



**Names of the trustees for the charity, if any, (for example, any custodian trustees)**

Name	Dates acted if not for whole year

**Names and addresses of advisers (Optional information)**

Type of adviser	Name	Address
Independent Examiner	Stuart Bates	Wenn Townsend, Chartered Accountants, 10 Broad Street, Abingdon OX14 3LH

**Name of chief executive or names of senior staff members (Optional information)**

**Description of the charity's trusts**

Type of governing document  
(eg. trust deed, constitution)

Constitution

How the charity is constituted  
(eg. trust, association, company)

Charitable Incorporated Organisation

Trustee selection methods  
(eg. appointed by, elected by)

Trustees are appointed by existing Trustees

**Additional governance issues (Optional information)**

You **may choose** to include additional information, where relevant, about:

- policies and procedures adopted for the induction and training of trustees;
- the charity's organisational structure and any wider network with which the charity works;
- relationship with any related parties;
- trustees' consideration of major risks and the system and procedures to manage them.

The Trustees are using the Charity Governance Code as a framework to build and improve on governance standards.

**Summary of the objects of the charity set out in its governing document**

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; and
3. The advancement of both the treatment and prevention of PSC and other liver disease and related disorders.

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

**Summary of the main activities undertaken for the public benefit in relation to these objects (include within this section the statutory declaration that trustees have had regard to the guidance issued by the Charity Commission on public benefit)**

**Additional details of objectives and activities (Optional information)**

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You **may choose** to include further statements, where relevant, about:

- policy on grantmaking;
- policy programme related investment;
- contribution made by volunteers.

A major aspect of PSC Support's work is to fund high-quality PSC research. There is currently no known curative treatment, or treatment that is known to slow the progression of PSC. Our priorities are to support and drive the development of a curative treatment, treatment which slows the progression of PSC and treatment that alleviates the symptoms and psychological effects of PSC and improves PSC patients' quality of life.

PSC Support has published and operates a clear policy on grant-making. Our conflicts of interest policy ensures that for each research funding application, all reviewers are independent and impartial.

### **Our research strategy - what we intend to fund:**

The establishment and development of:

- Biobanking
- Biomarkers

Research into:

- Prevalence/epidemiology
- Aetiology and identification of subpopulations of PSC patients
- Treatment
- Outcomes including liver transplantation
- Clinical trials in PSC

Social research to investigate:

- Quality of life
- Survivorship
- Transition to adult services
- Compliance and adherence

### **How we fund research**

- PSC Support funds high quality research related to PSC.
- We expect investigators to disseminate the results of their research to both the general public and the scientific community.
- PSC Support encourages multi-centre, collaborative research.
- PSC Support will encourage projects that link into other funding streams and national research priorities.
- Applications can include funding for pilot studies, funding equipment (but not IT equipment), and funding social and nursing research.
- Travel and internal audit grants will not normally be awarded except in exceptional circumstances.
- Funds will not be awarded retrospectively.

### **The funding mechanism for PSC Support Research Project Grants**

- The frequency and value of funds available for the Grant(s) will be determined each financial year, and are listed under information for applicants.
- Applicants may apply for grants up to the available amount.
- PSC Support reserves the right to offer funds to more than one applicant per round up to and including the amount of available Grant funds.
- PSC Support is an NIHR Non-Commercial Partner. PSC Support Research Project Grants can be eligible for NIHR Clinical Research Network (CRN) support.

### **Research grant scope**

- Worldwide

### **PSC Support Directed Research**

PSC Support also prioritises research and directs its own, patient-led research.

**Contribution made by volunteers**

Our Trustees and Treasurer are not remunerated aside from any expenses they directly incur on behalf of PSC Support.

The Board of Trustees recognises the significant contribution to the charity made by volunteers, including Martine Walmsley, who undertakes the day-to-day management and operational activities of the charity on a full-time basis, handles the PSC Support Helpline calls and emails and moderates the Facebook group; Keith Anderson, who is the charity Treasurer; and Lorraine Failes, who is a long-standing Facebook moderator for the PSC Support Facebook group. We are also very grateful to the long-term support from Gareth and Vicki Weeks in moderating our Facebook group, to Josie and Malcolm Eddy who send out PSC Support merchandise, to Iain McClenaghan for his support as webmaster, to Noelle Srivastava for graphic design services and to all the patients and families who have provided their perspectives in this year's support, advocacy and research initiatives.

PSC Support works with dedicated medical professionals, who give their time and expertise to PSC Support community at no cost. This year, we are grateful for the support from:

Professor David Adams, Professor Graeme Alexander, Dr Richard Aspinall, Dr Annika Bergquist, Dr Luke Boulter, Teresa Brevini, Dr Roger Chapman, Dr Clare Constantinou, Dr Emma Culver, Dr Jessica Dyson, Dr James Ferguson, Professor Michael Heneghan, Dr Deepak Joshi, Professor Ansgar Lohse, Dr Kate Lynch, Dr Elena Marcus, Dr Neil McDougall, Dr Kathy McKay, Dr Nabil Quraishi, Dr Mussarat Rahim, Dr Simon Rushbrook, Dr Fotis Sampaziotis, Dr Francesca Saffioti, Dr Christoph Schramm, Dr Keith Siau, Amanda Smith, Dr Brijesh Srivastava, Professor Douglas Thorburn, Dr Palak Trivedi, Dr Veronica Ranieri, Dr Mike Williams, and Dr Andrew Yeoman.

## Summary of the main achievements of the charity during the year

### Fundraising

Voluntary fundraising income for the charity for the year ending 5 April 2022 was £184,609, of which £2,063 was restricted for research only. For reference, the total income for the year ending 5 April 2022 was £185,682. Thanks to the remarkable innovation and commitment of patients and family members, we saw a 56% increase in donations compared to 2020/21.

### Expenditure

Total expenditure for the year ending 5 April 2022 was £42,795. Activities were reviewed and funds reallocated as the financial year progressed in order to maximise value for money and use charity resources efficiently.

### COVID-19

During this financial year, the charity's activities continued to be impacted by COVID-19. This meant travel and face-to-face meetings were infrequent, research activity in the UK continued to be affected, particularly academic research.

### Organisational risk, limitations and stability

The Trustees of PSC Support held quarterly virtual meetings and kept in close contact with the charity's volunteers through Martine Walmsley.

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 charity's part-time single member of staff (Programme Development Officer) commenced maternity leave in 2Q2021.

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.

### Research

The pandemic continued to impact the UK healthcare system and some (particularly research staff) were not appointed back to their original positions until towards end of the financial year.

Despite this, PSC research remained a priority for PSC Support. A funding round began in March 2022 and is due to complete in May/June 2022.

The charity also continued to dedicate time to supporting 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. We ended the financial year with clinical trials and research studies at 16 different sites across the UK.

Additional research activities included:

1. Being a co-applicant on national and international PSC research study funding applications;
2. Running focus groups of 8-10 people living with PSC each at regular intervals for academic research studies and steering

groups. We are very grateful to the patients who joined our research panels to provide feedback to researchers;

3. Representing PSC patients in the European Reference Network (ERN RARE-LIVER) as the Co-Lead of the PSC Working Group (MW) and conducting an international patient care survey to use to advocate for higher standards in PSC patient care.

#### Publications:

- Fatourou E, King D, Hyde S, Walmsley M, Alexander G, Trivedi P, Rushbrook S, Thorburn D, PSC IC. PMO-35 **UK national audit on diagnosis and management of colitis in patients with primary sclerosing cholangitis.** [dx.doi.org/10.1136/gutjnl-2021-BSG.174](https://doi.org/10.1136/gutjnl-2021-BSG.174)
- Francque SM, Marchesini G, Kautz A, Walmsley M, Dörner R, Lazarus JV, Zelber-Sagi S, Hallsworth K, Busetto L, Frühbeck G, Dicker D. **Non-alcoholic fatty liver disease: A patient guideline.** JHEP Reports. 2021 Oct 1;3(5):100322. <https://doi.org/10.1016/j.jhepr.2021.100322>
- Zecher B, Buescher G, Willemse J, Walmsley M, Taylor A, Leburgue A, Schramm C, Lohse AW, Sebode M. **Prevalence of COVID-19 in patients with autoimmune liver disease in Europe: A patient-oriented online survey.** United European Gastroenterol J. 2021 [doi.org/10.1002/ueg2.12100](https://doi.org/10.1002/ueg2.12100)

#### Support and information

Because of the challenges presented by COVID-19, people living with PSC needed more support than ever. Although we could not meet face-to-face, PSC Support continued to provide timely information, resources and support through the [www.pscsupport.org.uk](http://www.pscsupport.org.uk) website, news bulletins, social media, and online communities, as well as live, online presentations and Q&As ('Ask the Expert' sessions).

Special thanks to the volunteers who moderate our Facebook group and maintain our Helpline, who continued to provide support to people with PSC over all Bank Holidays, particularly holiday periods when other organisations temporarily halted support.

#### Launch of the PSC Support App

The PSC Support App was launched in June 2021 to empower PSC patients to manage symptoms and hospital appointments, and get the right care at the right time. The app provides the tools to:

- track health and symptoms
- share health reports
- customise questions for use in appointments
- understand the minimum UK care standards
- stay up-to-date with the latest PSC news and research
- access the digital PSC Alert Card
- access support

We are very proud that the PSC Support App was shortlisted as a finalist for the prestigious UK App Awards in October 2021.

#### Advocacy

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

The charity ended the financial year with the following key committed funds:	
Committed Designated Items	Amount
Research Reference: 040519UKPSC "The Primary Sclerosing Cholangitis (PSC) 600: A UK-PSC Initiative" (Final 10% of grant subject to satisfactory final report)	£2,000
Research Reference: 160219EG "The development of a diagnostic blood test for PSC" (Final 10% of grant subject to satisfactory final report)	£1,000
Research Reference: 20220310SREC "Validating a Diagnostic Biomarker in Primary Sclerosing Cholangitis" (subject to peer reviewed application appraisal in current funding round)	£30,000
Research Reference: FARGO "FAecal microbiota transplantation in primary sclerosing cholangitis" (subject to satisfactory milestone reports over four years)	£50,000
Liver Transplant Guidelines	£2,500
	<b>£85,500</b>

## Brief statement of the charity's policy on reserves

Our reserves policy is to maintain twelve months' operating costs (unrestricted funds) in addition to any designated funds, to enable normal operating activities to continue over a period of 12 months should a shortfall in income occur and to take account of potential risks and contingencies that may arise from time to time.

This also supports decision-making when planning additional support activities and making research grants. Operating costs are deemed to include expected on-going support costs (including e-bulletin production, website maintenance and feature enhancement, meeting costs), promotional materials and general administration costs. This allows PSC Support to plan additional projects whilst ensuring that operating costs continue to be met.

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 2021/22, focusing funds on the most important priorities.

The reserves value held by the charity (which equals one year of running costs), stands at £115,613. This includes the increased pay expenditure allocated to new staff.

PSC Support does not commit to expenditure if funding is not available.

## Details of any funds materially in deficit

No funds were materially in deficit.

## Further financial review details (Optional information)



You **may choose** to include additional information, where relevant about:

- the charity's principal sources of funds (including any fundraising);
- how expenditure has supported the key objectives of the charity;
- investment policy and objectives including any ethical investment policy adopted.

#### Financial position at the end of the period

At the end of the period, PSC Support held £401,158. The total unrestricted charity funds as at 5 April 2022 is £394,158, and restricted funds was £7,000.

Designated funds are expenditure that the charity has 'ringfenced' as future spend for specific items. These funds can either be 'committed', where the charity has made either a formal or informal commitment to spend, or 'flexible', where the charity has discretion about whether it would like to proceed with the spend. At the end of 2021/22, the charity has £111,507 of designated funds, with £59,543 of these 'committed' and an additional £143,730 set aside for reserves.

Research expenditure in 2021/22 was held back because of the COVID-19 pandemic. However, PSC Support's own research activities did not slow down and by the year end, £83,000 of the designated funds was committed to specific research projects.

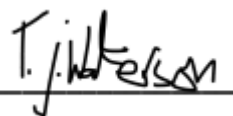
## Section F

## Other optional information

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature(s)



Full name(s)

Rick Dallaway

Tim Waterson

Position (eg Secretary, Chair, etc)

Trustee

Trustee

Date

7 October 2022

**PSC SUPPORT (CIO) - REGISTERED CHARITY NUMBER 1175427****RECEIPTS & PAYMENTS 6th APRIL 2021 to 5th APRIL 2022**

	Unrestricted Funds <u>2021/22</u>	Restricted Funds <u>2021/22</u>	Total Funds <u>2021/22</u>	Total Funds <u>2020/21</u>
<b><u>RECEIPTS</u></b>				
<b><u>Donations &amp; Fund Raising</u></b>				
General Donations & Fund Raising	168,830	-	168,830	98,986
Restricted Donations for PSC Research	-	2,000	2,000	5,550
Gift Aid Reclaimed (Including Via Internet)	13,716	63	13,779	13,422
	182,546	2,063	184,609	117,958
<b><u>Sale of PSC Support Merchandise</u></b>				
Hoodies, Polo & T Shirts	236	-	236	225
Running T Shirts & Vests	260	-	260	16
Mugs	44	-	44	38
Pin Badges	-	-	-	-
Wristbands	183	-	183	53
	723	-	723	332
<b><u>Other Receipts</u></b>				
Acute Cholangitis Alert Cards - Foreign Shipping	3	-	3	15
Refund of DBS Checks Fee	23	-	23	-
Refund of EASL & ILC Conference Fees	87	-	87	176
Refund of Outward Airfares to ECRD Stockholm Conference by Ryanair	-	-	-	86
Interest Credited to Deposit Accounts	237	-	237	494
Reimbursement for Personal Purchase Charged to Charity's Credit Card in Error	-	-	-	7
	350	-	350	778
<b>TOTAL RECEIPTS</b>	<b>183,619</b>	<b>2,063</b>	<b>185,682</b>	<b>119,068</b>

**PAYMENTS****General Administration**

Combined Charity Insurance	552	-	552	590
Credit Card Fee	30	-	30	30
Current Account Bank Charges	12	-	12	-
Data Protection Fee (Information Commissioner's Office)	35	-	35	40
DBS Checks on Volunteers	-	-	-	94
Microsoft Office 365 Annual Subscription	33	-	33	33
Postage	36	-	36	30
Printer Usage	29	-	29	42
Service User Surveys (Survey Monkey)	306	-	306	306
Soho66 Phone Services (Admin)	109	-	109	162

Stationery	2	-	2	-
UK Postbox	80	-	80	60
	1,224	-	1,224	1,387

#### **Staff Employment**

Gross Salary & SMP	16,711	-	16,711	22,890
Home Working Broadband Allowance	336	-	336	392
Home Working Heating & Lighting Allowance	200	-	200	200
Salary Deductions for Tax, NI, Pension & Student				
Loan Repayment	(2,709)	-	(2,709)	(5,066)
HMRC Payments (Employee & Employer)	1,374	-	1,374	4,151
Pension Contributions (Employee & Employer)	1,621	-	1,621	2,054
Payroll Charges - Wenn Townsend	462	-	462	546
Credit Card Fee	30	-	30	30
Employee Training	25	-	25	-
Mobile Phone Usage	24	-	24	96
Office Equipment, Furniture, Software & Sundries	57	-	57	446
Recruitment of CEO - Charisma Recruitment Ltd	5,000	-	5,000	-
Legal Costs re CEO's Contract of Employment	1,890	-	1,890	-
	25,021	-	25,021	25,739

#### **Advocacy**

Benefits & Work Publishing Subscription	77	-	77	97
Disability Rights UK Membership	-	-	-	102
EASL Annual Membership	88	-	88	188
Eurordis Annual Membership	175	-	175	91
Registration for Online EASL International Liver Congress	91	-	91	-
Registration for Online EURORDIS European Conference	-	-	-	72
Genetic Alliance UK Membership	50	-	50	-
	481	-	481	550

#### **Awareness & Support (Including Education)**

A6 Flyers	-	-	-	19
Acute Cholangitis Alert Cards	234	-	234	122
BASL Conference - Charge for PSC Support Stand	60	-	60	-
MailChimp Subscription for Newsletters	528	-	528	43
Mobile Phone Usage for Helpline (Giff Gaff)	56	-	56	-
Legal Fees re Privacy Policy & T&Cs (Patient Support App)	-	-	-	1,894
Legal Fees re Privacy Policy & T&Cs (Website)	-	-	-	3,788
Online Helpline Booking System	56	-	56	-
Patient Support App Development (APPOLY)	2,940	-	2,940	14,156
Patient Support App Hosting (APPOLY)	1,440	-	1,440	-
Legal Fees re Staffing Helpline	1,379	-	1,379	-
Soho66 Phone Services (Support)	77	-	77	162
Website Domain Registration Renewal (Fasthosts)	89	-	89	101
Website Hosting (Fasthosts)	162	-	162	126
Website Hosting (UpdraftPlus)	54	-	54	-
Zoom Pro Subscription	144	-	144	201
	7,219	-	7,219	20,612

**Fundraising**

A6 Flyers	-	-	-	19
Challenge Event Places (Nova)	670	-	670	-
Collection Boxes	24	-	24	-
Facebook Advertising	-	-	-	55
Fundraising Banner	-	-	-	47
Fundraising Training	6	-	6	225
Just Giving	561	-	561	562
London Marathons 2021 Entries (Virtual & In Person)	-	-	-	584
Virtual London Marathon 2021 Competition Prize	75	-	75	-
PayPal Fees Deducted from Donations Received	44	-	44	55
Postage & Packaging	196	-	196	17
	1,576	-	1,576	1,564

**Governance**

Independent Examination of 2020/21 Accounts	600	-	600	600
	600	-	600	600

**Purchase & Distribution of PSC Support Merchandise**

T Shirts	610	-	610	-
Running T Shirts	596	-	596	-
Wristbands	264	-	264	-
Merchandise Flyers	20	-	20	-
PayPal & eBay Fees	68	-	68	92
Postage & Packaging	98	-	98	36
	1,656	-	1,656	128

**Research**

Education / Research re Clinical Trials	496	-	496	-
Clinical Trials Packs - PayPal Fees Deducted from Donations	7	-	7	-
Dr Jesus Banales (Spain)	902	3,613	4,515	-
	1,405	3,613	5,018	-

**Other Expenditure**

Personal Purchase Charged to Charity's Credit Card in Error				
(Fully Reimbursed)	-	-	-	7
	-	-	-	7

**TOTAL PAYMENTS**

39,182	3,613	42,795	50,587
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**SURPLUS / DEFICIT**

144,437	(1,550)	142,887	68,481
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Transfers Between Restricted &amp; Unrestricted Funds

-	-	-	-
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**OPENING BANK BALANCES AT 6/4/2021**

249,721	8,550	258,271	189,790
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**CLOSING BANK BALANCES AT 5/4/2022**

Current Account	61,030	-	61,030	3,228
PayPal Account	128	-	128	43

Deposit Accounts	333,000	7,000	340,000	255,000
	<b>394,158</b>	<b>7,000</b>	<b>401,158</b>	<b>258,271</b>

### **MERCHANDISE & OTHER ASSETS HELD AT 5/4/2022**

Various Office Equipment & Furniture, Mobile Phone, Various Fund Raising & Informational Resources, 69 T Shirts, 20 Running T Shirts, 20 Running Vests, 55 Mugs, 725 Wristbands & Other Minor Items.

### **DEBTS / LIABILITIES / GUARANTEES**

The charity has no outstanding debts. It has made the following commitments:

- 1) It has guaranteed to pay a retained total of £3,000 to two researchers when their projects have been completed to the charity's satisfaction.
- 2) The charity has undertaken to contribute £2,500 towards the cost of producing new UK Liver Transplant Guidelines.
- 3) The charity has conditionally undertaken to contribute £30,000 to a Diagnostic Blood Test Research Project and £50,000 to the FARGO PSC Research Trial.

Keith V Anderson (PSC Support Treasurer) K V Anderson

Timothy Waterson (PSC Support Chair of Trustees) Tj Waterson

Date 30 / 12 / 2022





Section A

Independent Examiner's Report

Report to the trustees/  
members of

Charity Name  
PSC Support

On accounts for the year  
ended

5<sup>th</sup> April 2022

Charity no  
(if any)

1175427

Set out on pages

1 to 4

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 5<sup>th</sup> April 2022.

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 Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed 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 which gives me cause to believe that in, any material respect:

- accounting records were not kept in accordance with section 130 of the Act or
- the accounts do not accord with the accounting records

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

Signed:

Date:

22nd November 2022

Name:

Stuart Bates

Relevant professional  
qualification(s) or body  
(if any):

BA FCA CTA

Address:

Victoria House, 10 Broad Street

Abingdon

OX14 3LH

Section B

Disclosure

Only complete if the examiner needs to highlight matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

**Give here brief details of any items that the examiner wishes to disclose.**