

PBC FOUNDATION (UK) LIMITED

Trustees Annual Report & Accounts

for the year ended
31 December 2023

The Trustees, who are also Directors for the purposes of company law, present their report and financial statements of the PBC Foundation for the year ended 31st December 2023.

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Charity Name:	PBC Foundation (UK) Limited
Charity No.:	SC025619
Company Registration No.:	SC207493
Head Office and Registered Office:	Unit 1 Dunfermline Business Centre Izatt Avenue Dunfermline KY11 3BZ
Trustees:	Eileen Brownlie WS (died 4 May 2023) Professor James Neuberger (resigned 2 October 2023) Dr. George Mells MRCP Professor David Jones OBE David H Campbell NP (resigned 17 January 2024) Lynn Warren (resigned 17 January 2024) Jane Thomas Goksel Osman (resigned 26 January 2024) Louise Ferguson (resigned 17 January 2024) Bryan Rankin (died 9 March 2023) David S Sutherland Adam Cornick (appointed 2 October 2023) Iain M Cormack (appointed 2 October 2023, resigned 9 July 2024) June Seaber-Tellum (appointed 17 January 2024) Dr Natasha K Ratcliffe (appointed 12 October 2023) Feroz A Sultan (appointed 24 May 2024)
Secretary:	David H Campbell NP (resigned 17 January 2024) Dr Natasha K Ratcliffe (appointed 17 January 2024)
Auditor:	Ballards LLP Oakmoore Court Kingswood Road Hampton Lovett Droitwich Worcs WR9 OQH
Bankers:	Virgin Money 83 George Street Edinburgh EH2 3ES
Solicitors:	Anderson Strathern 58 Morrison Street Edinburgh EH3 8BP

OBJECTIVES AND ACTIVITIES

The PBC Foundation is the only organisation in the UK exclusively dedicated to providing free support and information to those affected by Primary Biliary Cholangitis (formerly known as Primary Biliary Cirrhosis), a rare, progressive and autoimmune liver condition with no known cause or cure.

The objects for which the charity was established are:

- i) The relief of persons suffering from the condition known as Primary Biliary Cholangitis by the setting up and organisation of support groups for the benefit of such persons and their families and by the provision of information about the condition and its treatment.
- ii) To promote research into the condition of Primary Biliary Cholangitis and into any other related areas as the charity may decide and to publish the results thereof, through either the provision, or assistance with the provision, of the necessary finance.
- iii) To advance the education of the public generally about the problems associated with Primary Biliary Cholangitis.

ACHIEVEMENTS AND PERFORMANCE

The PBC Foundation continues to be committed to the constant improvement of the services it provides, information it shares, methods of interaction and the extent of its outreach. It was another busy year for us, in which we worked hard to achieve our objectives and made many notable achievements.

- **Expanding our community:** Our small, Fife-based team made every effort to reach out and support as many people affected by PBC globally as possible. In 2023, we welcomed 1,015 new service users to our Foundation. 548 of those registered were from the UK, whilst 467 joined us from other countries around the world.
- **Our online presence:** We experienced an increased following on social media and rising traffic to our website, which continues to be a key source of information for people around the world.
- **Newly designed website:** User friendly, up to date and accurate information.
- **Global reach:** Strong digital engagement and 128,400 people reached with up-to-date and accurate GSK information.
- **USA Workshops** – Intercept funded five patient education & empowerment Workshop's which has allowed the beginnings of a strong volunteer network which we will support from the UK. The five cities that hosted these sessions were Chicago, Seattle, Washington, San Francisco and Boston.
- Monthly US virtual meetings began September 2023 and continue to grow and raise awareness within the USA.
- **Funded outreach project** – Two day event – Patient education and empowerment sessions day one and clinical team meetings day two to highlight the patients unmet need in itch. Nine hosting cities where Cambridge, London, Berkshire, Basingstoke, Southampton, Newcastle, Plymouth, Hull and Sheffield.
- **CGI Study** – We worked with Umeocrine Cognition throughout 2023 on their clinical trial for a drug for fatigue and brain fog. That included sourcing patients and facilitating interviews for the CGI study which is a tool for measuring symptoms such as fatigue, brain fog and itch. We also assisted in the patient recruitment for part A of the study.

- **Volunteer Conference:** 17th– 19th November 2023 in Edinburgh

Conference Outcomes

Volunteers with new and improved skill sets, empowered and confident
Meaningful 2-way conversation to inform and inspire the next generation of initiatives
Greater engagement with PBC community leading to less isolation
Improved knowledge of and access to services

- **6 new on-boarded volunteers** – Included newly introduced induction programme
- **Flagship International PBC Summit** -The Foundation is hosted its first International PBC Summit in Edinburgh, May 2023. The Summit was a series of one day events bringing together multiple stakeholders to discuss and address unmet need in PBC. Whilst attendance is face-to-face, there was some opportunity for virtual participation, and for sharing updates with the patient community at the end of each day
- **Patient Conference** - The Foundation is hosted its first PBC Patients Conference in Edinburgh, 9th and 10th Sept 2023. The conference was a two day event bringing together patients and multiple stakeholders to discuss and address unmet need in PBC. Attendance was face-to-face, including a host of smaller workshop sessions and an opportunity for sharing updates with the patient community. We had 8 companies supported our efforts and some even attended to listen to patients' first-hand and gain a better understanding of how it is living each day with PBC. We are enormously grateful that we are working together because these are the kind of working relationships that will lead to change.

Feedback;

"Better understanding of PBC, testing process and what I need to ask at consultant appointments"

"Better understanding of my partners PBC, feel less alone now I have met other partners of those with PBC."

"I have more Knowledge on the condition and now know there is support out there"

"Conference was very informative"

"As a partner of someone with PBC, the conference gave me real insight as to how PBC can affect everyday life"

"Amazing how much Knowledge and research has progressed within PBC"

"More knowledge"

"Empowered"

"Encouraged me to stay connected and share"

"Empowered, understood and built confidence"

"Made me more knowledgeable and confident in my choices I make and gave me more HOPE"

"Meeting other PBC people, I am no longer alone"

- **Helpline calls:** We strive to provide the most up-to-date accurate information to all our members and their support network of family and friends. To deal with this demand, we have maintained our 24/7 helpline services via our telephone line, emails and across our social media platforms. Throughout 2023 our staff have dealt with 1,865 helpline calls.
- **Online Services:** What has come to the fore, from patients' comments, is that they needed help to break their isolation, their feelings of hopelessness and helplessness. In 2020 we restructured and provided a number of new digital services. Throughout 2023 these services have grown in strength and support and continue to adapt and develop to meet the needs of members. Digital services include:
 - Webinars (every Thursday) Live Q&As with Medical Professionals.
 - Facebook Lives Wednesday and Friday- Informal online chat, quiz and singalong.
 - Weekly self-care focused sessions for the community – Choose me Tuesday.

Choose me Tuesday Feedback;

"You have a real ability to not only listen but to understand and encourage.... Turning round negative

"Just wanting to say thank you for tonight I really enjoyed it and found it so helpful!

A much needed reminder that I don't speak kindly to myself, it's something I struggle but it's something I am determined to work on."

- **Academic Conferences:** Due to feedback, we have successfully submitted a number of abstracts to recent academic conferences, including EASL (European Association for study of the liver) and ASSLD (American Association for the Study of Liver). These abstracts highlight the unmet need in the patient populations using both PREMS (Patient Reported Experience Measures) and PROMS (Patient Reported Outcome Measures). This feedback tells us that it is important to cover topics such as diagnosis, Urso response, symptom treatment, second-line therapies, and the importance of clinical trial opportunities being afforded to patients; these topics will be covered frequently within the programme.

- **PBC TV:** Continue to build our easy to navigate central resource of video presentations that explains the most pertinent FAQs and topics relative to PBC, accessible remotely by the worldwide community. The videos and information are invaluable so we can build up a great resource bank to help all affected by These videos allow those affected by PBC to learn from, to read others' questions, and to know there are thousands around the world who share your fears, your knowledge, and your experiences.

- **The Bear Facts:** We continued to provide our quarterly publication to over 18,000 readers. Issues included opportunities to participate in medical trials, interactive 'Q&A' sessions with our Medical Advisory Board, feedback from clinical studies and articles providing information to service users on issues such as bowels, TIPs and Sicca Syndrome.

PBC Mobile App: Our app is continually being updated with greater interactivity for users. Patients are now able to track their symptoms, mood and medicines, and answer surveys contributing anonymised data being to populate our patient registry. Patients can complete surveys which can be used to drive medical research and drug trials for PBC. We can carry out research which is centred on Patient Reported Experience Measures and Patient Reported Outcome Measures which feed into abstract submissions for improving patient care

MONITORING & EVALUATION

In order to ensure that we are addressing the needs of PBC sufferers as best we can, our work is regularly reviewed by our Board of Directors, Medical Advisory Board, volunteers and service users.

To ensure that our service users and volunteers can feed back to us as openly and honestly as possible, we continued to utilize a wide range of feedback systems, from direct communication to anonymous online surveys.

Recent research, used to determine if our services were able to meet EASL recommendations of supporting people with PBC, noted that:

- 83.8% either agreed or strongly agreed that accessing PBC Foundation Services had enabled them to manage their symptoms better.
- 93.65% either agreed or strongly agreed that accessing PBC Foundation services had enabled them to make more informed decisions about their PBC and its treatment.
- 90.6% either agreed or strongly agreed that accessing the PBC Foundation services had reduced their sense of isolation.

Additionally, service users tell us in their own words how grateful they are for the support and information that we provide:

- "The PBC Foundation is a lifeline and I feel they are there whenever I may need to access them."
- "Great supportive service, full of knowledge and assistance."
- "They are wonderful. I have learned so much about this disease as well as great advice from the Q&A and reading other people's thoughts who have PBC."
- "I do not feel so isolated."
- "I now have a better understanding of what PBC is."

FINANCIAL REVIEW

This year, our total income was £679,197 (2022 - £586,060) which resulted in a deficit of £96,644 (2022 - £138,370 surplus). Our funds at 31 December 2023 were £298,049 (2022 - £394,693) of which £231,396 (2022 - £310,521) represented unrestricted funds and £66,653 (2022 - £84,172) restricted funds.

Grant Making Policy

Research grants are made after advertisement of their availability in the appropriate medical press. Applications are then reviewed by the Foundation's Medical Advisory Committee using a recognised peer review process, in accordance with the Association of Medical Research Charities requirements.

Reserves Policy

The purpose of the reserves is to ensure that the PBC Foundation is able to meet its obligations against decline or interruptions in income, which is of particular concern during a recession. The risk to the PBC Foundation's income stream is that the donations may drop in value, and that the support provided by way of sponsorship is discontinued. The Foundation has no stocks or shares to generate income. At year end, we held £231,396 of unrestricted reserves, which equates to approximately six months' running costs. At year end, we also held £66,653 restricted reserves.

Principal source of funding

In the last financial year, our team raised a total of £266,585 from grant-giving bodies. The PBC Foundation would therefore like to thank the following grant-makers for their support:

UK Charitable Trusts

Davidson Nairn Charitable Trust, Holehird, JTH, Adnams Community trust, Aberbrothock Skea Trust, Mayor of Sefton, Sheffield Church Burgesses Trust, Daisy Trust, The Basil Death Trust, The Burges Salmon Charitable Trust, Prudential Small Donations Fund, Saints & Sinners Club Of Scotland, F Glenister Woodger, Dounreay Communities Fund, Halifax foundation, Sovereign Healthcare Community, The Pilkington Charities Fund, Forth Ports, Alexander Moncur Trust, Jimmie Cairncross Charitable Trust, Scottish Executive, Awards for all Northern Ireland, Glasgow commonwealth fund, Isabel Blackman Foundation, The Sir James Knott Trust, House of Industry, Enkalon, Shanly Foundation (The Michael Shanly Charitable Trust).

Corporate

Escient, Mirum Pharma, Dr Falk Pharma UK Ltd, Umecrine Cognition, Calliditas Therapeutics, Intercept Pharmaceuticals, Cymabay, GSK, Parvus, Advanz Pharma UK and Ireland Ltd.

Statutory

Royal Leamington Spa Town Council Community Grant, Belfast City Council

In Gratitude

We would like to thank all of our unpaid but highly valued volunteers in whatever capacity they have helped us, including our Board of Trustees, International Medical Advisory Board, regional and office volunteers, fundraisers and service users who have assisted us over the course of 2023.

We also thank the PBC Community around the world, particularly the patients who inspire us to be the best we can be.

FUTURE PLANS

In 2024, we shall continue our online services but shall also aim to bring back physical face to face services. Our intentions are to:

- The Foundation is hosting its second International PBC Summit in Edinburgh, April 2024. The Summit is a series of one day events bringing together multiple stakeholders to discuss and address unmet need in PBC
- PBC Patients Conference - Flag ship event in PBC. The Foundation is hosting its second PBC Patients Conference in Edinburgh, 7th and 8th Sept 2023. The conference is a two day event bringing together patients and multiple stakeholders.
- Volunteer conference - we will be hosting our Volunteers conference 9th – 10th Nov. The data tells us there is much more to be done to improve quality of life for PBC patients and the Volunteer Network is a huge part of that.
- Newly created 6 week self- care focussed programme delivered online.
- CGI Study - Moving in to 2024 we are carrying out more patient interviews to finalise the CGI tool along with assisting on recruitment for part B. We are also coaching other patient organisations in Europe on the method we used for recruitment so this can also be actioned in their areas.
- URSO calculator to be made available in Hebrew, Italian, German, Spanish, Bulgarian with support from PAGs
- Self-care Workshop's for 2024 to be carried out in Northern Ireland, wales, Scotland and England
- Weekly PBC Community Café beginning April 2024
- Introduction of family and friends monthly online sessions
- Continue to recruit and train new regional volunteers – Two scheduled to begin the induction programme April 2024.
- Train, support and develop volunteers on a number of volunteer-specific issues, e.g. holding local meetings F2F and online.
- Revised volunteer handbook to be launched, co-designed with volunteers.
- Engage with a wide range of stakeholders to drive forward improvements in the daily quality of life for PBC patients.
- Highlight use of the App and lay guidelines at workshops and online sessions.
- Build and support our UK and international membership and its App engagement.
- Partner with the pharmaceutical industry to develop surveys highlighting the patient experience, and unmet needs.
- Produce further data, e.g. in abstract form, from the App, to improve the patient experience.
- Highlight PBC Foundation services across all media channels, we will continue to present our research at a national and international level.
- Continue to support all those affected by PBC.
- Continue to represent the patient voice on national and international committees.

- Participate proactively at the EASL and BASL annual meetings.
- Attend physical patient
- organisation collaborative meetings (e.g. LPI annual conference in Europe).
- To safeguard the provision of valuable core services and the continued development of multi-channel communication. Unrestricted reserves contain 'designated funds' allocating specific amounts towards certain activities in 2024, as follows:
 - Website £3,480
 - Leaflets £2,021
 - Academic Conferences £54,867
 - Patient Support Services £14,725
 - Website Languages £15,000
 - Total £90,093

The purposes of these designated funds are detailed in note 18 of the accounts.

STRUCTURE, GOVERNANCE & MANAGEMENT

The PBC Foundation was initially a Charitable Trust and was established by deed of trust granted by the Trustees in November 1996. On 26 May 2000, the charity was incorporated as a Private Limited Company, which is limited by guarantee, and is governed by our Memorandum and Articles of Association. Under this governing document, the Trustees are not permitted to engage in permanent trading activities in the name of the Foundation. Reference and administrative details are shown in the schedule of members of the Board and Professional Advisors in the Financial Statements.

Governance

Our Board of Directors, which governs the organisation, consists of nine members (four of whom are PBC sufferers) who meet quarterly to ensure that the organisation operates in accordance with the Companies Act 2006, the Charities Accounts (Scotland) Amendment Regulations 2007 and the Charities Accounts (Scotland) Amendment Regulations 2010. Management accounts are prepared and circulated to the Board on a monthly basis.

Additional Committees

- **Finance Committee:** quorum of directors with financial experience, supported by specialist financial advisors, who advise the Board of Directors on financial matters.
- **Medical Advisory Board:** group of medical experts who advise the Board of Directors on issues relating to medical information, medical advice, and research. They peer review our medical publications, and applications for research grants.

Management

The Chief Executive Officer, Robert Mitchell Thain, is responsible for the routine management of the organisation. The CEO is accountable to the Board of Directors.

Risk management

The Trustees evaluate risks to the Foundation at least four times a year. The main risk is that income from donations and fundraising is not sufficient to cover our expenses. The Trustees are ready to take appropriate action in the event that the financial position of the Foundation becomes seriously threatened. Procedures are in place to ensure the compliance with health and safety of staff, volunteers and others.

Staff and volunteers

The charity is grateful for the tireless efforts of its appointed staff and volunteers who are involved in administration, service delivery and fundraising.

Service users and their representation

We are a community organisation, consisting of over 18,000 service users in 80 countries worldwide, including 13,000 in the UK, who rely on our services for support and information. As such, we provide support to more than half of the estimated 20,000 PBC sufferers in the UK. In order to ensure that our services continue to be provided in the best interests of people diagnosed with PBC we regularly seek feedback, both directly from users and through the 30 regional volunteers at our Annual Volunteers' Conference. Further to this, our head of Patient Services and two directors, all of whom have PBC, provide representation of these interests on the Board of Directors.

STATEMENT OF TRUSTEES RESPONSIBILITIES

The Trustees (who are also the Directors of The PBC Foundation for the purposes of company law) are responsible for preparing the Trustees' Annual Report, and the financial statements in accordance with applicable law and UK Accounting Standards.

Company law requires the Trustees to prepare financial statements for each financial year, which give a true and fair view of the state of affairs of the charitable company. In preparing these statements, 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 which are reasonable and prudent.
- State whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements.
- Prepare the financial statements on the going concern basis, unless it is inappropriate to presume that the charitable company will continue in operation.
- Safeguard the assets of the charitable company, and hence taking reasonable steps for the prevention of fraud and other irregularities.

In so far as the Trustees are aware:

- There is no relevant information of which the charitable company's auditor is unaware.
- The Trustees have taken all steps that they ought to have taken to make themselves aware of any relevant information, and to establish that the auditor is aware of that information.

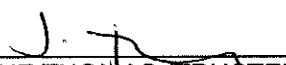
RE-APPOINTMENT OF AUDITORS

The re-appointment of the auditor, Ballards LLP, for the ensuing year will be considered, and if agreed, will be proposed at the Annual General Meeting.

SMALL COMPANY EXEMPTIONS

This report has been prepared in accordance with the provisions for small companies under Part 15 of the Companies Act 2006.

ON BEHALF OF THE BOARD OF DIRECTORS:



JANE THOMAS (TRUSTEE)

Independent Auditor's Report to the Trustees and Members of PBC Foundation (UK) Limited

Opinion

We have audited the financial statements of PBC Foundation (UK) Limited (the 'charitable company') for the year ended 31 December 2023 which comprise the Statement of Financial Activities, Balance Sheet, Statement of Cash Flows and Notes to the Financial Statements, including significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 *The Financial Reporting Standard applicable in the UK and Republic of Ireland* (United Kingdom Generally Accepted Accounting Practice).

This report is made solely to the charitable company's trustees, as a body, in accordance with the Charities and Trustee Investment (Scotland) Act 2005. Our audit work has been undertaken so that we might state to the charity's trustees those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and its trustees as a body, for our audit work, for this report, or for the opinions we have formed.

In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 December 2023, and of its results, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the auditor responsibilities for the audit of the financial statements section of our report. We are independent of the charitable company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charitable company's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Other information

The other information comprises the information included in the trustees' annual report, other than the financial statements and our auditor's report thereon. The trustees are responsible for the other information. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the course of the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the trustees' report, which includes the strategic report and the directors' report prepared for the purposes of company law, for the financial year for which the financial statements are

• Independent Auditor's Report to the Trustees and Members of PBC Foundation (UK) Limited (continued)

Matters on which we are required to report by exception

In the light of the knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the strategic report or the directors' report included within the trustees' report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 and the Charities Accounts (Scotland) Regulations 2006 requires us to report to you if, in our opinion:

- adequate and proper accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit.

Responsibilities of trustees

As explained more fully in the trustees' responsibilities statement, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charitable company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

Auditor responsibilities for the audit of the financial statements

We have been appointed as auditor under section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and under the Companies Act 2006 and report in accordance with the Acts and relevant regulations made or having effect thereunder.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

(Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud). The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

In identifying and assessing risks of material misstatement in respect of irregularities, including fraud and non-compliance with laws and regulations, we considered the following:

- the nature of the sector, control environment and charitable company performance;
- results of our enquiries of management about their own identification and assessment of the risks of irregularities;
- any matters we identified having obtained and reviewed the company's documentation of their policies and procedures relating to: – identifying, evaluating and complying with laws and regulations and whether they were aware of any instances of non-compliance; – detecting and responding to the risks of fraud and whether they have knowledge of any actual, suspected or alleged fraud; – the internal controls established to mitigate risks of fraud or non-compliance with laws and regulations;
- the matters discussed among the audit engagement team regarding how and where fraud might occur in the financial statements and any potential indicators of fraud.

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk is also greater regarding irregularities occurring due to fraud rather than error, as fraud involves intentional concealment, forgery, collusion, omission or misrepresentation.

As part of an audit in accordance with ISAs (UK), we exercise professional judgment and maintain professional scepticism throughout the audit. We also:

- Independent Auditor's Report to the Trustees and Members of PBC Foundation (UK) Limited (continued)
- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the charitable company's internal control.
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the trustees.
- Conclude on the appropriateness of the trustees' use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the charitable company's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related disclosures in the financial statements or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report. However, future events or conditions may cause the charitable company to cease to continue as a going concern.
- Evaluate the overall presentation, structure, and content of the financial statements, including the disclosures, and whether the financial statements represent the underlying transactions and events in a manner that achieves fair presentation (ie. gives a true and fair view).

We communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identify during our audit.

Use of our report

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006, and to the charitable company's trustees, as a body, in accordance with Regulation 10 of the Charities Accounts (Scotland) Regulations 2006. Our audit work has been undertaken so that we might state to the charitable company's members and trustees those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company, the charitable company's members as a body and the charitable company's trustees as a body, for our audit work, for this report, or for the opinions we have formed.



M A Skellum (Senior Statutory Auditor)
For and on behalf of Ballards LLP, Statutory Auditor

Oakmoore Court
11C Kingswood Road
Hampton Lovett
Droitwich
Worcestershire
WR9 0QH

Date: 26/9/24

PBC Foundation (UK) Limited

Statement of Financial Activities
(Incorporating an Income and Expenditure Account)
for the Year Ended 31 December 2023

		31.12.23			31.12.22	
		Unrestricted Funds	Designated funds	Restricted Funds	Total Funds	Total Funds
	Notes	£	£		£	£
INCOME FROM						
Donations and other fundraising	3	604,329	-	67,786	672,115	502,506
Other trading activities	4	4,462	-	-	4,462	83,479
Investment income	5	<u>2,620</u>	<u>-</u>	<u>-</u>	<u>2,620</u>	<u>75</u>
Total		<u>611,411</u>	<u>-</u>	<u>67,786</u>	<u>679,197</u>	<u>586,060</u>
EXPENDITURE ON						
Cost of generating voluntary income	6	61,908	129	-	62,037	50,568
Charitable activities	7	<u>555,172</u>	<u>57,128</u>	<u>101,504</u>	<u>713,804</u>	<u>397,122</u>
Total		<u>617,080</u>	<u>57,257</u>	<u>101,504</u>	<u>775,841</u>	<u>447,690</u>
NET INCOME/(EXPENDITURE)		(5,669)	(57,257)	(33,718)	(96,644)	138,370
Transfers between funds		<u>(43,806)</u>	<u>27,607</u>	<u>16,199</u>	<u>-</u>	<u>-</u>
Net movement in funds		(49,475)	(29,650)	(17,519)	(96,644)	138,370
RECONCILIATION OF FUNDS						
Total funds brought forward		190,778	119,743	84,172	394,693	256,323
TOTAL FUNDS CARRIED FORWARD		<u>141,303</u>	<u>90,093</u>	<u>66,653</u>	<u>298,049</u>	<u>394,693</u>

PBC Foundation (UK) Limited

Balance Sheet
As at 31 December 2023

	Notes	31.12.23 £	31.12.22 £
FIXED ASSETS			
Tangible fixed assets	13	3,793	6,428
Intangible fixed assets	14	<u>24,805</u>	<u>13,560</u>
		28,598	19,988
CURRENT ASSETS			
Stocks		604	884
Debtors	15	68,254	74,128
Cash at bank and in hand		<u>248,719</u>	<u>343,980</u>
		317,577	418,992
CREDITORS			
Amounts falling due within one year	16	<u>(48,126)</u>	<u>(44,287)</u>
NET CURRENT ASSETS		<u>269,451</u>	<u>374,705</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		<u>298,049</u>	<u>394,693</u>
NET ASSETS		<u>298,049</u>	<u>394,693</u>
FUNDS			
Unrestricted funds	17,18	231,396	310,521
Restricted funds	17,18	<u>66,653</u>	<u>84,172</u>
TOTAL FUNDS		<u>298,049</u>	<u>394,693</u>

These financial statements have been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small charitable companies.

The financial statements were approved by the Board of Trustees on and were signed on its behalf by:



FEROZ A SULTAN
TRUSTEE

PBC Foundation (UK) Limited

Cash Flow Statement

As at 31 December 2023

	31.12.23	31.12.22
	£	£
Net income/(expenditure) for the reporting period	(96,644)	138,370
Adjustment to cash flows from non-cash items:		
Depreciation and amortisation	4,890	8,222
(Increase)/decrease in stock	280	(613)
(Increase)/decrease in debtors	5,874	(67,087)
Increase/(decrease) in creditors	<u>3,838</u>	<u>(64,920)</u>
Net cash provided by (used in) operating activities	<u>(81,762)</u>	<u>13,972</u>
Cash flow from investing activities		
Purchase of property, plant and equipment	-	(5,712)
Purchase of intangible fixed assets	<u>(13,500)</u>	<u>(13,560)</u>
Net cash provided by (used in) investing activities	<u>13,500</u>	<u>19,272</u>
Change in cash and cash equivalents in the reporting period	(95,262)	(5,300)
Cash and cash equivalents at the beginning of the reporting period	<u>343,980</u>	<u>349,280</u>
Cash and cash equivalents at the end of the reporting period	<u>248,718</u>	<u>343,980</u>

1. LEGAL STATUS

The charity was incorporated as a private company, limited by guarantee, and governed by its memorandum and articles. The liability of the members is restricted to £1 each.

2. ACCOUNTING POLICIES

Basis of preparing the financial statements

The financial statements of the charitable company, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP 'Accounting and Reporting by Charities: Statement of Recommended Practice (2019), the Charities and Trustee Investment (Scotland) Act 2005 and the Companies Act 2006. The financial statements have been prepared under the historical cost convention.

Income

Income is recognised in the statement of financial activities in the period in which the charity is entitled to receipt and the amount can be measured with reasonable certainty.

Income is deferred only when the charity has to fulfil conditions before becoming entitled to it or where the donor has specified that the income is to be expended in a future period.

The following specific policies are applied to particular categories of income:

Legacies are brought into account when the charity is advised of an intended payment or transfer and has a reasonable estimate of the sum involved.

Donated services and facilities are included at the value to the charity where this can be quantified. The value of services provided by volunteers has not been included in these accounts

Expenditure

Expenditure is recognised in the period in which it is incurred and includes attributable vat which cannot be reclaimed.

Costs of generating funds comprise those costs associated with generating incoming resources from all sources other than undertaking charitable activities. It includes both costs that can be allocated directly as well as costs of an indirect nature.

Charitable activity expenditure comprises those costs incurred by the charity in the delivery of its objectives and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

All costs are allocated between costs of generating funds and the charitable activities on the basis of management's estimation of staff time or usage with the exception of project officer overheads and magazine costs. Project officer overheads are allocated on grant award budgeted figures and magazine costs are split between Awareness/ Helpline and Support activities on a percentage basis. Support costs are allocated to activities on the basis of staff time or usage.

Governance costs include those costs associated with meeting the constitutional and statutory requirements of the charity and include the independent examination fees.

Grants offered subject to conditions which have not been met at the year end date are noted as a commitment but not accrued as expenditure.

Tangible fixed assets

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

Plant and office equipment - 33% on cost

A part year's depreciation is charged when an asset is purchased during the year.
All fixed assets over £1,000 are initially recorded at cost.

2. ACCOUNTING POLICIES - continued

Intangible fixed assets

Amortisation is provided at the following annual rates in order to write off each asset over its estimated useful life.

Intangible fixed assets - 33% on cost

Amortisation begins when the intangible asset is available for use, ie when it is in the location and condition necessary for it to be usable in the manner intended.

Stocks

Stocks are valued at the lower of cost and net realisable value, after making due allowance for obsolete and slow moving items.

Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discounts offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

Creditors

Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

Pension costs and other post-retirement benefits

The charity operates a defined benefit pension scheme. Contributions payable to the charity's pension scheme are charged to the Statement of Financial Activities in the period to which they relate.

Taxation

The charity is exempt from corporation tax on its charitable activities.

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees. Unrestricted funds include designated funds, where the trustees, at their discretion, have created funds for specific purposes.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for specific purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

3. DONATIONS AND OTHER FUNDRAISING

	Unrestricted funds £	Restricted funds £	31.12.23 Total funds £	31.12.22 Total funds £
Donations	84,794	600	85,394	98,949
Legacies	9,313	-	9,313	8,500
Grants	199,399	67,186	266,585	216,171
Annual raffle	1,768	-	1,768	1,912
General sponsorship and fundraising	<u>309,055</u>	<u>-</u>	<u>309,055</u>	<u>176,974</u>
	<u>604,329</u>	<u>67,786</u>	<u>672,115</u>	<u>502,506</u>

PBC Foundation (UK) Limited

Notes to the Financial Statements - continued
for the Year Ended 31 December 2023

3. DONATIONS AND OTHER FUNDRAISING (CONTINUED)

Grants of £10,000 or more, received in each financial year, included in the above, are as follows:

	Unrestricted funds	Restricted funds	31.12.23 Total funds	31.12.22 Total funds
	£	£	£	£
Intercept Pharmaceuticals	-	38,000	38,000	35,000
Glaxo Smithkline	-	-	-	33,350
CymaBay Therapeutics	-	10,000	10,000	14,185
Dr Falk Pharma	12,000	-	12,000	15,000
Umecrine Cognition	113,241	-	113,241	19,994
Advanz Pharma	35,000	-	35,000	-
Other grants	<u>39,158</u>	<u>19,186</u>	<u>58,344</u>	<u>98,642</u>
	<u>199,399</u>	<u>67,186</u>	<u>266,585</u>	<u>216,171</u>

4. OTHER TRADING ACTIVITIES

	Unrestricted funds	Restricted funds	31.12.23 Total funds	31.12.22 Total funds
	£	£	£	£
App licence fees	-	-	-	80,000
Sale of goods	1,030	-	1,030	1,854
Consultancy	<u>3,432</u>	-	<u>3,432</u>	<u>1,625</u>
	<u>4,462</u>	-	<u>4,462</u>	<u>83,479</u>

5. INVESTMENT INCOME

	Unrestricted funds	Restricted funds	31.12.23 Total funds	31.12.22 Total funds
	£	£	£	£
Deposit account interest	<u>2,620</u>	-	<u>2,620</u>	<u>75</u>

6. RAISING FUNDS

	Direct costs	Support costs	31.12.23 Total funds	31.12.22 Total funds
	£	£	£	£
Costs of generating voluntary income (see note 8)	<u>53,956</u>	<u>8,081</u>	<u>62,037</u>	<u>50,568</u>

PBC Foundation (UK) Limited

Notes to the Financial Statements - continued
for the Year Ended 31 December 2023

7. CHARITABLE ACTIVITIES COSTS

	Direct costs	Support costs (See note 8)	Totals	31.12.22 Totals
	£	£	£	£
Awareness	193,492	12,173	205,665	107,079
Patient support and helpline	334,324	55,765	390,089	254,561
Health and professional information	60,633	3,232	63,865	31,114
Research	<u>52,573</u>	<u>1,612</u>	<u>54,185</u>	<u>4,368</u>
	<u>641,022</u>	<u>72,782</u>	<u>713,804</u>	<u>397,122</u>

8. SUPPORT COSTS

	Management	Governance costs	Totals
	£	£	£
Costs of generating voluntary income	6,959	1,122	8,081
Awareness	10,490	1,683	12,173
Patient support and helpline	48,023	7,742	55,765
Health and professional information	2,783	449	3,232
Research	<u>1,388</u>	<u>224</u>	<u>1,612</u>
	<u>69,643</u>	<u>11,220</u>	<u>80,863</u>

Support costs are allocated to activities on the basis of staff time or usage.

9. NET EXPENDITURE

Net expenditure is stated after charging

	31.12.23	31.12.22
	£	£
Depreciation - owned assets	2,635	1,155
Amortisation – owned assets	2,255	7,067
Auditors fee	<u>10,000</u>	<u>10,500</u>

10. TRUSTEES' REMUNERATION AND BENEFITS

None of the trustees received any remuneration or benefits (2022 nil) in respect of their position as trustees and no expenses were paid to trustees in the year ended 31 December 2023 (2022 nil).

David Sutherland, a trustee, received consultancy fees of £24,890 (from May 2022 £14,890).

PBC Foundation (UK) Limited

Notes to the Financial Statements - continued
for the Year Ended 31 December 2023

11. STAFF COSTS

	31.12.23	31.12.22
	£	£
Wages and salaries	295,730	220,161
Social security costs	25,949	17,110
Pension costs	<u>2,955</u>	<u>1,952</u>
	<u>324,634</u>	<u>239,223</u>

The value of the many and valued services provided by volunteers has not been included in these accounts.

The average monthly number of employees during the year was 8 (2022 - 6)

The key management personnel comprise of the Trustees and the Chief Executive Officer. Total remuneration paid to key management personnel in the year was £90,619 (2022 - £47,255)

The number of employees whose remuneration (salary, employer's ni and pension contributions) fell within the following bands:

	31.12.23	31.12.22
£60,000 - £69,999	1	-
£90,000 - £99,999	1	-

12. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

The Statement of Financial Activities for the year to 31 December 2023 on page 12 distinguishes between unrestricted and restricted funds. The comparative breakdown for the previous year is as follows:

	Unrestricted funds	Restricted funds	Total funds
	£	£	£
INCOME FROM			
Donations and other fundraising	430,407	72,099	502,506
Other trading activities	83,479	-	83,479
Investment income	<u>75</u>	<u>-</u>	<u>75</u>
Total	<u>513,961</u>	<u>72,099</u>	<u>586,060</u>
EXPENDITURE ON			
Raising funds	50,568	-	50,568
Charitable activities	<u>311,300</u>	<u>85,822</u>	<u>397,122</u>
Total	<u>361,868</u>	<u>85,822</u>	<u>447,690</u>
NET INCOME	152,093	(13,723)	138,370
Transfer between funds	<u>-</u>	<u>-</u>	<u>-</u>
Net movement in funds	152,093	(13,723)	138,370
RECONCILIATION OF FUNDS			
Total funds brought forward	<u>158,428</u>	<u>97,895</u>	<u>256,323</u>

PBC Foundation (UK) Limited

Notes to the Financial Statements - continued
for the Year Ended 31 December 2023

13. TANGIBLE FIXED ASSETS

	Office equipment £
COST	
At 1 January 2023	71,211
Additions	<u>-</u>
At 31 December 2023	<u>71,211</u>
DEPRECIATION	
At 1 January 2023	64,783
Charge for year	<u>2,635</u>
At 31 December 2023	<u>67,418</u>
NET BOOK VALUE	
At 31 December 2023	<u>3,793</u>
At 31 December 2022	<u>6,428</u>

14. INTANGIBLE FIXED ASSETS

	£
COST	
At 1 January 2023	116,040
Additions	<u>13,500</u>
At 31 December 2023	<u>129,540</u>
AMORTISATION	
At 1 January 2023	102,480
Charge for year	<u>2,255</u>
At 31 December 2023	<u>104,735</u>
NET BOOK VALUE	
At 31 December 2023	<u>24,805</u>
At 31 December 2022	<u>13,560</u>

15. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	31.12.23	31.12.22
	£	£
Trade debtors	55,000	63,011
Other debtors	<u>13,254</u>	<u>11,117</u>
	<u>68,254</u>	<u>74,128</u>

PBC Foundation (UK) Limited

Notes to the Financial Statements - continued
for the Year Ended 31 December 2023

16. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	31.12.23	31.12.22
	£	£
Trade creditors	15,788	12,448
Social security and other taxes	8,006	7,475
Accruals and deferred income	23,770	24,123
Other creditors	<u>562</u>	<u>241</u>
	<u>48,126</u>	<u>44,287</u>

17. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	Unrestricted funds	Restricted funds	31.12.23	31.12.22
	£	£	Total funds	Total funds
	£	£	£	£
Fixed assets	28,513	85	28,598	19,988
Current assets	251,009	66,568	317,577	418,992
Current liabilities	<u>(48,126)</u>	<u>-</u>	<u>(48,126)</u>	<u>(44,287)</u>
	<u>231,396</u>	<u>66,653</u>	<u>298,049</u>	<u>394,693</u>

18. MOVEMENT IN FUNDS

	At 1.1.23	Income	Expenditure	Transfers	At 31.12.23
	£	£	£	£	£
Unrestricted funds					
PBC Conference	14,903	-	(42,510)	27,607	-
Website	4,340	-	(860)	-	3,480
Leaflets	2,775	-	(754)	-	2,021
Academic Conferences	68,000	-	(13,133)	-	54,867
Patient Support Services	14,725	-	-	-	14,725
Website-Languages	<u>15,000</u>	<u>-</u>	<u>-</u>	<u>-</u>	<u>15,000</u>
Total Designated Funds	119,743	-	(57,257)	27,607	90,093
General Fund	<u>190,778</u>	<u>611,411</u>	<u>(617,080)</u>	<u>(43,806)</u>	<u>141,303</u>
Total Unrestricted Funds	<u>310,521</u>	<u>611,411</u>	<u>(674,337)</u>	<u>(16,199)</u>	<u>231,396</u>
Restricted funds					
Research	11,083	600	(5,005)	-	6,678
The Bear Facts	-	4,645	(5,167)	522	-
Workshops	36,351	7,416	(29,841)	40	13,966
Nursing in Practice	1,696	-	-	-	1,696
United States Workshops	-	38,000	(53,607)	15,607	-
Volunteer Training	582	-	(497)	-	85
App Project	15,000	-	-	-	15,000
Learning Portal	19,228	-	-	-	19,228
Webinars & Facebook Sessions	232	-	(232)	-	-
Scottish Government	-	7,125	(7,155)	30	-
Webinars & Translation Services	-	10,000	-	-	10,000
	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>
Total Restricted Funds	<u>84,172</u>	<u>67,786</u>	<u>(101,504)</u>	<u>16,199</u>	<u>66,653</u>
TOTAL FUNDS	394,693	679,197	775,841	-	298,049

18. MOVEMENT IN FUNDS -continued

Unrestricted Funds

Unrestricted funds are available for use at the discretion of the trustees in furtherance of the general objectives of the company.

Certain of the unrestricted fund balances have been used to create designated funds. These are unrestricted funds earmarked by the trustees for particular purposes.

The designation does not represent a restriction upon the use of these funds but represents the intention of the trustees regarding utilisation of the charity's resources.

The nature and purpose of the various unrestricted funds are noted as follows:

PBC Conference- For costs of the end of year members conference.

Website – To cover the costs of updating graphics and images, rolling banners and buttons.

Leaflets – For costs to update all 4 existing leaflets design and content in both hard copy and digital format.

Academic Conferences - To cover the costs of attending various academic conferences

Patient Support Services - To cover the costs of the various patient support services provided by the Foundation.

Website Languages - To cover the costs of translating the website into various languages.

Restricted Funds

The nature and purpose of the various restricted funds are noted as follows:

Research – To promote research into the condition of Primary Biliary Cholangitis and any other related conditions.

The Bear Facts – Publication of the quarterly magazine.

Workshops – Funding of self-management workshops for service users.

United States Workshops – Funding from Intercept Practice of self-management workshops for service users in the USA.

Nursing in Practice - Funding towards the cost of a Nursing In Practice event in Cardiff.

Volunteer training – Funding to assist in face to face and online training of volunteers to assist with the PBC Foundation.

App project – A project to create a PBC app for service users.

Learning portal – Funding from Intercept Practice and Policy for online GP education.

Helpline and Online Services – Funding to assist in the provision of services to members via various platforms on a 24/7 basis.

Webinars and Facebook Sessions – Funding to support the provision of weekly webinars, Thursday live, interactive Q&A webinars and informal Facebook sessions.

Scottish Government – Funding to assist with online digital sessions.

Website & Translation Services- Funding from CymaBay to cover the costs of translating the website into various languages.

PBC Foundation (UK) Limited

Notes to the Financial Statements - continued
for the Year Ended 31 December 2023

19. RELATED PARTY DISCLOSURES

One family member of David Sutherland, trustee, was employed by the Charity on a full time basis and received total emoluments of £39,222 (2022 £35,144).