

PBC FOUNDATION (UK) LIMITED

Trustees Annual Report & Accounts

for the year ended
31 December 2021

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 2021.

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Charity Name:	PBC Foundation (UK) Limited
Charity No.:	SC025619
Company Registration No.:	SC207493
Head Office and Registered Office:	2 nd Floor 6 Hill Street Edinburgh EH2 3JZ
Trustees:	Eileen Brownlie WS Collette A Thain MBE (resigned 21 May 2022) Professor James Neuberger Dr. George Mells MRCP Professor David Jones OBE Adrian C Innes (resigned 7 March 2022) David H Campbell NP Lynn Warren Sharon Stuart (resigned 13 April 2022) Jane Thomas Goksel Osman Louise Ferguson Bryan Rankin (appointed 26 February 2022)
Secretary:	David H Campbell NP
Independent Examiner:	Helen Lowe Limited 17-21 East Mayfield Edinburgh EH9 1SE
Bankers:	Virgin Money 83 George Street Edinburgh EH2 3ES
Solicitors:	Anderson Strathern 1 Rutland Court Edinburgh EH3 8EY

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. The Covid 19 pandemic continued to bring great uncertainty and we continually reviewed the changing needs and challenges of our membership.

- **Expanding our community:** Our small, Edinburgh-based team made every effort to reach out and support as many people affected by PBC globally as possible. In 2021, we welcomed 917 new service users to our Foundation. 448 of those registered were from the UK, whilst 469 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.
- **Website:** 102,800 users in 2021.
- **Global reach:** Strong digital engagement and 121,400 people reached with up-to-date and accurate information.
- **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 2021 our staff have dealt with 3,165 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 2021 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 Tuesday and Thursday) with Medical Professionals and guest speakers.
 - Facebook Lives Monday and Wednesday - Informal online coffee and a chit-chat.
- **Facebook Live:** During 2021 we hosted 175 Facebook Live interactive chats. An informal format where either our Head of Education and Development or our CEO hosts a chat with service users typing their responses. The videos are live and are recorded and shared afterwards. The sessions are interactive and light-hearted. The staff and members take part in quizzes, sing-alongs, chatter etc., which injects some fun and variety into the day whilst relieving stress and anxiety. This is proving a huge benefit to all sufferers particularly those who feel fear, uncertainty or isolation; through lack of family, or are experiencing shielding, quarantine or Covid-related social-isolation.

- **Webinars:** In 2021 we hosted 72 webinars; 49 Q&A Healthcare webinars and 23 Interactive self-management online sessions – adapting our face-to-face workshops for a wider reach. On Tuesdays the sessions are hosted by our Head of Education and Development and CEO and cover many aspects of self-management - physical, emotional and psychological - whilst living with PBC during the Covid era. Thursday sessions cover the latest Covid-19 news and any specialised medical information to PBC sufferers in a live, interactive Q&A format. These webinars are vital to show how varied the PBC journey is and how heterogeneous PBC is, as a disease. These sessions are with our CEO, a patient of some 26 years and a pre-eminent PBC specialist, virologist, etc.
- **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 Diseases). 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.
- **International PBC Day:** 2021 was the year to take what we knew, and to share it with the PBC community in bite-size chunks. As ever, there was a vastly knowledgeable, well respected international guest list who shared with you their knowledge. We released an entire series of short videos (under 15 minutes each) which covered a wide range of topics and saved them onto our YouTube channel. We drew upon our very successful "Word of the Day" and "Myth busting" campaigns from social media and shared these on our social media channels.
The first section we released were the "PBC and..." range of videos. PBC and Itch. PBC and Pregnancy. PBC and Men. PBC and Liver Tests. PBC and Urso response. PBC and Transplant.
As promised, PBC Day is not just for PBC Day so we continue to add to these videos. The second series we shared with you was "This is PBC". Again, approximately 10 minutes long, this is a series of introductions to PBC with slides in English and the voiceover in a range of languages from local doctors. The third series of videos was "PBC in my Locale". Now, for some the word "Locale" may mean country. For others, it may mean state or region. For others again, it may mean the Hospital. What we hope we have achieved is to show you best practice in your locale so that you are empowered to ensure you experience this best practice in your own PBC journey.
We have the opportunity to make a difference together. The videos and information are invaluable so we can build up a great resource bank to help all affected by PBC. On the day itself even if members were in the tightest lockdown imaginable, they could still have the opportunity to join, to watch, to learn and to share.
- **PBC TV:** We created an 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. International PBC Day's series of videos is presented by leading global PBC experts and provides a launch pad for the ongoing provision of vital education to our community on relevant and current topics. 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 12,000 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 used to populate a 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.

- **Digital Services Survey:** When the COVID pandemic emerged and continued to dictate our way of living, we had to adapt to design and deliver new online and remote services. This was to ensure patients could continue to access our invaluable core services whilst receiving new and enhanced support from the Foundation to overcome the added burdens of increased isolation and limited access to healthcare practitioners and treatment. The feedback we have received within our survey has been overwhelmingly positive and will help us to shape services going forward.

- 53.06% state that their online usage had increased or greatly increased during the Covid pandemic.
- 80.58% felt accessing PBC Services reduced their sense of isolation
- Accessing PBC Services has helped me manage my symptoms. 56.02% agreed, 27.08% strongly agreed
- 95.04% felt the PBC Foundation's online services have empowered the PBC community
- 79.01% felt the PBC Foundation's online services have empowered you individually

Of those who have been diagnosed for two years or less;

- 88.89% felt accessing PBC Services has reduced their sense of isolation
- 88.71% accessing PBC Services has helped them manage their symptoms
- 93.65% accessing PBC Services has helped them make more informed decisions about their PBC care.
- 85.94% believe the online services has empowered them individually
- 93.33% feel the App has empowered the PBC community

Most of these sufferers have had to deal with being newly diagnosed then live through the Covid-19 pandemic with limited or no access to their Doctor. This data shows how invaluable and important the PBC Foundation is for providing up to date and accurate information and support, especially in these uncertain of times.

Of those who attended a Live Chit Chat session during the Covid pandemic;

- 61.73% access PBC at least once a week or more
- 100% believe online services has empowered the PBC community
- 95% feel empowered individually by the online sessions

Of those who attended a Clinician Q&A online session during the Covid pandemic;

- 63.16% access PBC at least once a week or more
- 98.95% believe online services has empowered the PBC community
- 94.74% feel empowered individually by the online sessions

It is clear to see that as we have faced the toughest 20 months of many of our lives online and digital support has been a real lifeline to many. Many have had to become more tech knowledgeable and face a scary unknown world to their norm but overall it is clear that to many the positive have overtaken the negatives. Online digital activities and communities have been created and hopefully are here to stay to benefit many.

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:

"Thank you so much for the amazing and professional advice, newsletters and videos. I really appreciate being a member. Well done to all."

"What you all do is a lifeline for those of us with PBC"

"Live Q&A's and Facebook chats are a beneficial lifeline for PBC patients who feel isolated from family and friends during these times. All of the services have made the isolation so much more bearable."

"I now have a better understanding of what PBC"

"For informed, accurate, up-to-date and relevant information the PBC Foundation is the key referral point.

"Thanks to you for facilitating communication with such experienced PBC consultants. So many different questions and concerns can be addressed, and this knowledge benefits us all. This is a fabulous achievement and genuinely helpful."

"I would really like to take the opportunity to thank you all so much for such and informative and caring foundation. You have been a lifeline when feeling quite vulnerable and little shocked after been given a PBC diagnosis."

"This Foundation should be the template or the example that all organisations dealing with chronic diseases should follow."

FINANCIAL REVIEW

This year, our total income was £358,108 (2020 - £384,325) which resulted in a surplus of £29,513 (2020 - £58,753). Our funds at 31 December 2021 were £256,323 (2020 - £226,810) of which £158,428 (2020 - £91,194) represented unrestricted funds and £97,895 (2020 - £135,616) 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 £158,428 of unrestricted reserves, which equates to approximately six months' running costs. At year end, we also held £97,895 restricted reserves.

Principal source of funding

In the last financial year, our team raised a total of £156,337 from grant-giving bodies. The PBC Foundation would therefore like to thank the following grant-makers for their support:

UK Charitable Trusts

Awards for All Wales, Mrs Yvonne Flux Charitable Trust, Awards for All Northern Ireland, Denton's, The W M Mann Foundation, Halifax Foundation for Northern Ireland, Scottish Executive, The Duchy Health Charity Ltd, The Basil Death Trust, The JTH Charitable Trust, MEB Charitable Trust, Heathrow Community Fund - Communities Together, The Sovereign Healthcare Charitable Trust, Russell Trust, Prudential Small Donations Fund, Saints & Sinners Club Of Scotland, Alliance Scotland, Orcome Trust, Rosca Trust, The Rothley Trust, Thistledown Trust, The Constance Paterson Charitable Trust, Essex Community Foundation, Gatwick Airport Community Trust, Michael Cornish Charitable Trust, The D'Oyly Carte Charitable Trust, Hospital Saturday Fund, Bank of Scotland Foundation, Irene Ann MacDonald Charitable Trust, The Trades House of Glasgow Commonweal Fund, The Enkalon Foundation, Holehird Trust Fund, Colin Grant Charitable Trust, The Sir James Knott Trust, Shanly Foundation, The Bellahouston Bequest Fund, The West Derby Wastelands Charity.

Corporate

Cymabay, Cara Therapeutics, Dr. Falk Pharma UK Ltd, GSK, Escient, Intercept Pharmaceuticals, Mirum Pharma, Umeocrine Cognition.

Statutory

Belfast City Council, Royal Leamington Spa Town Council Community Grant.

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 2021.

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 2022, we shall continue our online services but shall also aim to bring back physical services, as Covid-19 allows. Our intentions are to:

- Continue to recruit and train new regional volunteers.
- Train and support volunteers on a number of volunteer-specific issues, e.g. holding local meetings F2F and online.
- 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.
- Release translated versions of the App.
- Continue to support all those affected by PBC.
- Continue to represent the patient voice on national and international committees.
- Publish a series of PBC videos incorporating medical professionals from a number of countries to address gaps in patient knowledge, as highlighted by patients.
- 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 2022, as follows:
 - Volunteer Support £14,951
 - PBC Day £13,930
 - PBC Conference £19,600
 - Website £7,460
 - Social Media £7,210
 - Leaflets £2,775
 - Total £65,926

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, Collette A Thain MBE, 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 13,800 service users in 80 countries worldwide, including 8,000 in the UK, who rely on our services for support and information. As such, we provide support to a third 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 50 regional volunteers at our Annual Volunteers' Conference. Further to this our CEO and three other 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 independent examiner 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 independent examiner is aware of that information.

Re-appointment of independent examiner

The re-appointment of the independent examiner for the ensuing year will be considered, and if agreed, will be proposed at the Annual General Meeting. 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:



BRYAN RANKIN CA (Chairman/Trustee)

DATE: 2 Sept 2022

Independent Examiner's Report to the Trustees of
PBC Foundation (UK) Limited

I report on the accounts for the year ended 31 December 2021 set out on pages 11 to 21.

Respective responsibilities of trustees and examiner

The charity's trustees are responsible for the preparation of the accounts in accordance with the terms of the Charities and Trustee Investment (Scotland) Act 2005 and the Charities Accounts (Scotland) Regulations 2006. The charity's trustees consider that the audit requirement of Regulation 10(1)(a) to (c) of the Accounts Regulations does not apply. It is my responsibility to examine the accounts as required under Section 44(1)(c) of the Act and to state whether particular matters have come to my attention.

Basis of the independent examiner's report

My examination was carried out in accordance with Regulation 11 of the Charities Accounts (Scotland) Regulations 2006. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently I do not express an audit opinion on the view given by the accounts.

Independent examiner's statement

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

- (1) which gives me reasonable cause to believe that, in any material respect, the requirements
 - to keep accounting records in accordance with Section 44(1)(a) of the 2005 Act and Regulation 4 of the 2006 Accounts Regulations; and
 - to prepare accounts which accord with the accounting records and to comply with Regulation 8 of the 2006 Accounts Regulations

have not been met; or

- (2) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

Yankowski

Lauren Jankowski CA
Helen Lowe Limited
17-21 East Mayfield
Edinburgh
EH9 1SE

Date: 15 September 2022

PBC Foundation (UK) Limited

Statement of Financial Activities
(Incorporating an Income and Expenditure Account)
for the Year Ended 31 December 2021

					31.12.21	31.12.20
		Unrestricted Funds	Designated funds	Restricted Funds	Total Funds	Total Funds
	Notes	£	£		£	£
INCOME FROM						
Donations and other fundraising	3	233,053	-	91,968	325,021	373,115
Other trading activities	4	32,890	-	-	32,890	10,648
Investment income	5	197	-	-	197	562
Total		<u>266,140</u>	<u>-</u>	<u>91,968</u>	<u>358,108</u>	<u>384,325</u>
EXPENDITURE ON						
Raising funds	6	36,441	-	-	36,441	42,102
Charitable activities	7	<u>131,893</u>	<u>19,737</u>	<u>140,524</u>	<u>292,154</u>	<u>283,470</u>
Total		<u>168,334</u>	<u>19,737</u>	<u>140,524</u>	<u>328,595</u>	<u>325,572</u>
NET INCOME		98,076	(19,737)	(48,556)	29,513	58,753
Transfers between funds		<u>(10,835)</u>	<u>-</u>	<u>10,835</u>	<u>-</u>	<u>-</u>
Net movement in funds		86,971	(19,737)	(37,721)	29,513	58,753
RECONCILIATION OF FUNDS						
Total funds brought forward		<u>5,531</u>	<u>85,663</u>	<u>135,616</u>	<u>226,810</u>	<u>168,057</u>
TOTAL FUNDS CARRIED FORWARD		<u>92,502</u>	<u>65,926</u>	<u>97,895</u>	<u>256,323</u>	<u>226,810</u>

The notes form part of these financial statements

PBC Foundation (UK) Limited

Balance Sheet
As at 31 December 2021

	Notes	31.12.21 £	31.12.20 £
FIXED ASSETS			
Tangible fixed assets	13	1,871	1,353
Intangible fixed assets	14	<u>7,067</u>	<u>36,467</u>
		8,938	37,820
CURRENT ASSETS			
Stocks		271	898
Debtors	15	7,041	8,896
Cash at bank and in hand		<u>349,280</u>	<u>216,656</u>
		356,592	226,450
CREDITORS			
Amounts falling due within one year	16	<u>(109,207)</u>	<u>(37,460)</u>
NET CURRENT ASSETS		<u>247,385</u>	<u>188,990</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		<u>256,323</u>	<u>226,810</u>
NET ASSETS		<u>256,323</u>	<u>226,810</u>
FUNDS			
Unrestricted funds	17,18	158,428	91,194
Restricted funds	17,18	<u>97,895</u>	<u>135,616</u>
TOTAL FUNDS		<u>256,323</u>	<u>226,810</u>

The charity is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 December 2021.

The members have not required the charity to obtain an audit of its financial statements for the year ended 31 December 2021 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for

- ensuring that the charity keeps accounting records that comply with Sections 386 and 387 of the Companies Act 2006 and
- preparing financial statements which give a true and fair view of the state of affairs of the charity as at the end of each financial year and of its surplus or deficit for each financial year in accordance with the requirements of Sections 394 and 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the charity.

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 02.09.2022 and were signed on its behalf by:


EILEEN BROWNLIE WS

Trustee

The notes form part of these financial statements

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 (2015)', 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	31.12.21 Total funds	31.12.20 Total funds
	£	£	£	£
Donations	94,599	660	95,259	89,602
Legacies	2,000	10,000	12,000	-
Grants	75,029	81,308	156,337	239,607
Collection boxes	120	-	120	147
Annual raffle	2,208	-	2,208	2,263
General sponsorship and fundraising	59,097	-	59,097	41,496
	<u>233,053</u>	<u>91,968</u>	<u>325,021</u>	<u>373,115</u>

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 £	31.12.21 Total funds £	31.12.20 Total funds £
Intercept Pharmaceuticals	30,150	-	30,150	34,758
Awards For All	-	13,720	13,720	29,615
Nottingham University Hospitals NHS Trust	-	-	-	10,500
The Robertson Trust	-	-	-	10,000
The City of Edinburgh Council	-	-	-	10,000
Glaxo Smithkline	-	-	-	15,000
Other grants	<u>44,879</u>	<u>67,588</u>	<u>112,467</u>	<u>129,734</u>
	<u>75,029</u>	<u>81,308</u>	<u>156,337</u>	<u>239,607</u>

4. OTHER TRADING ACTIVITIES

	Unrestricted funds £	Restricted funds £	31.12.21 Total funds £	31.12.20 Total funds £
App licence fees	30,000	-	30,000	-
Sale of goods	2,080	-	2,080	2,430
Consultancy	<u>810</u>	<u>-</u>	<u>810</u>	<u>8,218</u>
	<u>32,890</u>	<u>-</u>	<u>32,890</u>	<u>10,648</u>

5. INVESTMENT INCOME

	Unrestricted funds £	Restricted funds £	31.12.21 Total funds £	31.12.20 Total funds £
Deposit account interest	<u>197</u>	<u>-</u>	<u>197</u>	<u>562</u>

6. RAISING FUNDS

	Direct costs £	Support costs £	31.12.21 Total funds £	31.12.20 Total funds £
Fundraising costs	<u>33,116</u>	<u>3,325</u>	<u>36,441</u>	<u>42,102</u>

7. CHARITABLE ACTIVITIES COSTS

	Direct costs	Support costs (See note 8)	Totals	31.12.20 Totals
	£	£	£	£
Awareness	55,352	4,987	60,339	74,708
Patient support and helpline	184,000	22,930	206,930	194,127
Health and professional information	21,407	1,330	22,737	11,574
Research	<u>1,482</u>	<u>666</u>	<u>2,148</u>	<u>3,062</u>
	<u>262,241</u>	<u>29,913</u>	<u>292,154</u>	<u>283,470</u>

8. SUPPORT COSTS

	Management	Governance costs	Totals
	£	£	£
Costs of generating voluntary income	3,209	116	3,325
Awareness	4,813	174	4,987
Patient support and helpline	22,131	799	22,930
Health and professional information	1,284	46	1,330
Research	<u>643</u>	<u>23</u>	<u>666</u>
	<u>32,080</u>	<u>1,158</u>	<u>33,238</u>

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

9. NET EXPENDITURE

Net expenditure is stated after charging

	31.12.21	31.12.20
	£	£
Depreciation - owned assets	974	326
Amortisation - owned assets	29,400	32,573
Independent examiners fee	<u>960</u>	<u>960</u>

10. TRUSTEES' REMUNERATION AND BENEFITS

None of the trustees received any remuneration or benefits (2020 nil) in respect of their position as trustees and no expenses were paid to trustees in the year ended 31 December 2021 (2020 nil).

Collette Thain received a salary of £53,363 (2020 £41,780) in respect of her fulltime responsibilities as CEO of the Foundation.

Notes to the Financial Statements - continued
for the Year Ended 31 December 2021

11. STAFF COSTS

	31.12.21	31.12.20
	£	£
Wages and salaries	180,933	180,575
Social security costs	13,813	13,662
Pension costs	<u>2,130</u>	<u>1,448</u>
	<u>196,876</u>	<u>195,685</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 6 (2020 - 6)

No employees received emoluments in excess of £60,000.

12. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

The Statement of Financial Activities for the year to 31 December 2020 on page 11 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	263,414	109,701	373,115
Other trading activities	10,648	-	10,648
Investment income	<u>562</u>	<u>-</u>	<u>562</u>
Total	<u>274,624</u>	<u>109,791</u>	<u>384,325</u>
EXPENDITURE ON			
Raising funds	42,102	-	42,102
Charitable activities	<u>165,049</u>	<u>118,421</u>	<u>283,470</u>
Total	<u>207,151</u>	<u>118,421</u>	<u>325,572</u>
NET INCOME	67,453	(8,720)	58,753
Transfer between funds	<u>(24,626)</u>	<u>24,626</u>	<u>-</u>
Net movement in funds	42,847	15,906	58,753
RECONCILIATION OF FUNDS			
Total funds brought forward	<u>48,347</u>	<u>119,710</u>	<u>168,057</u>
TOTAL FUNDS CARRIED FORWARD	<u>91,194</u>	<u>135,616</u>	<u>226,810</u>

PBC Foundation (UK) Limited

**Notes to the Financial Statements - continued
for the Year Ended 31 December 2021**

13. TANGIBLE FIXED ASSETS

	Office equipment £
COST	
At 1 January 2021	64,007
Additions	<u>1,492</u>
At 31 December 2021	<u>65,499</u>
 DEPRECIATION	
At 1 January 2021	62,654
Charge for year	<u>974</u>
At 31 December 2021	<u>63,628</u>
 NET BOOK VALUE	
At 31 December 2021	<u>1,871</u>
At 31 December 2020	<u>1,353</u>

14. INTANGIBLE FIXED ASSETS

	£
COST	
At 1 January 2021	102,480
Additions	<u>-</u>
At 31 December 2021	<u>102,480</u>
 AMORTISATION	
At 1 January 2020	66,013
Charge for year	<u>29,400</u>
At 31 December 2021	<u>95,413</u>
 NET BOOK VALUE	
At 31 December 2021	<u>7,067</u>
At 31 December 2020	<u>36,467</u>

15. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	31.12.21 £	31.12.20 £
Trade debtors	-	-
Other debtors	<u>7,041</u>	<u>8,896</u>
	<u>7,041</u>	<u>8,896</u>

Notes to the Financial Statements - continued
for the Year Ended 31 December 2021

16. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	31.12.21	31.12.20
	£	£
Trade creditors	21,120	23,476
Social security and other taxes	4,792	7,484
Accruals and deferred income	82,724	6,500
Other creditors	571	-
	<u>109,207</u>	<u>37,460</u>

17. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	31.12.21	31.12.20
	Total funds	Total funds
	£	£
Fixed assets	8,937	37,819
Current assets	245,438	226,451
Current liabilities	(87,010)	(37,460)
	<u>158,428</u>	<u>226,810</u>

18. MOVEMENT IN FUNDS

	At 1.1.21	Income	Expenditure	Transfers	At 31.12.21
	£	£	£	£	£
Unrestricted funds					
Volunteer Support	14,951	-	-	-	14,951
PBC Day	13,930	-	-	-	13,930
App Research and Promotion	10,812	-	(10,812)	-	-
Monthly Bulletin	2,300	-	(2,300)	-	-
PBC Conference	19,600	-	-	-	19,600
Website	11,140	-	(3,680)	-	7,460
Social Media	9,830	-	(2,620)	-	7,210
Leaflets	3,100	-	(325)	-	2,775
Total Designated Funds	85,663	-	(19,737)	-	65,926
General Fund	5,531	266,140	(168,334)	(10,835)	92,502
Total Unrestricted Funds	<u>91,194</u>	<u>262,140</u>	<u>(188,071)</u>	<u>(10,835)</u>	<u>158,428</u>
Restricted funds					
Research	6,314	10,660	(2,148)	-	14,826
The Bear Facts	-	16,796	(27,631)	10,835	-
Workshops	32,387	-	-	-	32,387
Nursing In Practice	1,696	-	-	-	1,696
Volunteer Training	14,989	7,236	(21,146)	-	1,079
App Project	51,467	-	(29,400)	-	22,067
Volunteers Conference	5,683	-	137	-	5,820
Learning Portal	19,228	-	-	-	19,228
Helpline & Online Services	2,500	26,775	(29,275)	-	-
Webinars & Facebook Sessions	1,352	-	(560)	-	792
PBC Day	-	22,961	(22,961)	-	-
Urso Calculator Cards	-	7,540	(7,540)	-	-
Total Restricted Funds	<u>135,616</u>	<u>91,968</u>	<u>(140,524)</u>	<u>10,835</u>	<u>97,895</u>
TOTAL FUNDS	<u>226,810</u>	<u>358,108</u>	<u>(328,595)</u>	<u>-</u>	<u>256,323</u>

18. MOVEMENT IN FUNDS -continued

Transfers Between Funds

Transfers were made from unrestricted funds to restricted funds during the year to cover excess expenditure on these funds.

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:

Volunteer Support-For costs of ongoing support, training and online support.

PBC Day- To cover the costs of the annual PBC Day event.

App-Research and Promotion - For costs of research and promotion of the PBC app.

Monthly Bulletin- For staff costs and distribution costs of the monthly bulletin.

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.

Social Media – For costs relating to creation of brand -publication of new graphics, new logos and promotional tiles.

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

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.

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.

Volunteers' conference – Funding toward the cost of the annual conference.

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 Tuesday webinars hosted by our Head of Education and Development and CEO, Thursday live, interactive Q&A webinars and informal Facebook sessions.

Website Improvements – Funding to assist in the first stage of improvements to the PBC website.

18. MOVEMENT IN FUNDS -continued

PBC Day- To cover the costs of the annual PBC Day event.

Urso Calculator – Funding to develop calculator to help check and track the Urso dose is correct depending on weight of PBC sufferer.

19. RELATED PARTY DISCLOSURES

Two family members (one family member 2020) of Collette Thain, trustee, were employed by the Charity on a full time basis and received total emoluments of £44,943 (2020 £47,294).