accounts carried out under section 145 of the 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 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 charity as required by section 130 of the Act; or
2. the accounts do not accord with those records or
3. the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair view' which is not a matter considered as part of an independent examination.

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.

Stuart Bates FCA CTA
Wenn Townsend
10 Broad Street
Abingdon
OX14 3LH

11 January 2024

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STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 5 APRIL 2023

		Unrestricted funds	Restricted funds	Total 2023	Total 2022 (Restated)
	Notes	£	£	£	£
Income					
Donations and legacies	-	216,657	26,010	242,667	168,593
Grants	2	-	550	550	2,000
Investment income	3	2,223	-	2,223	237
Gift aid		10,678	6,250	16,928	13,971
Other charitable activities		1,319	-	1,319	836
Total		230,877	32,810	263,687	185,457
Expenditure					
Grants payable		8,504	38	8,542	5,018
Fundraising		3,925	-	3,925	2,874
Direct charitable expenditure		114,010	-	114,010	34,076
Governance costs		600	-	600	600
Total	4	127,039	38	127,077	42,568
Net movement in funds		103,838	32,772	136,610	142,889
Fund balances at 6 April 2022 (restated)		398,564	7,000	405,564	262,675
Fund balances at 5 April 2023		502,402	39,772	542,174	405,564

PSC SUPPORT
STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 5 APRIL 2022 (Comparative figures, Restated)

	Unrestricted funds	Restricted funds	Total 2022 (Restated)
	£	£	£
Income			
Donations and legacies	168,593	-	168,593
Grants	-	2,000	2,000
Investment income	237	-	237
Gift aid	13,728	63	13,791
Other charitable activities	836	-	836
Total	183,394	2,063	185,457
Expenditure			
Grants payable	1,405	3,613	5,018
Fundraising	2,874	-	2,874
Direct charitable expenditure	34,076	-	34,076
Governance costs	600	-	600
Total	38,955	3,613	42,568
Net movement in funds	144,439	(1,550)	142,889
Fund balances at 6 April 2021	254,125	8,550	262,675
Fund balances at 5 April 2022	398,564	7,000	405,564

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BALANCE SHEET AS AT 5 APRIL 2023

		2023	2022 (Restated)
	Notes	£	£
Fixed Assets			
Tangible Assets	6	2,776	215
Current Assets			
Stocks		1,162	1,174
Debtors	7	15,472	3,738
Cash at Bank and in hand		<u>525,971</u>	<u>401,158</u>
		<u>542,605</u>	<u>406,070</u>
Creditors: amounts falling due within one year	8	<u>3,207</u>	<u>721</u>
		<u>539,398</u>	<u>405,349</u>
Net current assets		<u>542,174</u>	<u>405,564</u>
Total assets less current liabilities			
Income funds			
Restricted Funds		39,772	7000
Unrestricted Funds		<u>502,402</u>	<u>398,564</u>
		<u>542,174</u>	<u>405,564</u>

The accounts were approved by the Trustees on 10th January 2024

Tim Waterson (Trustee)

PSC SUPPORT

NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 5 APRIL 2023

1 Accounting policies

1.1 Basis of preparation

The charity constitutes a public benefit entity as defined by FRS 102. The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) issued in October 2019, the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS102), the Charities Act 2011 and applicable regulations.

The charity has applied Update Bulletin 1 as published on 2 February 2016 and does not include a cash flow statement on the grounds that it is applying FRS 102 Section 1A.

The financial statements are prepared on a going concern basis under the historical convention (modified to include certain items at fair value). The financial statements are presented in sterling which is the functional currency of the charity and rounded to the nearest pound.

The financial statements have been prepared under the historical cost convention as modified by the inclusion of investments at market value.

1.2 Incoming resources

Donations, legacies and other forms of voluntary income are recognised as incoming resources when receivable.

1.3 Tangible fixed assets and depreciation

Tangible fixed assets are stated at cost less depreciation. Depreciation is provided at rates calculated to write off the cost less estimated residual value of each asset over its expected useful life, as follows:

Fixtures, fittings & equipment	25% straight line
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1.4 Investments

Fixed asset investments are stated at market value.

Unrealised gains or losses are recognised each year within the Statement of Financial Activities.

1.5 Stock

Stock is valued at the lower of cost and net realisable value.

1.6 Restricted funds

Restricted funds are subject to specific conditions by donors as to how they may be used. The purposes and uses of the restricted funds are set out in the notes to the accounts.

PSC SUPPORT

NOTES TO THE ACCOUNTS (CONTINUED) FOR THE YEAR ENDED 5 APRIL 2023

	2023	2022
	£	£
2 Grants		
Clinical Trials	<u>550</u>	<u>2000</u>
3 Interest Receivable	<u>2,223</u>	<u>237</u>

PSC SUPPORT

NOTES TO THE ACCOUNTS (CONTINUED) FOR THE YEAR ENDED 5 APRIL 2023

	Total	Total
	2023	2022
	£	£
4 Total resources expended		
Grants		
Restricted funds	38	3,613
Unrestricted funds	8,504	1,405
	<u>8,542</u>	<u>5,018</u>
Direct charitable expenditure		
Salaries (including employer NI and pensions)	86,341	16,880
Other Staff costs	6,409	8,030
General administration	3,140	1,277
Advocacy	4,072	541
Awareness and Support	9,845	7,082
Other	3,148	-
Depreciation	1,055	266
	<u>114,010</u>	<u>34,076</u>
Fundraising		
Advertising and promotion	2,678	1,490
Merchandise	1,247	1,384
	<u>3,925</u>	<u>2,874</u>
Governance costs		
Independent examiner	600	600
	<u></u>	<u></u>
Total resources expended	<u>127,077</u>	<u>42,568</u>

PSC SUPPORT

NOTES TO THE ACCOUNTS (CONTINUED) FOR THE YEAR ENDED 5 APRIL 2023

5 Trustees

None of the trustees (nor any persons connected with them) received any remuneration during the year, but one was reimbursed a total of £122 travelling and office expenses (2022: no trustee expenses were reimbursed).

	£
6 Fixed Assets	
Cost at 6 April 2022	1,064
Purchases at cost	3,616
Cost at 5 April 2023	4,680
Depreciation at 6 April 2022	849
Charge for the year	1,055
Depreciation at 5 April 2023	1,904
Net book value at 5 April 2023	2,776
Net book value at 5 April 2022	215

	2023 £	2022 £
7 Debtors		
Accrued income	15,448	3,671
Prepayments	24	67
	15,472	3,738

	2023 £	2022 £
8 Creditors: amounts falling due within one year		
Accruals	3,027	721
	3,027	721

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NOTES TO THE ACCOUNTS (CONTINUED) FOR THE YEAR ENDED 5 APRIL 2023

9 Restricted Funds

	Movement in funds			
	Balance at 6 April 2022	Incoming Resources & Transfers	Outgoing Resources & Transfers	Balance at 5 April 2023
	£	£	£	£
PSC Research	7,000	32,260	38	39,222
Education	-	550	-	550
As 5 April 2023	7,000	32,810	38	39,772

	Balance at 6 April 2021	Incoming Resources & Transfers	Outgoing Resources & Transfers	Balance at 5 April 2022
	£	£	£	£
PSC Research	8,550	2,063	3,613	7,000
As 5 April 2022	8,550	2,063	3,613	7,000

Description of restricted funds

Research – two separate donations were received and restricted to research in 2022-23: one for £25,000 and one for £1,010. £6,250 gift aid was received for the £25,000 donation making a total restricted income for research of £32,260.

Education – one donation for £550 was received from pharmaceutical company Chemomab to produce clinical trials booklets.

Total received in restricted income for 2022-23 was £32,810.

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NOTES TO THE ACCOUNTS (CONTINUED) FOR THE YEAR ENDED 5 APRIL 2023

10 Analysis of net assets between funds

	Unrestricted Funds £	Restricted Funds £	Total Funds £
Fund balances at 5 April 2023 are represented by:			
Fixed assets	2,776	-	2,776
Current assets	502,833	39,772	542,605
Creditors: amounts falling due within one year	(3,207)	-	(3,207)
	502,402	39,772	542,174

2023
£

2022
£

11 Commitments

At 5 April 2023 the charity had committed funds

Research	53,000	44,500
	53,000	44,500

2023
£

2022
£

12 Employees

During the year 2022-23 there were 3 employees
(During the year 2021-22 there was 1 employee)

Salary costs including NI	82,564	16,711
Pension	3,777	-
	86,341	16,711