

PSC SUPPORT

England & Wales · Charity number 1175427

Details

Status Registered

Legal form CIO

Registered 2017-10-27

Register [View on the Charity Commission register](#)

Contact

Address Unit 23056
Uk Postbox
PO Box 4336
Manchester

Phone 01235 253545

Email hello@pscsupport.org.uk

Website www.pscsupport.org.uk

Activities

Objects: (1) THE OBJECTS OF THE CIO ARE:(A) THE RELIEF OF THOSE SUFFERING FROM LIVER DISEASES OR DISORDERS (IN PARTICULAR BUT WITHOUT LIMITATION PSC) AND RELATED DISORDERS;(B) THE ADVANCEMENT OF PUBLIC AWARENESS OF PSC, OTHER LIVER DISEASE AND RELATED DISORDERS; AND(C) THE ADVANCEMENT OF BOTH THE TREATMENT AND PREVENTION OF PSC AND OTHER LIVER DISEASE AND RELATED DISORDERS.

Activities: Our activities are to improve the lives of people affected by primary sclerosing cholangitis through support, education, research and advocacy.

Classification

- **How:** Makes Grants To Organisations, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, Elderly/old People, People With Disabilities

Geography

- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-04-05	£557,632	£528,679	£668,140	4
2024-04-05	£405,606	£308,593	-	-
2023-04-05	£263,687	£127,077	-	-
2022-04-05	£185,682	£42,795	-	-
2021-04-05	£119,068	£50,587	-	-

Trustees

Name	Role	Appointed
TIM WATERSON	Chair	2020-03-08
Charlene Lynnette Oke		2023-06-26
Helen Elder		2023-01-10
JAMES BROWN		2020-06-07
Mark William Dean		2023-02-08
NICHOLAS KANE		2020-06-08
PROFESSOR DAVID HARVEY ADAMS		2017-10-27
RICK DALLAWAY		2020-06-13

PSC SUPPORT

England & Wales - Charity number 1175427

Accounts

Charity Registration No. 1175427

PSC SUPPORT
TRUSTEES' REPORT AND ACCOUNTS
FOR THE YEAR ENDED 5 APRIL 2025



PSC SUPPORT

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FOR THE YEAR ENDED 5 APRIL 2025

REFERENCE AND ADMINISTRATIVE DETAILS

Name	PSC SUPPORT
Charity registration no.	1175427
Address	Unit 23056, UK Postbox PO Box 4336 MANCHESTER M61 0BW
Bankers	NatWest 250 Bishopsgate London EC2N 4AA
Independent Examiner	Wenn Townsend Chartered Accountants Victoria House 10 Broad Street Abingdon Oxon OX14 3LH
Solicitors	Stone King Boundary House 91 Charterhouse Street London EC1M 6HR

Trustees serving on the date the report was approved

Tim Waterson (Chair)
Harrison Moller – resigned 17/09/2025
Mark Dean
Helen Elder
Rick Dallaway
Nicholas Kane
James Brown
David Adams
Charlene Oke

Senior Staff Members

Paula Hanford (CEO) – resigned 31/12/2025
Martine Walmsley (Head of Research Strategy)
Mark Chatterley (Operations Manager)

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PSC SUPPORT

TRUSTEES' REPORT

FOR THE YEAR ENDED 5 APRIL 2025

The Trustees present their report and financial statements for the year ended 5 April 2025.

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

PSC Support is a Charitable Incorporated Organisation (CIO) registered with the Charity Commission. The charity uses a constitution as its governing document. 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. As set out in the CIO Constitution, new trustees must be appointed for a term of three years by a resolution passed at a properly convened meeting of the charity trustees. Potential and new trustees are given a copy of the current version of the Constitution and a copy of the CIO's latest Trustees' Annual Report and statement of accounts. A charity induction and ongoing training is provided.

Organisation and Decision Making

The Board of Trustees has ultimate responsibility for the governance, strategy and finances of the Charity. Day-to-day management is delegated to the CEO. The trustees meet quarterly to review performance, risks, research commitments and financial management.

Operational decisions are delegated appropriately to the CEO against strategy, financial performance and risks.

Pay Setting

The Remuneration Committee meets annually to discuss and recommend pay increases to the full board. The Committee uses sector benchmarks and affordability criteria to determine salary increases ensuring salaries are appropriate and proportionate to the charity in scale and resources.

Finance Committee

As well as the Remuneration Committee, the board has a Finance Sub Committee, made up of three board members, Operations Manager and CEO. The finance committee meets quarterly prior to the full board meeting to monitor the charity's financial position and recommend the finance report to the full board.

Partnerships and Networks

PSC Support works closely with patients, clinicians, researchers, regulators and partner organisations. These relationships enable the charity to influence care, research and policy at national and international levels.

Related Parties

Trustees and advisors may serve on external panels, research committees or clinical initiatives. Any potential conflict of interest are declared, documented and managed according to the charity's policy.

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TRUSTEES' REPORT

FOR THE YEAR ENDED 5 APRIL 2025

OBJECTIVES, AIMS, STRATEGIES AND ACTIVITIES

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.

Objectives

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.

Aims and Strategic Priorities

Primary Sclerosing Cholangitis is a rare, chronic and progressive liver disease with no licensed medical treatment and an unpredictable course. People living with PSC face significant physical and emotional burdens, including the risk of liver failure, cancer, the need for transplantation, and the impact of associated conditions such as inflammatory bowel disease. Due to its rarity, PSC is often poorly understood, leading to delayed diagnosis, inconsistent standards of care, limited access to specialist expertise and a lack of coordinated support.

In addition, despite significant progress in research in the last two decades, PSC remains a complex, poorly understood disease that lacks effective treatments. People affected by PSC frequently experience isolation, uncertainty and a lack of reliable, evidence-based information. PSC Support seeks to address these challenges by improving awareness and understanding of PSC, advocating for better and more equitable care, accelerating research, and ensuring that the voices and lived experiences of people with PSC are central to research, clinical practice and policy decisions.

The trustees' strategic priorities are:

1. Research

Improve understanding of the biology behind PSC and turn new discoveries into tools and treatments that can quickly diagnose PSC, identify those most at risk, and manage symptoms and complications.

We aim to accelerate PSC research through powerful partnerships by:

- Investing in the highest quality research from the best teams.
- Building strong partnerships with industry, universities, other funders, regulators, and other patient organisations, while encouraging new ideas.
- Elevating the voices of people with PSC to guide and shape research
- Supporting participation in clinical trials and studies

2. Information and Support

Knowledge is power for people living with PSC which is why providing information and support is central to what we do.

We aim to engage and inform a wider PSC community with quality information by:

- Continuing to be a trusted source of clear, up-to-date PSC education and trial information for doctors and patients
- Making information easier for patients to access
- Increasing PSC knowledge among healthcare providers, especially those working with related conditions.

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TRUSTEES' REPORT

FOR THE YEAR ENDED 5 APRIL 2025

- Using new technology early to connect better with new and existing audiences

3. Improving Patient Care

People with PSC need to feel confident in their care no matter where they live.

We aim to improve outcomes for people living with PSC by:

- Expanding our reach and engagement of the PSC patient community.
- Advocating for the needs and priorities of PSC patients in clinical guidelines.
- Building stronger partnerships with regulators and policymakers to speed up approval, access, and coverage for new tests and treatments.
- Working with our partners to influence government and medical bodies to raise awareness of PSC and address the unmet need.

HOW WE MEASURE SUCCESS

We use a combination of quantitative data and qualitative feedback to understand our impact, guide improvement and demonstrate accountability to our community and stakeholders.

Community Reported Outcomes

We listen carefully to feedback from people affected by PSC to understand how our services make a difference.

We monitor:

- Feelings of connection with others
- Emotional and practical support received
- Confidence in managing PSC
- Satisfaction with services including webinars, helpline support and in-person events

We measure this through surveys, event evaluations and testimonials

Reach and Engagement

We track how widely our information and support are accessed, and how people engage with us.

We monitor:

- Website usage
- Attendance at webinars and events
- Growth in newsletter subscribers and click/ open rates
- Engagement across social media platforms

Contribution to National and International Guidelines

We assess our influence on clinical standards and best practice.

We monitor:

- Involvement in advisory groups, committees and working groups
- Number of publications co-authored by PSC Support

Accelerating Research

We measure how effectively we stimulate and support PSC research.

We monitor:

- Total research funding awarded
- Number of research projects funded

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FOR THE YEAR ENDED 5 APRIL 2025

- Outcomes from funded projects
- New projects triggered by PSC funded research
- Number of funding applications supported
- Number of clinical trials supported

Patient and Public Involvement (PPIE)

We ensure that the PSC community is meaningfully involved in shaping research.

We monitor:

- Number of research projects supported through PPIE
- Total PPIE hours contributed by people affected by PSC

Advocacy and Policy Influence

We track our role in shaping policy and improving access to care.

We monitor:

- Contributions to NICE, MHRA, NHS and rare disease policy discussions
- Progress towards equitable access to treatments, including outcomes of processes such as the National Liver Offering Scheme review

Representation and Voice

We assess whether the PSC community is represented where decisions are made.

We monitor:

- Invitations to key advisory, strategic and decision-making bodies
- Evidence that the PSC patient voice is included in policy, clinical and research decisions

Community Strength

We look at indicators of a growing and engaged community.

We monitor:

- Growth in social media audiences
- Attendance at events
- Qualitative feedback from the community

Fundraising Performance

We review the sustainability of our income.

We monitor

- Growth
- Diversification of income streams

Operational Effectiveness

We assess how well the organisation is run.

We monitor:

- Delivery against strategic objectives
- Strong financial management and governance

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TRUSTEES' REPORT

FOR THE YEAR ENDED 5 APRIL 2025

ACTIVITIES AND ACHIEVEMENTS

Fundraising/ Income

The charity received a total income of £557,632 including £541,352 from fundraising, donations and merchandise sales for the year ending 5th April 2025. Fundraising income was again dramatically up on the previous year with a 48% increase. While the general economy remains difficult this increase is a testament to our work and our supporters who are motivated by our charity's aims and objectives, particularly in relation to funding high quality research. £220,300 of the total was in restricted income.

Expenditure

PSC Support trustees place the utmost importance on spending the charity's money in the best possible way for our beneficiaries. Our expenditure in this financial year was £528,679 up from £308,593 the previous year. In the main this was accounted for by our research funding which was £248,468 in 2024-5.

Staff

No new staff were recruited during this period. Our Fundraising and Events Officer was on maternity leave this year, which meant our staff base was reduced to 3.

Volunteers

Our volunteers continue to make an immense contribution to the charity, and the trustees recognise their pivotal role in our success.

In particular, trustees would like to recognise the long-standing contribution of Facebook moderators Lorraine Failes, Gareth Weeks and Vicki Weeks, who have worked tirelessly over a number of years to ensure the Facebook group is well moderated and remains a safe and supportive space. Gareth Weeks stepped down from his volunteer roles in January 2025, and trustees wish to place on record their thanks for his many years of dedicated service. Trustees are also very grateful to Josie and Malcolm Eddy, who manage merchandise and support fundraising activities, as well as to research volunteer Maria Richardson who joined the charity this year.

The trustees would additionally like to recognise all those affected by PSC who have contributed their lived experience and perspectives across this year's support, advocacy and research initiatives. Gareth Weeks served alongside Christopher Forde, Jenny Nelson and Gary Taylor as patient representatives on our Expert Panel, where they each play a crucial role. Christopher Forde also serves as a lay member of the Scientific Review Committee, alongside Edward Sims and Iain M.

Finally, trustees extend their thanks to all members of Patient Panels and to all volunteers who supported our Information Days, for generously sharing their time, experience and insights

Partners

PSC Support recognises that meaningful progress in PSC research and advocacy can only be achieved by working together. Throughout the year, we collaborated with many individuals and organisations to drive forward research and influence policy. These partnerships remain central to our mission, and we thank all those who have worked alongside us to improve outcomes for the PSC community including:

- Angela Leburgue
- Dr Brian Thorsen
- Dr Steve Rossi
- Mary Vyas
- Joan Beddington
- Shivani Sharma
- Ryan James
- UK-PSC
- European Liver Patients Association
- PSC Partners Seeking A Cure
- European Reference Network
- UK-PSC
- National Liver Alliance

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TRUSTEES' REPORT

FOR THE YEAR ENDED 5 APRIL 2025

During this year, our CEO, became the Chair of the National Liver Patients Alliance.

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

- Professor David Adams
- Professor Doug Thorburn
- Professor Annika Bergquist
- Professor Angsar Lohse
- Professor Catherine Williamson
- Professor Shaid Khan
- Professor Alaistair O'Brien
- Professor Palak Trivedi
- Professor Bettina Hansen
- Professor Chris Bowlus
- Professor Dave Jones
- Professor David Assis
- Professor Ian Rowe
- Professor Luke Boulter
- Professor James Ferguson
- Professor Jesús Bañales
- Professor Johannes Hov
- Professor Marco Carbone
- Professor Matthew Armstrong
- Professor Rory Smoot
- Alice Freer
- Dr Roger Chapman
- Dr Deepak Joshi
- Dr Simon Rushbrook
- Dr Emma Culver
- Dr Richard Aspinall
- Dr Jessica Dyson
- Dr Andrew Yeoman
- Dr Kate Lynch
- Dr Francesca Saffioti
- Dr Christoph Schramm
- Dr Brijesh Srivastava
- Dr Nora Cazzagon
- Dr Amera Elzubeir
- Dr Cyriel Ponsioen
- Dr Dorothee Schwinge
- Dr Franziska Stallbaum
- Dr Leona Dold
- Dr Ludwig Horst
- Dr Marianne Samyn
- Dr Nabil Quraishi
- Dr Nasir Hussain
- Dr Pedro Rodrigues
- Dr Pierre-Antoine Soret
- Dr Sarah Al-Shakhshir
- Dr Thomas Drake

Support from the Pharmaceutical Industry

The following companies sponsored Information Days and Projects during the financial year:

- Dr Falk Pharma
- Pliant Therapeutics
- Chemomab Therapeutics
- Mirum Pharmaceutical

While we are incredibly grateful for their financial support, these companies have had no influence over content or event agendas.

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Other Corporates and Trusts

We are delighted to have received donations from the following:

- Generation Investment Management
- The Britford Bridge Trust
- Habadashers Trust
- The Fordham Family Fund
- Fusion 21 Foundation
- Foundation Scotland
- Old Verulamians Masonic Lodge
- The Cheesy Toast Shack
- Ecclesiastical
- ICON
- Bank of Scotland
- Whitby SeaFoods
- Arrow Electronics
- Movement for Good

Donors and Fundraisers

The trustees extend their sincere thanks to everyone who supported the charity through donations or fundraising during the year, including those who chose to give regularly. Every contribution, regardless of size, has played an important role in enabling us to continue and develop our work in support of those affected by PSC.

Legacy Giving

During the year, the charity developed a new legacy income stream through a partnership with Free Gifts in Wills. This is a longer-term initiative and, while still in its early stages, several legacy gifts have already been pledged and there has been encouraging uptake of will packs, indicating positive early engagement.

Trusts and Foundations

During the year, the charity began developing a new trusts and foundations income stream, with early success in securing funding. This work is being undertaken as a strategic priority, with plans to build capacity and scale activity in the following year to support longer-term sustainability and growth.

Information and Support

Digital Engagement

2024 was a year of significant growth in our digital engagement, reflecting the vital role social media and online events play for people affected by PSC. Across all social media platforms, our audience grew by 2,000 people, finishing the year with just over 12,000 followers. Our well-moderated private Facebook group grew by 10% during the year and now has nearly 4450 members. This group provides essential peer support, helping to reduce isolation and create a safe, supportive space where people can share experiences, advice, and encouragement. Social media is particularly important for our audience, as many live with a rare and often isolating condition; it allows them to connect with others, access timely information, and engage with experts, no matter where they are. Huge thanks go to our volunteer moderators, who maintain the group to a very high standard, even during holiday periods.

“When Rhys was diagnosed with PSC and ulcerative colitis, the news shattered our lives. I had never heard of PSC and didn't know where to turn for advice. I Googled PSC — a big mistake! That absolutely terrified us. Thankfully, I found PSC Support and joined their Facebook group. I put up a post asking for advice and was immediately met with replies from people going through the same experiences — patients, parents, and relatives — all offering amazing support and guidance.”

Our Ask the Experts webinars also experienced strong growth, with over 663 attendees in 2024-25, a 37% increase on the previous year's 485. These webinars provide crucial access to expert clinicians, the latest research and treatment updates, and the opportunity to ask questions about PSC and related conditions. They empower our community with knowledge, practical guidance, and confidence in managing the condition.

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FOR THE YEAR ENDED 5 APRIL 2025

Direct Support

In 2024-25, PSC Support continued to provide vital direct support to people affected by PSC through our in-person events and Helpline.

We delivered two Information Days in Glasgow and Birmingham, reflecting our commitment to accessible support. These events attracted a total of 162 attendees, a more than 50% increase compared with the previous year, when a single face-to-face event was held in Oxford. The Information Days help reduce isolation by connecting people affected by PSC, updating them on the latest research developments, and providing direct access to PSC experts. Attendees also gain practical guidance on managing their condition. Feedback was overwhelmingly positive, with 100% of participants indicating they would recommend the events to others.

Our Helpline also saw increased use, receiving over 120 emails and calls during the year. The transition to a nurse-led Helpline has been a great success, offering expert guidance, reassurance, and practical support to people affected by PSC.

"I remember phoning up ages ago in a total mess, looking for help and understanding about what I was going through both physically and mentally. The person I spoke to really helped me feel less alone and gave me some hope about the future. Thank you!"

Together, these services ensure that people affected by PSC have access to both expert information and peer support, helping them feel connected, informed, and supported in managing their condition.

Research

PSC Support, in particular Martine Walmsley our Head of Research Strategy, continued to play a pivotal role in advancing PSC research in 2024/25. The charity agreed to fund £565,160 of new projects addressing key unmet needs, including:

- Screening for or preventing colorectal cancer and bile duct cancer
- Improving care for patients with PSC during pregnancy
- Understanding the biological mechanisms of fatigue in PSC
- Investigating the biological processes involved in PSC progression and cancer development

We supported 11 research funding applications and 3 studies, helping to secure £14 million in funding for these projects.

The charity also continued to support clinical trial development by working with pharmaceutical companies to ensure trial protocols and patient information were appropriate and fit for purpose for the UK PSC community. In total, we supported 7 clinical trials during the year.

Members of our patient panels contributed 92 hours of their time to ensure the research we fund reflects the needs and priorities of people living with PSC.

Our Head of Research Strategy also represented PSC patients in the European Reference Network (ERN RARE-LIVER) as a member of the Management Board and as Co-Lead of the PSC Working Group, ensuring the patient perspective remains central to research at a European level.

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FOR THE YEAR ENDED 5 APRIL 2025

PSC Support has contributed to the following publications this year:

Elzubeir A, High J, Hammond M, Shepstone L, Pond M, Walmsley M, Trivedi P, Culver E, Aithal G, Dyson J, Thorburn D. **Assessing brodalumab in the treatment of primary sclerosing cholangitis (SABR-PSC pilot study): protocol for a single-arm, multicentre, pilot study.** *BMJ Open Gastroenterology.* 2025 Mar 1;12(1):e001596.

Quraishi MN, Cheesbrough J, Rimmer P, Mullish BH, Sharma N, Efstathiou E, Acharjee A, Gkoutus G, Patel A, Marchesi JR, Camuzeaux S. **Open Label Vancomycin in Primary Sclerosing Cholangitis-Inflammatory Bowel Disease: Improved Colonic Disease Activity and Associations With Changes in Host-Microbiome-Metabolomic Signatures.** *Journal of Crohn's and Colitis.* 2025 Feb;19(2):jjae189.

Stallbaum F, Adao I, Auhuber C, Cazzagon N, Dalekos G, Drenth JP, Gerussi A, Gevers TJ, Janik MK, Kuiper M, Lambert H. **Exploring the Role of Social Determinants of Health in autoimmune liver disease—a pilot study within the European Reference Network on hepatological diseases.** *Zeitschrift für Gastroenterologie.* 2025 Jan;63(01):P2-30.

Horst LJ, Kempster J, Walmsley M, Huber S, Schramm C. **PSC and colitis: A complex relationship.** *Hepatology.*:10-97. (Jan 2025)

Quraishi MN, Cheesbrough J, Rimmer P, Mullish BH, Sharma N, Efstathiou E, Acharjee A, Gkoutus G, Patel A, Marchesi JR, Camuzeaux S. **Open label vancomycin in primary sclerosing cholangitis-inflammatory bowel disease: improved colonic disease activity and associations with changes in host-microbiome-metabolomic signatures.** *Journal of Crohn's and Colitis.* 2024 Dec 14:jjae189.

Hussain N, Ferguson J, Gungabissoon U, Casillas L, Mukherjee S, Ribeiro A, McLaughlin M, Walmsley M, Hanford P, Trivedi P. **P342 Pruritus in primary sclerosing cholangitis and implications for clinical trial design.**

Rossi S, Walmsley M, Thorsen B, Hatchett J, Evon D, Reeve B, Gomel R, Vyas M, Safer R, Goldsmith K, Garfield A. **Defining Acute Cholangitis As A Clinical Outcomes Endpoint In Adults With Primary Sclerosing Cholangitis (Psc): Results Of A Multinational Patient Survey To Develop A Patient-Reported Outcomes Measure (PROM).** *HEPATOLOGY* 2024 Oct 1 (Vol. 80, pp. S1828-S1829).

Hussain N, Ma C, Hirschfield G, Walmsley M, Hanford P, Vesterhus M, Kowdley K, Bergquist A, Ponsioen C, Levy C, Assis D. **Protocol for the development of a core outcome set for clinical trials in primary sclerosing cholangitis.** *BMJ open.* 2024 Jun 1;14(6):e080143.

Hussain N, Ferguson J, Abbas N, Gungabissoon U, Bhandal K, Burke E, Hull D, Rogers P, Casillas L, Mukherjee S, Ribeiro A. **THU-160 Long-term variability of pruritus in primary sclerosing cholangitis and implications for future clinical trial design.** *Journal of Hepatology.* 2024 Jun 1;80:S332.

Soret PA, Tomsin B, Willemse JA, Walmsley M, Gnutti V, Papenthin W, Uhlenbusch N, Gevers TJ, Cazzagon N, Schramm C, Corret P. **WED-158-YI Disease experience and care expectations in european patients with immune-mediated liver disease.** *Journal of Hepatology.* 2024 Jun 1;80:S712.

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FOR THE YEAR ENDED 5 APRIL 2025

Advocacy

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

This included:

- Participation in PSC Partners Seeking A Cure International Collaborative Network
- Cholangiocarcinoma clinical practice guideline updates
- Liver transplant for bile duct cancer service development
- European Reference Network for Rare Liver Disease
- Rare Disease Research (UK) Platform Advisory Group and Regulatory Pathways and Registries and Data Working Groups
- New PSC Guidelines working group
- UK Liver Alliance

Events Attended

During the year, the charity attended a range of events to stay up to date with developments in PSC research, to connect with and influence regulators and healthcare professionals, and to strengthen relationships with other PSC organisations and pharmaceutical partners.

These included the following:

- European Association for the Study of the Liver annual congress
- British Association for the Study of the Liver annual meeting
- British Society of Gastroenterologists annual conference
- American Association for Liver Diseases annual meeting
- AMMF annual conference

WHAT WENT WELL AND CHALLENGES FACED

What went well

Strong income growth

The charity experienced a very strong financial year, with income increasing by 40% compared to the previous year. This growth was driven by a combination of excellent community fundraising, generous individual donations and increased corporate support.

Progress in research funding

Our commitment to research continued to grow with the charity agreeing to fund £565,460 of innovative research projects as part of our Mission 2030 campaign. These investments reflect ongoing determination to support work that has the potential to lead to breakthroughs in the diagnosis and treatment of PSC.

Increase in engagement and reach

Engagement across our platforms increased significantly. We saw dramatic growth across our social media channels, including our private Facebook group, alongside a record number of attendees at our webinars. This reflects both growing awareness of PSC Support and the value of the information and support we provide.

Successful transition to a nurse-led helpline

The move to a nurse-led helpline has been a significant success. More people accessed the service than in the previous year and feedback from service users has remained consistently excellent, demonstrating the impact and quality of this service.

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FOR THE YEAR ENDED 5 APRIL 2025

Challenges

Capacity Constraints

As a small team, we experienced capacity challenges across 3 staff roles during the year. While demand for our work continues to grow, limited staff capacity meant we were not always able to progress initiatives as quickly as we would have liked.

Timing of project delivery

Some projects progressed more slowly than anticipated and moved into the following financial year. For example, while work on the e-learning platform guidelines began during this year, completion has shifted into the next financial year.

FUTURE PLANS

PSC Support has ambitious plans for the future to further support those with PSC and fund research. We plan to:

- Continue investing in relevant, high-quality research projects as part of the Mission 2030 campaign. The increase in our research funding commitments has resulted in a corresponding increase in administrative burden. The investment in and implementation of a grant management system in future years will allow PSC Support to better focus its efforts on supporting the research applications while having the administration handled by the system.
- Continue our programme of in-person Information Days to facilitate information sharing from experts to patients and their support networks while also providing a networking opportunity for patients with a rare disease. Feedback from previous Information Days will be used to generate the programme for the events as well as inform the locations chosen.
- Invest in and develop an e-learning platform aimed at doctors and other allied healthcare professionals to ensure that the PSC Clinical Practice Guidelines are embedded into the healthcare system. PSC Support's experience at events has highlighted a gap in some healthcare professionals' knowledge when it comes to PSC and the e-learning platform will directly address this.
- Develop and create a PSC-focused podcast drawing on patient experiences. PSC Support's experience of speaking to patients through our activities confirms the heterogeneity of PSC (different PSC patients experience different symptoms at different intensities). The creation of a patient-experience focused podcast will directly address this by exploring multiple patient experiences of the disease.

Organisational Risk, Limitations and Stability

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

PSC SUPPORT

TRUSTEES' REPORT FOR THE YEAR ENDED 5 APRIL 2025

FINANCIAL REVIEW

The detailed accounts for the year ended 5 April 2025 are shown on pages 15-25. The accounts show that at the end of the financial year PSC Support held £668,140 in funds. This was broken down as total unrestricted £648,380 and total restricted £19,760

At the year ended 5 April 2025 the charity had conditionally undertaken to contribute £482,692 to the projects listed in note 11. These commitments are reliant on milestones being reached and spread over years up to and including 2031

No funds were materially in deficit.

Policy on reserves

In 2024-5 reserves contingency was nine months operating costs. These reserves would enable normal operating activities to continue over a period of 9 months should a shortfall in income occur. It also takes into account any potential risks and contingencies that may arise from time to time.

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 on a quarterly basis.

The Trustees regularly reviewed funds/reserves levels throughout 2024/25, focusing funds on the most important priorities.

The reserves value held by the charity (which equals to roughly 9 months of running costs), stands at £147k

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.

Approved by the Trustees and signed on their behalf on 2 February 2026 by:

.....

Tim Waterson
(Trustee)

PSC SUPPORT

STATEMENT OF TRUSTEES' RESPONSIBILITIES FOR THE YEAR ENDED 5 APRIL 2025

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

STATEMENT OF TRUSTEES' RESPONSIBILITIES FOR THE YEAR ENDED 5 APRIL 2025

I report to the charity trustees on my examination of the accounts of the charity for the year ended 5 April 2025 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

Since the charity's gross income exceeded £250,000 your examiner must be a member of a body listed in section 145 of the Act. I confirm that I am qualified to undertake the examination because I am a member of the Institute of Chartered Accountants of England and Wales, which is one of the listed bodies.

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

2 February 2026

PSC SUPPORT

STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 5 APRIL 2025

		Unrestricted funds	Restricted funds	Total 2025	Total 2024
	Notes	£	£	£	£
Income					
Donations and legacies		269,798	152,800	422,598	298,102
Grants	2	12,000	30,000	42,000	31,651
Investment income	3	14,798	-	14,798	15,410
Gift aid		39,254	37,500	76,754	36,438
Other charitable activities		1,482	-	1,482	24,005
Total		337,332	220,300	557,632	405,606
Expenditure					
Research payable		-	248,468	248,468	86,000
Fundraising		17,055	-	17,055	22,286
Direct charitable expenditure		225,136	33,240	258,376	186,364
Governance costs		4,780	-	4,780	13,943
Total	4	246,971	281,708	528,679	308,593
Net Income (Expenditure)		90,361	(61,408)	28,953	97,013
Transfers between funds		(59,393)	59,393	-	-
Net movement in funds		30,968	(2,015)	28,953	97,013
Fund balances at 5 April 2024		617,412	21,775	639,187	542,174
Fund balances at 6 April 2025		648,380	19,760	668,140	639,187

PSC SUPPORT

STATEMENT OF FINANCIAL ACTIVITIES

FOR THE YEAR ENDED 5 APRIL 2024 (COMPARATIVE FIGURES)

		Unrestricted funds	Restricted funds	Total 2024
	Notes	£	£	£
Income				
Donations and legacies		263,648	34,454	298,102
Grants	2	-	31,651	31,651
Investment income	3	15,410	-	15,410
Gift aid		29,967	6,471	36,438
Other charitable activities		6,005	18,000	24,005
		<hr/>	<hr/>	<hr/>
Total		315,030	90,576	405,606
Expenditure				
Research payable		-	86,000	86,000
Fundraising		22,286	-	22,286
Direct charitable expenditure		142,654	43,710	186,364
Governance costs		13,943	-	13,943
		<hr/>	<hr/>	<hr/>
Total	4	178,883	129,710	308,593
Net Income (Expenditure)		136,147	(39,134)	97,013
Transfers between funds		(21,137)	21,137	-
		<hr/>	<hr/>	<hr/>
Net movement in funds		115,010	(17,997)	97,013
Fund balances at 5 April 2023		502,402	39,772	542,174
		<hr/>	<hr/>	<hr/>
Fund balances at 6 April 2024		617,412	21,775	639,187

PSC SUPPORT

BALANCE SHEET FOR THE YEAR ENDED 5 APRIL 2025

		2025		2024	
	Notes	£	£	£	£
Fixed Assets					
Tangible Assets	6		2,507		3,359
Current Assets					
Stocks		3,533		3,119	
Debtors	7	38,785		60,749	
Cash at Bank and in hand		<u>779,851</u>		<u>581,975</u>	
		822,169		645,843	
Creditors: amounts falling due within one year	8	<u>156,536</u>		<u>10,015</u>	
Net current assets			<u>665,663</u>		<u>635,828</u>
Total assets less current liabilities			<u>668,140</u>		<u>639,187</u>
Income funds					
Restricted Funds			19,760		21,775
Designated Funds			482,692		-
Unrestricted Funds			<u>165,688</u>		<u>617,412</u>
			<u>668,140</u>		<u>639,187</u>

The accounts were approved by the Trustees on 2 February 2026

Tim Waterson (Trustee)

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PSC SUPPORT

STATEMENT OF CASH FLOWS FOR THE YEAR ENDED 5 APRIL 2025

	Total 2025	Total 2024
	£	£
Cash flows from operating activities		
Net movement in funds	28,953	97,013
Adjustments for:		
Depreciation	1,611	1,484
Interest receivable	(14,798)	(15,410)
Working Capital Changes:		
Movement in current assets:		
(Increase)/Decrease in stock	(414)	(1,957)
(Increase)/Decrease in debtors	21,964	(45,277)
Movement in current liabilities:		
(Increase)/Decrease in creditors	146,521	6,808
Net cash inflow/(outflow) from operating activities	183,837	42,661
Cash flows from investing activities		
Interest received	14,798	15,410
Purchase of tangible fixed assets	(759)	(2,067)
Cash used in investing activities	14,039	13,343
Increase in cash and cash equivalents in the year	197,876	56,004
Cash and cash equivalents at the beginning of the year	581,975	525,971
Total cash and cash equivalents at the end of the year	779,851	581,975

PSC SUPPORT

NOTES TO THE ACCOUNTS (CONTINUED) FOR THE YEAR ENDED 5 APRIL 2025

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.

PSC Support is a charity in England and Wales. The address of the registered office is given in the charity information contents page of these financial statements.

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 Expenditure and liabilities

Expenditure is accounted for on an accrual basis and recognised at the time the liability is incurred.

1.4 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
--------------------------------	-------------------

1.5 Investments

Fixed asset investments are stated at market value.

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

1.6 Stock

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

1.7 Financial instruments

A financial asset or a financial liability is recognised only when the entity becomes a party to the contractual provisions of the instrument. Basic financial instruments are initially recognised at the amount receivable or payable including any related transaction costs, unless the arrangement constitutes a financing transaction, where it is recognised at the present value of the future payments discounted at a market rate of interest for a similar debt instrument. Current assets and current liabilities are subsequently measured at the cash or other consideration expected to be paid or received and not discounted.

1.8 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 2025

	2025	2024
	£	£
2 Grants		
Information Days	12,000	10,426
E-Learning (restricted)	20,000	21,225
Walking the Journey (restricted)	5,000	-
Helpline (restricted)	5,000	-
	<u>42,000</u>	<u>31,651</u>
3 Interest Receivable	<u>14,798</u>	<u>15,410</u>

PSC SUPPORT

NOTES TO THE ACCOUNTS (CONTINUED) FOR THE YEAR ENDED 5 APRIL 2025

	Total	Total
	2025	2024
	£	£
4 Total resources expended		
Research payable		
Restricted funds	248,468	86,000
	<u>248,468</u>	<u>86,000</u>
Direct charitable expenditure		
Salaries (including employer NI and pensions)	145,576	100,597
Salaries restricted (including employer NI and pensions)	-	31,806
Other Staff costs	3,127	12,398
General administration	4,561	3,042
Advocacy	54,355	15,994
Awareness and Support (unrestricted)	15,906	9,139
Awareness and Support (restricted)	33,240	11,904
Depreciation	1,611	1,484
	<u>258,376</u>	<u>186,364</u>
Fundraising		
Advertising and promotion	13,394	19,371
Merchandise	3,661	2,915
	<u>17,055</u>	<u>22,286</u>
Governance costs		
Accountancy	3,217	5,529
Legal cost	773	7,664
Independent examiner	790	750
	<u>4,780</u>	<u>13,943</u>
Total resources expended	<u>528,679</u>	<u>308,593</u>

5 Trustees

PSC SUPPORT

NOTES TO THE ACCOUNTS (CONTINUED) FOR THE YEAR ENDED 5 APRIL 2025

None of the trustees (nor any persons connected with them) received any remuneration during the year. Four (2024: nil) trustees were reimbursed for travelling expenses totaling £362 (2024: £Nil).

	£
6 Fixed Assets	
Cost at 6 April 2024	6,747
Purchases at cost	759
Cost at 5 April 2025	<u>7506</u>
Depreciation at 6 April 2024	3,388
Charge for the year	1,611
Depreciation at 5 April 2025	<u>4,999</u>
Net book value at 5 April 2025	<u>2,507</u>
Net book value at 5 April 2024	<u>3,359</u>

	2025	2024
	£	£
7 Debtors		
Accrued income	11,260	55,712
Prepayments	13,238	1,855
Other Debtors	14,287	3,182
	<u>38,785</u>	<u>60,749</u>

	2025	2024
	£	£
8 Creditors: amounts falling due within one year		
Aged creditors	10,561	6,260
Accruals	145,975	3,755
	<u>156,536</u>	<u>10,015</u>

PSC SUPPORT

NOTES TO THE ACCOUNTS (CONTINUED) FOR THE YEAR ENDED 5 APRIL 2025

9 Restricted Funds

	Movement in funds				
	Balance at 6 April 2024	Incoming Resources	Outgoing Resources	Fund Transfer	Balance at 5 April 2025
	£	£	£		£
PSC Research	-	190,300	(248,468)	58,168	-
Helpline	-	5,000	(240)	-	4,760
Walking the Journey Together	-	5,000	-	-	5,000
Education & E-Learning	21,775	20,000	(33,000)	1,225	10,000
As 5 April 2025	21,775	220,300	(281,708)	59,393	19,760
	Movement in funds				
	Balance at 6 April 2023	Incoming Resources	Outgoing Resources	Fund Transfer	Balance at 5 April 2024
	£	£	£		£
PSC Research	39,222	78,584	(117,806)	-	-
Information Days	-	11,904	(11,904)	-	-
Education	550	88	-	21,137	21,775
As 5 April 2024	39,772	90,576	(129,710)	21,137	21,775

Description of restricted funds

Research – to be spent on research projects relating to PSC

Helpline – free, confidential support service for people affected by PSC.

Walking the Journey Together – website development

Education & E-Learning – Educational PSC project for medical practitioners

Information Days – to be spent on events to support and inform people with PSC and their support networks

PSC SUPPORT

NOTES TO THE ACCOUNTS (CONTINUED) FOR THE YEAR ENDED 5 APRIL 2025

10 Analysis of net assets between funds

	Unrestricted Funds	Designated Funds	Restricted Funds	Total Funds
	£	£	£	£
Fund balances at 5 April 2025 are represented by:				
Fixed assets	2,507	-	-	2,507
Current assets	186,809	615,600	19,760	822,169
Creditors: amounts falling due within one year	(23,628)	(132,908)	-	(156,536)
	165,688	482,692	19,760	679,140

11 Commitments

	2025	2024
	£	£
Research fund code:		
Fargo	29,500	39,500
20220310SREC	4,000	4,000
JMBPROJ23	30,000	-
EJPROJ23	20,000	-
NISEED23	1,500	-
AGPROJ23B	22,500	-
CRRTF24	2,000	-
ABPROJ24	20,000	-
DJPROJ24	6,561	-
CSPROJ24	49,849	-
RMSEED24	15,000	-
AFRTF24	277,783	-
GNSEED24	2,000	-
JSSEED24	2,000	-
	482,693	43,500

PSC SUPPORT

NOTES TO THE ACCOUNTS (CONTINUED) FOR THE YEAR ENDED 5 APRIL 2025

	2025	2024
	£	£
12 Employees		
During the year 2024-25 there were 4 employees (During the year 2023-24 there were 4 employees)		
Salary costs including NI	138,330	126,447
Pension	7,246	5,956
	<hr/> 145,576	<hr/> 132,403

No employees received employee benefits (excluding employer pension costs) of more than £60,000.

PSC SUPPORT

England & Wales - Charity number 1175427

Accounts

Charity Registration No. 1175427

PSC SUPPORT
TRUSTEES' REPORT AND ACCOUNTS
FOR THE YEAR ENDED 5 APRIL 2024



PSC SUPPORT

CONTENTS

FOR THE YEAR ENDED 5 APRIL 2024

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 Moller
Mark Dean
Helen Elder
Rick Dallaway
Nicholas Kane
James Brown
David Adams
Charlene Oke (from 26/6/23)

PSC SUPPORT

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FOR THE YEAR ENDED 5 APRIL 2024

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PSC SUPPORT

TRUSTEES' REPORT

FOR THE YEAR ENDED 5 APRIL 2024

The Trustees present their report and financial statements for the year ended 5 April 2024. 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 funding co-applicants for PSC research
2. Providing high-quality, medically checked information on our website, social media, newsletters and at PSC Support events
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.

PSC SUPPORT

TRUSTEES' REPORT

FOR THE YEAR ENDED 5 APRIL 2024

ACHIEVEMENTS AND PERFORMANCE

Fundraising/ Income

The charity received a total income of £405,606 including £381,601 from fundraising, donations and merchandise sales for the year ending 5th April 2024. Fundraising income was again dramatically up on the previous year with a 54% increase. While the general economy remains difficult this increase is a testament to our work and our supporters who are motivated by our charity's aims and objectives, particularly in relation to funding high quality research. £90,576 of the total was in restricted income which was broken down as £10,426 for Information Days, £21,225 for a new e-learning platform on PSC guidelines and £58,925 for PSC research.

Expenditure

PSC Support trustees place the utmost importance on spending the charity's money best possible way for our beneficiaries. Our expenditure in this FY was £308,593 up from £127,077 the previous year. Research funding, an additional staff member, freelance support and bolstering our back-office systems including fundraising accounted for this rise in our expenditure.

Staff

The charity recruited a new member of staff during the year. Mark Chatterley became the new Administration Manager and has proved to be a great asset to the charity.

Martine Walmsley become our new Head of Research Strategy in line with her strengths and significant experience in this area of work.

Volunteers

Our volunteers make an immense contribution to the charity and trustees recognise their pivotal role.

In particular they would like to recognise the following: Keith Anderson, the charity's long-standing Treasurer, who resigned after 12 years of service during the financial year 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 and 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.

Trustees would like to recognise all those affected by PSC 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. Additionally, Gareth Weeks and Chris Forde are also lay members of our Scientific Review Committee.

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:

Professor David Adams
Professor Doug Thorburn
Professor Annika Bergquist
Professor Ansgar Lohse

PSC SUPPORT

TRUSTEES' REPORT

FOR THE YEAR ENDED 5 APRIL 2024

Professor Catherine Williamson
Professor Shaid Khan
Professor Alaistair O'Brien
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 Andrew Yeoman
Dr Kate Lynch
Dr Francesca Saffioti
Dr Christoph Schramm
Dr Brijesh Srivastava
Dr Nora Cazzagon
Dr Norman Junge
Dr George Mells
Dr Amara Elzubeir
Dr Nicholas Illott

Fundraising Products

20K Your Way was a new fundraising product designed to engage our community more and provide another way to fundraise for the charity. This campaign produced over £22k in revenue for the charity in its first year and will now become an annual fundraising campaign.

Support from the Pharmaceutical Industry

The following companies sponsored Information Days:

- Mirum Pharmaceuticals
- Chemomab Therapeutics
- Dr Falk Pharma UK

While we are incredibly grateful for their financial support, these companies have had no influence over content or the agendas of the events.

Information and Support

Social media – the charity has over 10k followers across all social media platforms. We post daily to engage with the community and to provide up to date information. Our well-moderated private Facebook group of over 4,000 people offers peer support. Huge thanks go to our volunteer moderators and staff moderator, Martine Walmsley, who work tirelessly to make sure the private support group is moderated to a very high standard even during holiday periods.

Ask the Experts – Over 700 people attended our webinars which were scheduled as monthly events in the second half of the financial year. These events gave those affected by PSC access to expert clinicians, helped them find out the latest developments and ask questions about PSC and related conditions.

PSC SUPPORT

TRUSTEES' REPORT

FOR THE YEAR ENDED 5 APRIL 2024

Information Days – we delivered one face-to-face event in this financial year in Oxford. 105 people attended the event (despite a national train strike) and we received excellent feedback. Attendees rated the event 4.9 out of 5.

'I thoroughly enjoyed the event and catching up with others or finally meeting some of those I've only known through the Facebook group. There was a great mix of speakers and either personal experiences or medical information, for those newly diagnosed and those pre or post-transplant. The panel discussion sounded interesting too from the feedback and good to have a wellbeing session. Well done to you and the volunteers who helped make the day possible, they are so valuable for PSCers. Thank you.'

Helpline – We had over 100 emails to or calls to our Helpline. Special thanks to Martine Walmsley who has managed this service for a number of years. We receive excellent feedback from those who have accessed the helpline and they were very grateful for her support.

'Thank you so much for listening to me talk and addressing my worries and concerns'

Research (including publications)

PSC research remains a priority for the charity. We launched a new research campaign called **Mission 2030** in an attempt to do everything we can to find an effective treatment for PSC. This campaign committed to fund £1 million worth of research by 2030. Funding will include research projects and a Research Training Fellowship.

Mission 2030 includes:

- 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

We were delighted to agree funding for five research projects in the first year of the campaign with a total value of £207,500.

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).

Publications:

1. *Rushbrook S, Kendall TJ, Zen Y, Albazaz R, Manoharan P, Pereira SP, Sturgess R, Davidson B, Malik H, Manas D, Heaton N. British Society of Gastroenterology Guidelines for the Diagnosis and Management of Cholangiocarcinoma. Gut. 2023 Sep 5.*
2. *Hussain N, Hirschfield B, Ferguson J, Abbas N, Bhandal K, Rogers P, Burke E, Hull D,*

PSC SUPPORT

TRUSTEES' REPORT

FOR THE YEAR ENDED 5 APRIL 2024

Gungabissoon U, Casillas L, Mukherjee S. P34 Burden, impact and variability of pruritus in primary sclerosing cholangitis (PSC) over time: a prospective observational study. Gut. 2023 72 S3

3. *Walmsley M, Tornai D, Cazzagon N, Leburgue A, Mrzljak A, Lenzen H, Carbone M, Madaleno J, Lleo A, Junge N, Schramm C, Bergquist, A. Patient-reported quality of care in primary sclerosing cholangitis. Liver International. 2023 Jun 13*
4. *Hussain N, Hirschfield B, Ferguson J, Abbas N, Bhandal K, Rogers P, Burke E, Hull D, Gungabissoon U, Casillas L, Mukherjee S. Burden, impact and variability of pruritus in primary sclerosing cholangitis (PSC) over time: a prospective observational study. Journal of Hepatology. 2023. Jun. 78, SUPPLEMENT 1, S398-S399*
5. *Bergquist A, Walmsley M, Tornai D, Cazzagon N, Leburgue A, Mrzljak A, Lenzen H, Carbone M, Madaleno J, Lleo A, Junge N. Patient reported gaps between current practice and new practice guidelines for primary sclerosing cholangitis. Journal of Hepatology. 2023 Jun 1;78:S383-4*
6. *Kowdley KV, Safer R, Gomel R, Hatchett J, Walmsley M, Burman JA, Weinbaum S, Goldsmith K, Garner W, McKibben A, Chien E. Tu1587 IMPACT OF PRURITUS IN PRIMARY SCLEROSING CHOLANGITIS (PSC) FROM THE PATIENT PERSPECTIVE: A MULTI-NATIONAL STUDY. Gastroenterology. 2023 May 1;164(6):S-1426*

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.

The Board 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 Administration Manager.

During the financial year the charity moved its accounts onto the accountancy software package, Xero.

FINANCIAL REVIEW

The detailed accounts for the year ended 5 April 2024 are shown on pages 10-20. The accounts show that at the end of the financial year PSC Support held £639,187 in funds. This was broken down as total unrestricted £617,412 and total restricted £21,775.

At the end of the financial year the charity held £43,500 of committed funds for research.

No funds were materially in deficit.

Policy on reserves

PSC SUPPORT

TRUSTEES' REPORT FOR THE YEAR ENDED 5 APRIL 2024

In 2023-24 reserves contingency was nine months operating costs. These reserves would enable normal operating activities to continue over a period of 9 months should a shortfall in income occur. It also takes into account any potential risks and contingencies that may arise from time to time.

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 on a quarterly basis.

The Trustees regularly reviewed funds/reserves levels throughout 2023/24, focusing funds on the most important priorities.

The reserves value held by the charity (which equals 9 months of running costs), stands at £134,162. This includes the increased pay expenditure allocated to new staff.

Future plans

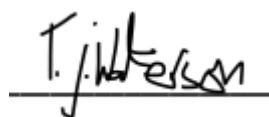
These include the following:

- The continued funding of high-quality research as part of the Mission 2030 campaign.
- Producing two in person Information Days a year in different locations to ensure PSC experts are accessible to those affected by PSC
- The development of an e-learning platform for doctors and nurses to increase their knowledge about the PSC guidelines
- The production of an infographic patient journey on the PSC Support website and a general update of the website
- Moving to a nurse managed helpline

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.

Approved by the Trustees and signed on their behalf on 22nd January 2025 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 2024 which are set out on pages 9-17.

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

Since the charity's gross income exceeded £250,000 your examiner must be a member of a body listed in section 145 of the Act. I confirm that I am qualified to undertake the examination because I am a member of the Institute of Chartered Accountants of England and Wales, which is one of the listed bodies.

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

..... 28 January 2025

PSC SUPPORT

STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 5 APRIL 2024

		Unrestricted funds	Restricted funds	Total 2024	Total 2023
	Notes	£	£	£	£
Income					
Donations and legacies		263,648	34,454	298,102	242,667
Grants	2	-	31,651	31,651	550
Investment income	3	15,410	-	15,410	2,223
Gift aid		29,967	6,471	36,438	16,928
Other charitable activities		6,005	18,000	24,005	1,319
		<hr/>	<hr/>	<hr/>	<hr/>
Total		315,030	90,576	405,606	263,687
Expenditure					
Research payable		-	86,000	86,000	8,542
Fundraising		22,286	-	22,286	3,925
Direct charitable expenditure		142,654	43,710	186,364	114,010
Governance costs		13,943	-	13,943	600
		<hr/>	<hr/>	<hr/>	<hr/>
Total	4	178,883	129,710	308,593	127,077
Net Income (Expenditure)		136,147	(39,134)	97,013	136,610
Transfers between funds		(21,137)	21,137	-	-
		<hr/>	<hr/>	<hr/>	<hr/>
Net movement in funds		115,010	(17,997)	97,013	136,610
Fund balances at 5 April 2023		502,402	39,772	542,174	405,564
		<hr/>	<hr/>	<hr/>	<hr/>
Fund balances at 6 April 2024		617,412	21,775	639,187	542,174
		<hr/>	<hr/>	<hr/>	<hr/>

PSC SUPPORT

STATEMENT OF FINANCIAL ACTIVITIES

FOR THE YEAR ENDED 5 APRIL 2023 (COMPARATIVE FIGURES)

	Unrestricted funds	Restricted funds	Total 2023
	£	£	£
Income			
Donations and legacies	216,657	26,010	242,667
Grants	-	550	550
Investment income	2,223	-	2,223
Gift aid	10,678	6,250	16,928
Other charitable activities	1,319	-	1,319
Total	230,877	32,810	263,687
Expenditure			
Grants payable	8,504	38	8,542
Fundraising	3,925	-	3,925
Direct charitable expenditure	114,010	-	114,010
Governance costs	600	-	600
Total	127,039	38	127,077
Net movement in funds	103,838	32,772	136,610
Fund balances at 6 April 2022	398,564	7,000	405,564
Fund balances at 5 April 2023	502,402	39,772	542,174

PSC SUPPORT

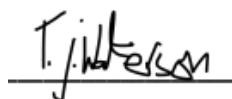
BALANCE SHEET

FOR THE YEAR ENDED 5 APRIL 2024

		2024		2023	
	Notes	£	£	£	£
Fixed Assets					
Tangible Assets	6		3,359		2,776
Current Assets					
Stocks		3,119		1,162	
Debtors	7	60,749		15,472	
Cash at Bank and in hand		<u>581,975</u>		<u>525,971</u>	
		645,843		<u>542,605</u>	
Creditors: amounts falling due within one year	8	<u>10,015</u>		<u>3,207</u>	
			<u>635,828</u>	<u>539,398</u>	
Net current assets					
Total assets less current liabilities			<u>639,187</u>	<u>542,174</u>	
Income funds					
Restricted Funds			21,775		39,772
Unrestricted Funds			<u>617,412</u>		<u>502,402</u>
			<u>639,187</u>		<u>542,174</u>

The accounts were approved by the Trustees on 22nd January 2025

Tim Waterson (Trustee)


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PSC SUPPORT

BALANCE SHEET

FOR THE YEAR ENDED 5 APRIL 2024

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.

PSC Support is a charity in England and Wales. The address of the registered office is given in the charity information contents page of these financial statements.

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 Expenditure and liabilities

Expenditure is accounted for on an accrual basis and recognised at the time the liability is incurred.

1.4 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
--------------------------------	-------------------

1.5 Investments

Fixed asset investments are stated at market value.

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

1.6 Stock

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

1.7 Financial instruments

A financial asset or a financial liability is recognised only when the entity becomes a party to the contractual provisions of the instrument. Basic financial instruments are initially recognised at the amount receivable or payable including any related transaction costs, unless the arrangement constitutes a financing transaction, where it is recognised at the present value of the future payments discounted at a market rate of interest for a similar debt instrument. Current assets and current liabilities are subsequently measured at the cash or other consideration expected to be paid or received and not discounted.

1.8 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 2024

	2024	2023
	£	£
2 Grants		
Information Days	10,426	-
E-Learning	21,225	
Clinical Trials	-	550
	<u>31,651</u>	<u>550</u>
3 Interest Receivable	<u>15,410</u>	<u>2,223</u>

PSC SUPPORT

NOTES TO THE ACCOUNTS (CONTINUED) FOR THE YEAR ENDED 5 APRIL 2024

	Total	Total
	2024	2023
	£	£
4 Total resources expended		
Grants		
Restricted funds	86,000	38
Unrestricted funds	-	8,504
	<hr/> 86,000	<hr/> 8,542
Direct charitable expenditure		
Salaries unrestricted (including employer NI and pensions)	100,597	86,341
Salaries restricted (including employer NI and pensions)	31,806	-
Other Staff costs	12,398	6,409
General administration	3,042	3,140
Advocacy	15,994	4,072
Awareness and Support (unrestricted)	9,139	9,845
Awareness and Support (restricted)	11,904	-
Other	-	3,148
Depreciation	1,484	1,055
	<hr/> 186,364	<hr/> 114,010
Fundraising		
Advertising and promotion	19,371	2,678
Merchandise	2,915	1,247
	<hr/> 22,286	<hr/> 3,925
Governance costs		
Accountancy	5,529	-
Legal cost	7,664	-
Independent examiner	750	600
	<hr/> 13,943	<hr/> 600
Total resources expended	<hr/> 308,593	<hr/> 127,077

PSC SUPPORT

NOTES TO THE ACCOUNTS (CONTINUED) FOR THE YEAR ENDED 5 APRIL 2024

5 Trustees

Trustees were reimbursed a total of £358.48 during the year for travel expenses (2023: £122).

6 Fixed Assets

	£
Cost at 6 April 2023	4,680
Purchases at cost	2,067
Cost at 5 April 2024	<u>6,747</u>
Depreciation at 6 April 2023	1,904
Charge for the year	1,484
Depreciation at 5 April 2024	<u>3,388</u>
Net book value at 5 April 2024	<u>3,359</u>
Net book value at 5 April 2023	<u>2,776</u>

	2024	2023
	£	£
Accrued income	55,712	15,448
Prepayments	1,855	24
Other Debtors	3,182	-
	<u>60,749</u>	<u>15,472</u>

	2024	2023
	£	£
Aged creditors	6,260	-
Accruals	3,755	3,027
	<u>10,015</u>	<u>3,027</u>

PSC SUPPORT

NOTES TO THE ACCOUNTS (CONTINUED) FOR THE YEAR ENDED 5 APRIL 2024

9 Restricted Funds

	Movement in funds			
	Balance at 6 April 2023	Incoming Resources & Transfers	Outgoing Resources & Transfers	Balance at 5 April 2024
	£	£	£	£
PSC Research	39,222	78,584	117,806	-
Information Days	-	11,904	11,904	-
Education	550	21,225	-	21,775
As 5 April 2024	39,772	111,713	129,710	21,775

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

Description of restricted funds

Research – to be spent on research projects relating to PSC.

Information Days – to be spent on events to support and inform people with PSC and their support networks

Education – Educational PSC project for medical practitioners

PSC SUPPORT

NOTES TO THE ACCOUNTS (CONTINUED) FOR THE YEAR ENDED 5 APRIL 2024

Analysis of net assets between funds

	Unrestricted Funds £	Restricted Funds £	Total Funds £
Fund balances at 5 April 2024 are represented by:			
Fixed assets	3,359	-	3,359
Current assets	624,068	21,775	645,843
Creditors: amounts falling due within one year	(10,015)	-	(10,015)
	<u>617,412</u>	<u>21,775</u>	<u>639,187</u>

2024
£

2023
£

11 Commitments

At 5 April 2024 the charity had committed funds

Research	<u>43,500</u>	<u>53,000</u>
	<u>43,500</u>	<u>53,000</u>

2024
£

2023
£

12 Employees

During the year 2023-24 there were 4 employees
(During the year 2022-23 there were 3 employee)

Salary costs including NI	126,447	82,564
Pension	<u>5,956</u>	<u>3,777</u>
	<u>132,403</u>	<u>86,341</u>

No employees received employee benefits (excluding employer pension costs) of more than £60,000.

PSC SUPPORT

England & Wales - Charity number 1175427

Accounts

Charity Registration No. 1175427

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



PSC SUPPORT

CONTENTS

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)

PSC SUPPORT

CONTENTS *FOR THE YEAR ENDED 5 APRIL 2023*

Trustees report	1-7
Statement of trustees' responsibilities	8
Independent examiner's report	9
Statement of financial activities	10-11
Balance sheet	12
Notes to the accounts	13-18

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

PSC SUPPORT

TRUSTEES' REPORT

FOR THE YEAR ENDED 5 APRIL 2023

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:

PSC SUPPORT

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.

PSC SUPPORT

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).

PSC SUPPORT

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.

PSC SUPPORT

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

PSC SUPPORT

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		<u>230,877</u>	<u>32,810</u>	<u>263,687</u>	<u>185,457</u>
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	<u>127,039</u>	<u>38</u>	<u>127,077</u>	<u>42,568</u>
Net movement in funds		103,838	32,772	136,610	142,889
Fund balances at 6 April 2022 (restated)		<u>398,564</u>	<u>7,000</u>	<u>405,564</u>	<u>262,675</u>
Fund balances at 5 April 2023		<u>502,402</u>	<u>39,772</u>	<u>542,174</u>	<u>405,564</u>

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

PSC SUPPORT

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
--------------------------------	-------------------

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
4 Total resources expended	2023	2022
	£	£
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>600</u>	<u>600</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

PSC SUPPORT

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
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.

PSC SUPPORT

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)
	<u>502,402</u>	<u>39,772</u>	<u>542,174</u>
		2023	2022
		£	£

11 Commitments

At 5 April 2023 the charity had committed funds

Research	<u>53,000</u>	<u>44,500</u>
	<u>53,000</u>	<u>44,500</u>
	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	-
	<u>86,341</u>	<u>16,711</u>

PSC SUPPORT

England & Wales - Charity number 1175427

Accounts

Trustees' Annual Report for the period

	Period start date	Period end date	
From	06 April 2021	05 April 2022	To

Charity name	PSC Support
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Other names charity is known by

Registered charity number (if any) 1175427

Charity's principal address	3 Gary O'Donnell Drive
	Didcot
	Oxfordshire
	Postcode OX11 6BT

Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	David Adams			Trustees
2	Roger Chapman			Trustees
3	Martine Walmsley		Trustee from 10 May 2021 to 16 May 2022	Trustees
4	James Gosney		Trustee until 22 April 2022	Trustees
5	Gary Taylor		Trustee until 12 May 2021	Trustees
6	James Brown			Trustees
7	Tim Waterson			Trustees
8	Nick Kane			Trustees
9	Rick Dallaway			Trustees
10	Shelley Spence			Trustees
11				
12				
13				
14				
15				
16				
17				
18				
19				
20				

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)

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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)

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

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

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

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, Dornier 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

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 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 of 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
	£85,500

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.


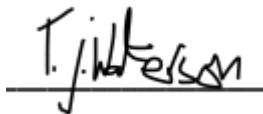
Designated funds are expenditure that the charity has 'ringfenced' as future spend for specific items. These funds can either be 'committed', where the charity has made either a formal or informal commitment to spend, or 'flexible', where the charity has discretion about whether it would like to proceed 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

	<u>Unrestricted</u> <u>Funds</u> <u>2021/22</u>	<u>Restricted</u> <u>Funds</u> <u>2021/22</u>	<u>Total</u> <u>Funds</u> <u>2021/22</u>	<u>Total</u> <u>Funds</u> <u>2020/21</u>
<u>RECEIPTS</u>				
<u>Donations & Fund Raising</u>				
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
	<u>182,546</u>	<u>2,063</u>	<u>184,609</u>	<u>117,958</u>
<u>Sale of PSC Support Merchandise</u>				
Hoodies, Polo & T Shirts	236	-	236	225
Running T Shirts & Vests	260	-	260	16
Mugs	44	-	44	38
Pin Badges	-	-	-	-
Wristbands	183	-	183	53
	<u>723</u>	<u>-</u>	<u>723</u>	<u>332</u>
<u>Other Receipts</u>				
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
	<u>350</u>	<u>-</u>	<u>350</u>	<u>778</u>
TOTAL RECEIPTS	183,619	2,063	185,682	119,068
<u>PAYMENTS</u>				
<u>General Administration</u>				
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
	<u>1,576</u>	<u>-</u>	<u>1,576</u>	<u>1,564</u>

Governance

Independent Examination of 2020/21 Accounts	600	-	600	600
	<u>600</u>	<u>-</u>	<u>600</u>	<u>600</u>

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
	<u>1,656</u>	<u>-</u>	<u>1,656</u>	<u>128</u>

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	-
	<u>1,405</u>	<u>3,613</u>	<u>5,018</u>	<u>-</u>

Other Expenditure

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

TOTAL PAYMENTS

39,182	3,613	42,795	50,587
---------------	--------------	---------------	---------------

SURPLUS / DEFICIT

144,437	(1,550)	142,887	68,481
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Transfers Between Restricted & 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
	<u>394,158</u>	<u>7,000</u>	<u>401,158</u>	<u>258,271</u>

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

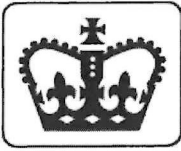
The charity has no outstanding debts. It has made the following commitments:

- 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**

5th 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 5th 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.

PSC SUPPORT

England & Wales - Charity number 1175427

Accounts

Trustees' Annual Report for the period						
		Period start date			Period end date	
From	06	April	2020	To	05	April 2021

Section A Reference and administration details

Charity name PSC Support

Other names charity is known by

Registered charity number (if any) 1175427

Charity's principal address

3 Gary O'Donnell Drive	
Didcot	
Oxfordshire	
Postcode	OX11 6BT

Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	David Adams			Trustees
2	Roger Chapman			Trustees
3	Martine Walmsley		To 27 October 2020	Trustees
4	James Gosney			Trustees
5	Gary Taylor			Trustees
6	James Brown		From 07 June 2020	Trustees
7	Tim Waterson		From 08 June 2020	Trustees
8	Nick Kane		From 08 June 2020	Trustees
9	Rick Dallaway		From 13 June 2020	Trustees
10	Shelley Spence		From 20 July 2020	Trustees
11	Michael McVerry		From 08 June 2020 to 14 March 2021	Trustees
12				
13				
14				
15				
16				
17				
18				
19				
20				

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)

Volunteer CEO: Martine Walmsley
 One staff member: Maxine Tapp (Programme Development Officer)

Section B Structure, governance and management

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.

Section C Objectives and activities

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 objectives:

- provide information and support to those affected by primary sclerosing cholangitis (PSC).
- work with partners to promote awareness of PSC, current research and the need for organ donation.
- support PSC-related medical practitioners and researchers by:
 - giving people affected by PSC access to the latest relevant medical information to promote patient participation in essential trials;
 - providing grants towards projects that have specific target outcomes;
 - providing patient input into research projects at all points in the research cycle.
- develop effective partnerships between PSC Support and medical practitioners, researchers, policy makers and people affected by 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)

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

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

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

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, in particular 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 Gareth and Vicki Weeks for their dedication 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 Luke Boulter, Dr Roger Chapman, Dr Clare Constantinou, Dr Emma Culver, Dr Jessica Dyson, Dr James Ferguson, Dr Hermien Hartog, Professor Michael Heneghan, Dr Deepak Joshi, Dr Eilis Kennedy, Professor Ansgar Lohse, Dr Kate Lynch, Dr Kathy McKay, Dr Nabil Quraishi, Dr Mussarat Rahim, Dr Simon Rushbrook, Dr Francesca Saffioti, Dr Christoph Schramm, Dr Keith Siau, Amanda Smith, Dr Brijesh Srivastava, Professor Douglas Thorburn, Dr Palak Trivedi, Dr Veronica Ranieri and Dr Andrew Yeoman.

Section D

Achievements and performance

Summary of the main achievements of the charity during the year

Fundraising

Voluntary fundraising income for the charity for the year ending 5 April 2021 was £117,958, of which £8,550 was restricted for research only. For reference, the total income for the year ending 5 April 2021 was £119,068.

Expenditure

Total expenditure for the year ending 5 April 2021 was £50,587.

COVID-19

During this financial year, the charity was impacted by COVID-19. The UK was locked down for much of the period, and the volunteers and staff member were considered clinically vulnerable. This meant travel and face-to-face meetings were not possible (as was the case for much of the world). In addition, research activity in the UK ground to a halt, including recruitment to PSC clinical trials. Fundraising events were unable to take place and the first quarter of this financial year saw the charity's income cut in half. Thanks to the remarkable innovation and commitment of patients and family members of PSC Support, the charity ended the year with only 20% less income than would have been predicted in a non-COVID financial year.

Organisational risk, limitations and stability

The Trustees of the CIO held quarterly virtual meetings and kept in close contact with the volunteer CEO. To ensure that the charity was well-governed and able to thrive despite the COVID-19 pandemic, six new Trustees were appointed in June and July 2020, bringing in professional skills that included legal, data protection, income generation, communications and human resource experience and expertise.

The new Trustees have each made significant contributions to the governance and operation of PSC Support during their first year.

In this financial year, the new Board held a series of meetings to review the charity's short-, medium- and long-term strategy (continuing into the first quarter of the 2021 financial year). Finding a balance between prudence to ensure the long-term viability versus proactively spending to meet the strategic aims of the charity, was paramount throughout the year. The Trustees thus planned for a substantially reduced income over the year and was able to continue to support our beneficiaries in line with our charitable objects.

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.

Research

The pandemic naturally impacted our whole healthcare system and PSC clinicians, nurses and researchers were reposted into general medicine to care for COVID-19 patients or to conduct COVID-19 related research studies. This meant that minimal research took place, many academic and commercial research studies were paused and there was uncertainty about when and if they would resume.

PSC Support granted 'no cost extensions' to existing PSC Support-funded research projects i.e. allowed studies a time extension to complete at no additional cost to PSC Support. In the financial 2020/21,

there was no expenditure on research. However, PSC research remained a priority for PSC Support. Activities were reviewed and funds reallocated as the financial year progressed in order to maximise value for money and use charity resources efficiently.

The charity ended the financial year with the following key committed funds for research:

1. It has guaranteed to pay a retained total of £7,500 to three researchers when their projects have been completed. This is the 10% held in our accounts until completion of the research projects.
2. The charity has conditionally undertaken to contribute £30,000 to a Diagnostic Blood Test Research Project following positive initial findings. This is subject to the usual stringent peer review evaluation of the application.
3. The charity has conditionally undertaken to contribute £50,000 to the FARGO PSC Research Trial. This is a clinical trial to evaluate the benefit of faecal microbiota transplantation as a treatment for PSC. The project is currently being evaluated by a potential co-funder. The outcome of the evaluation is expected in the first quarter of 2021.

Even though clinical trials were on hold, we 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. Our close partnerships with PSC researchers meant that there were five different clinical trials testing drugs in 2020 with more in the pipeline. We also worked with researchers to develop machine perfusion research projects and repurposing existing drugs for PSC trials. We are very grateful to the patients who joined our research panels.

Support and information

Because of COVID-19, people living with PSC needed more support than ever. Although we could not meet face-to-face, PSC Support continued to provide information, resources and support through the www.pscsupport.org.uk website, news bulletins, social media, and online communities.

The beginning of the pandemic saw our Facebook activity level triple. People with PSC needed PSC-specific information about the risks of coronavirus, COVID-19 restrictions and what the changes meant for PSC patients, their healthcare and social limitations, and information about their eligibility for the COVID-19 vaccines. We worked with experts to ensure that PSC patients had a strategy to safely handle cholangitis during the lockdowns. Information from the government was haphazard and confusing, and inaccurate information was circulating online to the general public. PSC Support ensured people with PSC had the right information at the right time.

One patient said, "I've personally found the speediness of...up-to-date information remarkable... thank you."

PSC Support was agile in its response to the impact of COVID, and invited additional Facebook group moderators to work with us to ensure that our Facebook group continued to be well-moderated, so members could rely on the information in the group and have a safe space to discuss any aspect of PSC. We moderated nearly 40,000 comments over the year. At the height of the first wave, we also ran daily online 'drop-ins' to allow members to connect and enjoy light-hearted conversation when

they needed it. One Facebook group member said, "...this is the best place to be for all your questions..."

The PSC Support Helpline continued to be a valuable source of support for patients. Calls are handled by a volunteer and feedback includes:

"The person I spoke to really helped me to feel less alone"

"Thank you for helping me make sense of what the doctor said"

"...a lifeline..."

Since face-to-face meetings were out of the question, the charity ran nine 'Ask the Expert' sessions, using Zoom. These were live, online Q&As with PSC specialists. These sessions were popular and attracted over 8,000 views.

Feedback included, "Thanks so much for this I've learned loads!"

"Thanks a million it was very informative and reassuring"

The valuable wallet-sized PSC Alert Card, launched on 01 February 2020 was converted into a pdf so that it was downloadable and available to all patients even when COVID-19 restrictions meant we couldn't post out the cards.

One patient said, "Excellent, used on my last admission to hospital."

Another said, "a true lifesaver."

Advocacy

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

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 2020/21, focusing funds on the most important priorities, and repurposing some flexible designated funds from projects that were unlikely to go ahead successfully because of COVID-19 restrictions.

The reserves value held by the charity (which equals one year of running costs), stands at £44,072. This is a provisional reserves figure based on employing one member of staff pending decisions made by Trustees regarding staffing and strategic priorities for 2021/22 (meetings planned May 2021). The lower operating costs than planned at the beginning of the 2020/21 financial year reflect the anticipated reduction in travel and attendance at face-to-face meetings because of COVID.

PSC Support does not commit to funding if the money 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 £258,271. The total unrestricted charity funds as at 5 April 2021 is £249,721, and restricted funds is £8,550.

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 2020/21, the charity has £95.1k of designated funds, with £90.1k of these 'committed'.

Research expenditure in 2020/21 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, £87,500 of the designated funds was committed to specific research projects.

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Section G Declaration

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

Signed on behalf of the charity's trustees

Signature(s)

M. Walmsley	T. Waterson
-------------	-------------

Full name(s)

Martine Clare Walmsley	Tim Waterson
------------------------	--------------

Position (eg Secretary, Chair, etc)

Trustee	Trustee
---------	---------

Date

16 May 2021

PSC SUPPORT (CIO) - REGISTERED CHARITY NUMBER 1175427

RECEIPTS & PAYMENTS 6th APRIL 2020 to 5th APRIL 2021

	<u>Unrestricted</u> <u>Funds</u> <u>2020/21</u>	<u>Restricted</u> <u>Funds</u> <u>2020/21</u>	<u>Total</u> <u>Funds</u> <u>2020/21</u>	<u>Total</u> <u>Funds</u> <u>2019/20</u>
<u>RECEIPTS</u>				
<u>Donations & Fund Raising</u>				
General Donations & Fund Raising	98,986	-	98,986	88,910
Restricted Donations for PSC Research	-	5,550	5,550	19,867
Gift Aid Reclaimed (Including Via Internet)	10,422	3,000	13,422	7,842
	<u>109,408</u>	<u>8,550</u>	<u>117,958</u>	<u>116,619</u>
<u>Sale of PSC Support Merchandise</u>				
Hoodies, Polo & T Shirts	225	-	225	658
Running T Shirts & Vests	16	-	16	145
Mugs	38	-	38	33
Pin Badges	-	-	-	6
Wristbands	53	-	53	118
	<u>332</u>	<u>-</u>	<u>332</u>	<u>960</u>
<u>Other Receipts</u>				
Acute Cholangitis Alert Cards - Foreign Shipping	15	-	15	124
Expenses Reimbursed by Third Parties (Re Employee)	-	-	-	536
Expenses Reimbursed by Third Parties (Re Trustee)	-	-	-	435
Partial Refund of ILC Conference Fees	176	-	176	-
Return of Newport Information Day Cash Float	-	-	-	100
Refund of Outward Airfares to ECRD Stockholm Conference by Ryanair	86	-	86	-
Partial Refund of Trustees' Safeguarding Checks Charge	-	-	-	18
Interest Credited to Deposit Accounts	494	-	494	1,219
PayPal Giving Fund Recredits Following Merchandise Sales	-	-	-	40
Reimbursement for Personal Purchase Charged to Charity's Credit Card in Error	7	-	7	-
	<u>778</u>	<u>-</u>	<u>778</u>	<u>2,472</u>
TOTAL RECEIPTS	110,518	8,550	119,068	120,051
<u>PAYMENTS</u>				
<u>General Administration</u>				
Combined Charity Insurance	590	-	590	445
Credit Card Fee	30	-	30	30
Data Protection Fee (Information Commissioner's Office)	40	-	40	-
DBS Checks on Volunteers	94	-	94	-
Go Cardless Annual Subscription	-	-	-	74

Microsoft Office 365 Annual Subscription	33	-	33	33
Postage	30	-	30	37
Printer Usage	42	-	42	42
Service User Surveys (Survey Monkey)	306	-	306	306
Soho66 Phone Services (Admin)	162	-	162	179
Stationery	-	-	-	2
UK Postbox	60	-	60	100
	<u>1,387</u>	-	<u>1,387</u>	<u>1,248</u>

Staff Employment

Gross Salary & Bonus	22,890	-	22,890	22,441
Home Working Broadband Allowance	392	-	392	596
Home Working Heating & Lighting Allowance	200	-	200	200
Salary Deductions for Tax, NI, Pension & Student Loan Repayment -	5,066	- -	5,066 -	5,115
HMRC Payments (Employee & Employer)	4,151	-	4,151	4,237
Pension Contributions (Employee & Employer)	2,054	-	2,054	2,276
Payroll Charges - Cox & Co	-	-	-	324
Payroll Charges - Wenn Townsend	546	-	546	42
Credit Card Fee	30	-	30	30
Mobile Phone Usage	96	-	96	95
Office Equipment, Furniture, Software & Sundries	446	-	446	407
	<u>25,739</u>	-	<u>25,739</u>	<u>25,533</u>

Advocacy

Benefits & Work Publishing Subscription	97	-	97	97
Disability Rights UK Membership	102	-	102	102
EASL Annual Membership	188	-	188	178
Eurordis Annual Membership	91	-	91	101
Registration for Online EURORDIS European Conference	72	-	72	-
Genetic Alliance UK Membership	-	-	-	100
ILC London Registration	-	-	-	183
2019 Research Survey Prize	-	-	-	50
Employee's Expenses Attending Various Meetings & Conferences	-	-	-	2,839
Trustees' Expenses Attending Various Meetings & Conferences	-	-	-	3,180
Volunteer's Expenses Attending a Meeting	-	-	-	30
	<u>550</u>	-	<u>550</u>	<u>6,860</u>

Awareness & Support (Including Education)

A6 Flyers	19	-	19	-
Acute Cholangitis Alert Cards	122	-	122	1,717
BASL Conference - Charge for PSC Support Stand	-	-	-	240
Display Stands	-	-	-	21
Graphic Design & Printing of Leaflets	-	-	-	100
Information Days	-	-	-	3,463
MailChimp Subscription for Newsletters	43	-	43	-
Patient Support App Development	14,156	-	14,156	17,640
Legal Fees re Privacy Policy & T&Cs (Patient Support App)	1,894	-	1,894	-

Legal Fees re Privacy Policy & T&Cs (Website)	3,788	-	3,788	-
Pull Up Banners	-	-	-	132
Postage & Packaging	-	-	-	12
Soho66 Phone Services (Support)	162	-	162	179
Website Domain Registration Renewal (Fasthosts)	101	-	101	73
Website Hosting (Fasthosts)	126	-	126	-
Website Hosting & Support (White Fuse Media)	-	-	-	78
Zoom Pro Subscription	201	-	201	-
Employee's Travel Expenses Attending Meetings	-	-	-	479
Trustee's Travel Expenses Attending Meetings	-	-	-	350
	20,612	-	20,612	24,484

Fundraising

A6 Flyers	19	-	19	-
A6 Postcards for a Wedding	-	-	-	13
Collection Boxes	-	-	-	143
Facebook Advertising	55	-	55	-
Fundraising Banner	47	-	47	-
Fundraising Training by Institute of Fundraising	225	-	225	-
Just Giving	562	-	562	562
London Vitality Half Marathon 2020 - 5 Places	-	-	-	425
London Marathons 2021 Entries (Virtual & In Person)	584	-	584	-
Employee's Expenses Attending the 2019 London Marathon to Support the Charity's Runners	-	-	-	87
PayPal Fees Deducted from Donations Received	55	-	55	104
Postage & Packaging	17	-	17	96
	1,564	-	1,564	1,430

Governance

Accounting Advice & Independent Examination of Accounts	600	-	600	600
DBS Check on Employee	-	-	-	67
Employee's Expenses Attending Meetings with Trustees	-	-	-	155
Trustees' Travel Expenses Attending Trustees' Meetings	-	-	-	209
	600	-	600	1,031

Purchase & Distribution of PSC Support Merchandise

T Shirts	-	-	-	348
PayPal & eBay Fees	92	-	92	216
Postage & Packaging	36	-	36	172
	128	-	128	736

Research

Dr Jesus Banales (Spain)	-	-	-	40,550
Drs Goode & Rushbrook (Norfolk & Norwich) (PSC Diagnostic Blood Test)	-	-	-	9,000
Dr Palak Trivedi (Birmingham) (PSC 600)	-	-	-	18,000
Legal Costs re Research Grants (Stone King)	-	-	-	4,676
Legal Costs re New Research Contract (Wright Hassall)	-	-	-	2,535
	-	-	-	74,761



Section A

Independent Examiner's Report

**Report to the trustees/
members of**

Charity Name
PSC Support

**On accounts for the year
ended**

5th April 2021

**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 5th April 2021.

**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:

04/01/2022

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).