Charity Registration Number: 1089609

The British Porphyria Association
Financial Statements
For the Year Ending
31 March 2024

JANE ASCROFT ACCOUNTANCY LIMITED

Chartered Accountants
Enterprise House
Harmire Enterprise Park
Barnard Castle
County Durham
DL12 8XT

Financial Statements

Year Ended 31 March 2024

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Trustees' Annual Report

Year Ended 31 March 2024

The trustees present their report and the unaudited financial statements of the charity for the year ended 31 March 2024.

Objectives and Aims

The charity's objectives are the relief of sickness and the protection and preservation of the health of persons affected by Porphyria and any related condition and their families and carers, in particular by, but not restricted to:

- a) The advancement of the education of the medical profession and the general public into Porphyria and its implications for the family.
- b) The promotion of research into the causes, effects, treatment and management of Porphyria and to disseminate the useful results thereof.

Activities and Achievements

The 2023-2024 financial year has again been very busy for the BPA. We continued to work towards our aims to advocate for, support and educate porphyria patients, as well as relatives and medical professionals, so as to improve the quality of life for those living with the different types of porphyria. We continued to promote awareness and the advancement of research into new therapies.

We expanded our themes of support by adding SHARE to our themes of CONNECT, UNDERSTAND and TAKE CONTROL.

PORPHYRIA AWARENESS

Commencing on 19 April 2023, Global Porphyria Day (GPD), previously known as Porphyria Awareness Week, provided the opportunity to raise awareness about porphyria as well as opportunities for patients and their families and friends to get involved in the theme of This Is My Porphyria. The day produced great engagement across many countries.

Trustees' Annual Report (continued)

Year Ended 31 March 2024

CONFERENCES AND EVENTS

In June 2023, we were pleased to hold a face-to-face patient conference at the SnowDome Conference Facility in Tamworth. The event began with a quiz and social evening on the Saturday giving families the opportunity to connect informally. The feedback was overwhelmingly positive and enjoyed by all in attendance. The Sunday brought together some excellent patient stories followed by research updates and Q&A sessions with UK porphyria experts.

A handful of the BPA team presented and took part in the BIPNET (British & Irish Porphyria Network – a clinician-led best practice network) Annual Conference the following day. The joint collaboration between BIPNET and the BPA is a great opportunity for reciprocal knowledge sharing and education.

We had planned a two-day residential event in September 2023 however, due to unforeseen circumstances, the event was postponed until October 2024.

Our AGM was held virtually in October 2023, so we took the opportunity to hold an online social gathering where people could connect with others with their type of porphyria, and gain more input from our community on what young people would value on the postponed residential activity. During the AGM two attendees volunteered their services as trustees, Dr Vicky McGuire, who is also a BPA patron and Victoria Harold, one of our committee members. They were both duly appointed trustees on 29 November 2023.

We returned to Dublin on Sunday 3 March 2024 for a much-needed Patient Day in Ireland. The event was organised with the support of St James's Hospital, Dublin and the BIPNET team. The programme included doctor and patient talks, research updates from pharmaceutical companies, and Q&A sessions, and was attended by patients, their families and friends, and medical professionals. The patient day was again followed by the BIPNET Annual Conference, where the BPA took an active role in collaborating with medical professionals and lab staff to enhance the porphyria knowledge base.

In March 2024, we also held our first online Peer Support Group Drop-In Session to support patients with EPP/XLP and other skin porphyrias. The session was open to all ages, and families affected were encouraged to attend together. This is a new programme of support that aims to help people living with porphyria to understand their condition, connect with others and build the confidence to take control and share their story.

BPA TEAM

We were delighted that in March 2024, Claire Jarvis, who had been volunteering for the BPA during the financial year, agreed to become our new Treasurer and a Trustee. Claire was appointed a trustee on 19 March 2024.

WEBSITE, SOCIAL MEDIA & HELPLINES

With the continuing support of the BPA's paid administrator, the BPA have made great strides this year in engaging a larger audience on social media, where content interaction saw a 56% increase on the prior year and our reach increased by 20%. Our net followers increased by 97 (an increase of 53%) in the 2023-2024 year.

Twice yearly newsletters were produced and sent out to our members and merchandise was purchased for fundraising and awareness. BPA funds were used for administration fees, printing and postage. A Christmas fundraising campaign was held again in 2023, selling Christmas cards and baubles.

ADVOCACY We continued to take an active part in appraisals of new treatments for porphyria and maintain our involvement with researchers and companies exploring potential treatments to ensure the

Trustees' Annual Report (continued)

Year Ended 31 March 2024

patient voice is considered at the early stages of research, and that the impact of the condition on patients is considered throughout the process.

The BPA has been well-represented internationally through Liz Gill's role as the patient representative on the Executive Board of Ipnet (International Porphyria Network – a global clinician-led network). As well as being one of the BPA's strategic leads, Liz is also heavily involved in the Ipnet Acute Clinical Guidelines project, which aims to develop evidence-based guidelines for the care of acute porphyria patients around the world.

Holding an instrumental role, Sue Burrell is the Global Porphyria Advocacy Coalition (GPAC) President, as well as one of the BPA's strategic leads. She works with other patient organisations and pharmaceutical companies to raise awareness of the porphyrias and develop resources for patients, as well as ensuring that the BPA is at the forefront of collaborations with new drug development research.

Grant Making

It is the policy of the charity to give assistance to sufferers of porphyria to help towards their medical and physical requirements. Funds are made available to assist our members to attend our events with £50 towards travel and £50 towards an overnight stay.

Monies in the Helen Gibbs Fund will continue to be allocated to acute porphyria patients who are eligible to receive the new treatment Givlaari, but who are unable to cover the cost of travelling to a porphyria centre to be able to receive this life changing treatment. These patients will need to visit a porphyria centre once a month for the first six months to receive the treatment and for ongoing monitoring and data collection. After the first six months, patients will receive their treatment at home. We expect there to be a handful of new patients each year that need this support for the first six months of treatment.

Trustees' Annual Report (continued)

Year Ended 31 March 2024

Financial Review

The BPA funds at 31 March 2024 consist of general funds of £15,557 and restricted funds totalling £19,171: £17,038 in the Helen Gibbs fund for research into acute porphyria, £920 in the Light Protection Fund reserved for grants to EPP patients and £1,213 in the Festival 2019 fund.

Our reserves policy is to hold sufficient funds to fund working capital and, as the charity is growing, to fund unexpected expenditure. These will include relevant meetings, for example the charity's involvement in the approval process of new drugs and attending meetings in the UK and overseas in the interests of the charity and our members. It will also include providing additional paid hours to fulfil other required obligations. As the charity's income is by way of subscriptions and donations the reserves will be used to cover any shortfalls in income or changes in circumstances.

Funding

BPA income derives from donations, fundraising and sponsored events, merchandise sales, grants, and sponsorship.

Thank you to all who have made donations and have raised funds for the BPA. We really couldn't continue to do the work that we are doing without these amazing efforts.

Our corporate supporters, Alnylam Pharmaceuticals, Disc Medicine, Mitsubishi Tanabe Pharma Company, Clinuvel UK, and Alpkit Foundation helped to support our events and attendance of key BPA personnel. Their sustained assistance enables us to continue helping and supporting porphyria patients and their families through valued BPA events and opportunities to gain further knowledge.

During the 2024-2025 financial year, we will be seeking funding to enable us to focus on, strengthen and protect our core organisational resilience as part of a development project.

Trustees' Annual Report (continued)

Year Ended 31 March 2024

Future Developments

In 2024 we are updating our two-year strategic plan. In addition to the day-to-day running of the charity and to fulfil our overarching advocacy principles of support, education and research, through our themes of Understand, Connect, Take Control and Share, some of the things we would like to achieve in the coming year are:

- Continue to provide a focus on the mental health of people living with porphyria.
- Host a two-day Residential Event in October at Thorpe Woodlands Adventure Centre, Thetford Forest. The event is designed to offer a safe residential environment with numerous outdoor activities for children and young people affected by Erythropoietic protoporphyria (EPP). We will also be arranging for family members to meet with other parents/siblings to build our EPP support community further.
- We plan to send representatives to the International Congress on Porphyrins and Porphyria (ICPP) in Pamplona, Spain on 21-25 September 2024. As always, we will be actively engaged (alongside clinicians, researchers, scholars, patients and their families) over a number of days to build further connections and learn about the latest research and developments in the field of porphyria.
- Develop our resilience as an organisation by making plans to update technology and processes, as well as consider succession planning to ensure that we remain strong as an organisation and able to deliver vital services.
- Continue with legacy video-editing work from the Festival in 2019 and Reconnect Dundee in 2022 to make presentations available to enhance knowledge and understanding of porphyria. These are available online to patients, relatives and medical professionals working with porphyria patients.
- Facilitate further online Peer Support Drop-in Sessions during 2024.
- Hold our AGM virtually in Autumn 2024 followed by a social event.

As always, we continue to encourage and support research into finding better treatments for all the porphyrias, and maintain and foster networks in the UK, Europe and globally.

Structure, Governance and Management

Governing document

The charity is governed by a constitution which is available from the trustees and represents an unincorporated charity.

Risk management

The trustees have a duty to identify and review the risks to which the charity is exposed and to ensure appropriate controls are in place to provide reasonable assurance against fraud and error.

Re-appointment of trustees

The trustees hold office for three years with no more than one third retiring at the annual general meeting. Subject to eligibility those retiring may be re-elected or re-appointed.

Trustees' Annual Report (continued)

Year Ended 31 March 2024

Reference and Administrative Details

Registered charity name

The British Porphyria Association

Charity registration number

1089609

Principal office

136 Devonshire Road

Durham City County Durham DH1 2BL

The Trustees

A Newton (Treasurer)
J W Chamberlayne

K E Harris A Molyneux R Bennett N Chadwick V Harrold V McGuire C Jarvis

Independent Examiner

Jane Ascroft FCA MA (Cantab)

Enterprise House

Harmire Enterprise Park

Barnard Castle County Durham DL12 8XT

The trustees' annual report was approved on12. June.2024 and signed on behalf of the board of trustees by:

J W Chamberlayne

John Chamberlayne

Trustee

Independent Examiner's Report to the Trustees of The British Porphyria Association

Year Ended 31 March 2024

I report to the trustees on my examination of the financial statements of The British Porphyria Association ('the charity') for the year ended 31 March 2024.

Responsibilities and Basis of Report

As the trustees of the charity you are responsible for the preparation of the financial statements in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the charity's financial statements carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent Examiner's Statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

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

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

Jane Ascroft FCA MA (Cantab) Independent Examiner

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Enterprise House Harmire Enterprise Park Barnard Castle County Durham DL12 8XT

Statement of Financial Activities

Year Ended 31 March 2024

	Note	Unrestricted funds	2024 Restricted funds £	Total funds	2023 Total funds
Income and endowments		_	-	-	~
Donations	4	34,056	500	34,556	40,722
Other trading activities	5	81	_	81	508
Investment income	6	144	228	372	96
Other income	7	3,645		3,645	2,223
Total income		37,926	728	38,654	43,549
Expenditure Expenditure on raising funds: Costs of other trading activities Expenditure on charitable activities	8 9,10	203 43,796	_ 163	203 43,959	345 47,787
Total expenditure		43,999	163	44,162	48,132
	_	<u></u>			
Net expenditure and net movement funds	in	(6,073)	565	(5,508)	(4,583)
Reconciliation of funds					
Total funds brought forward		20,274	19,107	39,381	43,964
Total funds carried forward		14,201	19,672	33,873	39,381

The statement of financial activities includes all gains and losses recognised in the year. All income and expenditure derive from continuing activities.

The notes on pages 10 to 16 form part of these financial statements.

Statement of Financial Position

31 March 2024

Current Assets	Note	2024 £	2023 £
Debtors	15	_	108
Cash at bank and in hand		34,727	39,573
		34,727	39,681
Creditors: amounts falling due within one year	16	854	300
Net Current Assets		33,873	39,381
Total Assets Less Current Liabilities		33,873	39,381
Net Assets		33,873	39,381
Funds of the Charity			
Restricted funds		19,672	19,107
Unrestricted funds		14,201	20,274
Total charity funds	18	33,873	39,381

A Newton (Treasurer)

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Trustee

Notes to the Financial Statements

Year Ended 31 March 2024

1. General Information

The charity is a public benefit entity and a registered charity in England and Wales and is unincorporated. The address of the principal office is 136 Devonshire Road, Durham City, County Durham, DH1 2BL.

2. Statement of Compliance

These financial statements have been prepared in compliance with FRS 102, 'The Financial Reporting Standard applicable in the UK and the Republic of Ireland', the Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (Charities SORP (FRS 102)) and the Charities Act 2011.

3. Accounting Policies

Basis of Preparation

The financial statements have been prepared on the historical cost basis, as modified by the revaluation of certain financial assets and liabilities and investment properties measured at fair value through income or expenditure.

The financial statements are prepared in sterling, which is the functional currency of the entity.

Going Concern

There are no material uncertainties about the charity's ability to continue.

Judgements and Key Sources of Estimation Uncertainty

The preparation of the financial statements requires management to make judgements, estimates and assumptions that affect the amounts reported. These estimates and judgements are continually reviewed and are based on experience and other factors, including expectations of future events that are believed to be reasonable under the circumstances. The Trustees consider that there are no significant estimates or judgements affecting these financial statements.

Fund Accounting

Unrestricted funds are available for use at the discretion of the trustees to further any of the charity's purposes.

Designated funds are unrestricted funds earmarked by the trustees for particular future project or commitment.

Restricted funds are subjected to restrictions on their expenditure declared by the donor or through the terms of an appeal, and fall into one of two sub-classes: restricted income funds or endowment funds.

Notes to the Financial Statements (continued)

Year Ended 31 March 2024

3. Accounting Policies (continued)

Income

All income is included in the statement of financial activities when entitlement has passed to the charity, it is probable that the economic benefits associated with the transaction will flow to the charity and the amount can be reliably measured. The following specific policies are applied to particular categories of income:

- income from donations or grants is recognised when there is evidence of entitlement to the gift, receipt is probable and its amount can be measured reliably.

Expenditure

Expenditure is recognised on an accruals basis as a liability is incurred. Expenditure includes any VAT which cannot be fully recovered, and is classified under headings of the statement of financial activities to which it relates:

- expenditure on charitable activities includes all costs incurred by a charity in undertaking activities that further its charitable aims for the benefit of its beneficiaries, including those support costs and costs relating to the governance of the charity apportioned to charitable activities.

All costs are allocated to expenditure categories reflecting the use of the resource. Direct costs attributable to a single activity are allocated directly to that activity. Shared costs are apportioned between the activities they contribute to on a reasonable, justifiable and consistent basis.

Financial Instruments

The charity only has financial assets and liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value.

Debtors

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

Accrued income and tax recoverable is included at the best estimate of the amounts receivable at the balance sheet date.

Cash at Bank and in Hand

Cash at bank and cash in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

Notes to the Financial Statements (continued)

Year Ended 31 March 2024

3. Accounting Policies (continued)

Creditors

Creditors 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 are normally recognised at their settlement amount after allowing for any trade discounts due.

Taxation

The company is considered to pass the tests set out in Paragraph 1 Schedule 6 of the Finance Act 2010 and therefore it meets the definition of a charitable company for UK corporation tax purposes. Accordingly, the company is potentially exempt from taxation in respect of income or capital gains received within categories covered by Chapter 3 Part 11 of the Corporation Tax Act 2010 or Section 256 of the taxation of Chargeable Gains Act 1992, to the extent that such income or gains are applied exclusively to charitable purposes.

4. Donations

	Unrestricted Funds £	Restricted Funds £	Total Funds 2024 £
Donations			
Donations and subscriptions	10,982	_	10,982
Gift aid	1,069	_	1,069
Other income	482	-	482
Grants			
Clinuvel Pharmaceuticals grant	2,000	-	2,000
Alnylam grant	10,000	_	10,000
Mitsubishi Tanab	_	_	-
Disc Medicine	9,523	_	9,523
Alpkit		500	500
	34,056	<u>500</u>	34,556
	Unrestricted	Restricted	Total Funds
	Funds	Funds	2023
	£	£	£
Donations			
Donations and subscriptions	16,438	-	16,438
Gift aid	1,400	_	1,400
Other income	_	_	_

Notes to the Financial Statements (continued)

Year Ended 31 March 2024

4.	Donations (continued)				
			Unrestricted Funds £	Restricted Funds £	Total Funds 2023 £
	Grants Clinuvel Pharmaceuticals grant Alnylam grant Mitsubishi Tanab Disc Medicine National Lottery Community Fund		10,000 2,500 — — 30,338	884 9,500 10,384	10,000 2,500 884 9,500 40,722
5.	Other Trading Activities				
		Unrestricted Funds £	Total Funds 2024 £	Funds £	Total Funds 2023 £
	Merchandise sales	<u>81</u>	<u>81</u>	508	508
6.	Investment Income				
	Bank interest receivable Dividends receivable		Unrestricted Funds £ 132 12 144	Restricted Funds £ 228 228	Total Funds 2024 £ 360 12 372
			Funds £ 132 	Funds £ 228 	2024 £ 360 12
7.	Dividends receivable Bank interest receivable		Funds £ 132 12 144 Unrestricted Funds £ 40 14	Funds £ 228 228 Restricted Funds £ 42	2024 £ 360 12 372 — Total Funds 2023 £ 82 14
7.	Dividends receivable Bank interest receivable Dividends receivable	Unrestricted Funds £ 3,645	Funds £ 132 12 144 Unrestricted Funds £ 40 14	Funds £ 228 228 Restricted Funds £ 42 42	2024 £ 360 12 372 — Total Funds 2023 £ 82 14

Notes to the Financial Statements (continued)

Year Ended 31 March 2024

8.	Costs of Other Trading Activities				
		Funds		Funds	2023
	Merchandise costs	£ 203	£ 203	£ 345	£ 345
9.	Expenditure on Charitable Activities	by Fund Type	•		
			Unrestricted Funds £	Restricted Funds £	Total Funds 2024 £
	Costs of charitable activities		43,796	163	43,959
			Unrestricted Funds £	Restricted Funds £	Total Funds 2023 £
	Costs of charitable activities		37,054	10,733	47,787
10.	Expenditure on Charitable Activities I	by Activity Ty	/pe		
		directly		Total funds 2024	Total fund 2023
	Costs of charitable activities	£ 43,796	£ 163	£ 43,959	£ 47,787
11.	Analysis of Grants				
	Grants to Individuals			2024 £	2023 £
	Travel bursaries Other grants			50 113	349 300
				163	649
	Total grants			<u>163</u>	649
12.	Independent Examination Fees				
	Face payable to the independent examin	nor for		2024 £	2023 £
	Fees payable to the independent examination of the financial			300	300

13. Staff Costs

The average head count of employees during the year was Nil (2023: Nil).

Notes to the Financial Statements (continued)

Year Ended 31 March 2024

13. Staff Costs (continued)

No employee received employee benefits of more than £60,000 during the year (2023: Nil).

14. Trustee Remuneration and Expenses

There were no trustees' remuneration or other benefits for the current or previous year.

During the year expenses of £1,046 were reimbursed to 4 trustees (2023 - £2,682 to 5 trustees).

15. Debtors

		2024 £	2023 £
	Gift aid receivable		108
16.	Creditors: amounts falling due within one year		

	2024	2023
	£	£
Accruals and deferred income	854	300

17. Deferred Income

	2024	2023
	£	£
Amount deferred in year	554	_

18. Analysis of Charitable Funds

Unrestricted funds

General funds	At 1 April 2023 £ 20,274	Income £ 37,926	Expenditure £ (43,999)	Transfers £ 	At 31 March 2024 £ 14,201
General funds	At 1 April 2022 £ 24,545	Income £ 33,123	Expenditure £ (37,399)	Transfers £	At 31 March 2023 £ 20,274

Notes to the Financial Statements (continued)

Year Ended 31 March 2024

18. Analysis of Charitable Funds (continued)

Restricted funds

					At
	At			3	1 March 202
	1 April 2023	Income	Expenditure	Transfers	4
	£	£	£	£	£
Helen Gibbs Fund	16,885	203	(50)	_	17,038
Light Protection Fund	1,022	11	(113)	_	920
Festival 2019 fund	1,200	14	-		1,214
Alpkit		<u>500</u>		_	500
	19,107	728	(163)	_	19,672
				_	
					At
	At			3	1 March 202
	1 April 2022	Income	Expenditure	Transfers	3
	£	£	£	£	£
Helen Gibbs Fund	17,197	37	(349)	_	16,885
Light Protection Fund	1,025	2	· _	(5)	1,022
Festival 2019 fund	1,197	3	_	-	1,200
National Lottery					
Community Fund	_	9,500	(9,500)	_	_
Disc Medicine		884	(884)		
	19,419	10,426	(10,733)	(5)	19,107
		-	` 		

The Helen Gibbs fund is for research into acute porphyria and the Light Protection Fund is reserved for grants to EPP patients.

The Festival 2019 fund includes a grant from Orphan Europe to help towards our Porphyria Festival in October 2019 to celebrate our 20th anniversary.

19. Analysis of Net Assets Between Funds

Current assets Creditors less than 1 year	Unrestricted Funds £ 15,055 (854)	Restricted Funds £ 19,672	Total Funds 2024 £ 34,727 (854)
Net assets	14,201	19,672	33,873
	Unrestricted Funds £	Restricted Funds £	Total Funds 2023
Current assets	21,458	18,223	39,681
Creditors less than 1 year	(300)		(300)
Net assets	21,158	18,223	39,381



Detailed Statement of Financial Activities

Year Ended 31 March 2024

	2024 £	2023 £
Income and endowments		
Donations		
Donations and subscriptions	10,982	16,438
Gift aid	1,069	1,400
Other income	482	-
Clinuvel Pharmaceuticals grant	2,000	-
Alnylam grant	10,000	10,000
Mitsubishi Tanab	0.500	2,500
Disc Medicine	9,523	884
National Lottery Community Fund	_ 500	9,500
Alpkit	500	
	34,556	40,722
Other trading activities	•	
Merchandise sales	<u>81</u>	508
Investment income	200	00
Bank interest receivable	360	82
Dividends receivable	_12	14
	372	96
Other income		
Consultancy fees	3,645	2,223
		40.540
Total income	38,654	43,549

Detailed Statement of Financial Activities (continued)

Year Ended 31 March 2024

	2024	2023
Expenditure	£	£
Costs of other trading activities		
Merchandise costs	203	345
Expenditure on charitable activities		
Activities undertaken directly		
BPA events	10,608	10,935
Counselling & wellbeing	_	230
BIPNET collaboration event	2,600	4 000
Insurance	1,141	1,068
International conference fees	1 046	1,231
Trustees' ordinary travel expenses	1,046	2,682
Ordinary travel expenses	3,150 264	4,152 300
Accountancy fees Storage fees	589	584
Printing, postage, stationery and telephone	1,726	1,244
Newsletter	665	550
Advertising and promotional goods	-	586
Subscriptions	389	346
IT and software	523	519
Fundraising	775	684
Sundry costs	188	_
Administration fees	20,132	19,804
Administration fees - Festival	_	2,223
	42.706	47 120
	43,796	47,138
Grant funding activities		
Grants given	<u>163</u>	649 —
Expenditure on charitable activities	43,959	47,787
Total expenditure	44,162	48,132
Net expenditure	(5,508)	(4,583)