

Advancing Care in Primary Immunodeficiency

# **Annual Report 2022**

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## **Trustees' Report**

For the period ended 31 December 2022

#### What we do and why it matters

The United Kingdom Primary Immunodeficiency Network (UKPIN) is the professional body for Immunologists, Specialist Nurses, Healthcare and Academic Scientists in the UK.

#### **Our mission**

UKPIN's mission is to advance the health among those with primary immunodeficiency disorders and advancing education in PID and related subjects.

We accomplish this by:

- . Developing common best practice approaches to diagnosis and management of PID and related disorders
- . Developing clinical guidelines by means of setting consensus standards based upon agreed UK best practice
- Promoting improved understanding of PID and related disorders among healthcare professionals and istudents

The Trustees confirm they have referred to the Charity Commission's guidance on public benefit when reviewing the Charity's aims and objectives, planning future activities and setting the annual operating plan.

#### Our details

Charity registration number 1164466

Company registration number 09273983 (England and Wales)

Registered address 9 Appold Street London

EC2A 2AP

#### Our strategic objectives

Following discussions over the last two years, UKPIN was acquired by the British Society for Immunology in December 2022. This has resulted in the establishment of a new professional network for clinical immunology, the BSI Clinical Immunology Professional Network (BSI-CIPN).

The BSI-CIPN will fully represent all aspects of clinical immunology practice in the UK. It will deliver better support for the immunology community to network and engage with each other across many disciplines, building closer links between clinical practitioners and basic scientists. It also combines the expertise of the BSI and UKPIN to strengthen the voice of clinical immunology in policy and the public arena to increase the impact of our work in advocating for the care of patients with immunodeficiencies.

UKPIN has achieved much since its formation to bring together the clinical immunology community. Through this merger, the BSI-CIPN hope to provide an even stronger platform for clinicians, healthcare professionals and scientists to engage and share best practice.

#### 1 Development of best practice guidelines

UKPIN works on the updating and development of Clinical guidelines for the diagnosis and management of immunodeficiency diseases. This work will be passed to the BSI-CIPN.

#### Keeping you informed

The Charity has worked hard to keep our members informed about our activities and developments in primary immunodeficiency in the wider world.

#### 2 Clinical leadership of the QPIDS accreditation scheme

The QPIDS team ran virtual training sessions to support services through the accreditation process. Following the new QPIDS standards being launched in September 2020 services have been submitting evidence on the revised standards.

#### 3 Maintenance of the UK PID registry

In April 2022 became independent from UKPIN with funding obtained from industry. This is sufficient to provide a Registry Coordinator to maintain the register.

#### 4 Advance education in primary immunodeficiency

UKPIN continues to offer an opportunity to receive funding for doctors, nurses and scientists who are UKPIN members to further their knowledge of primary immune deficiencies. These awards help support periods training in other academic or clinical centres. Funding of these awards have been transferred to the BSI following the acquisition in December 2022.

#### 5 Communications and networking

2022 was a non-meeting year for UKPIN. Although the inaugural meeting of the BSI-CIPN took place in December alongside the BSI Congress. The event brought together consultants, trainees, nurses and scientists who form the BSI-CIPN to hear from expert speakers and network with each other.

#### Charitable status and administrative details

The Charity is registered as a charity (Charity number 1164466) and incorporated in England and Wales as a company, limited by guarantee (Company number 09273983). It has no share capital and the liability of its members is limited to a sum not exceeding £1. The charity's governing document is the Memorandum and Articles of Association, which was amended 20 December 2022.

#### **Board of Trustees**

The Trustees are charity Trustees for the purposes of the Charities Act 2011. The Chair, Honorary Secretary and Treasurer are also company directors for the purposes of the Companies Act. The current trustees, and any past Trustees who served during the year are listed on page 18.

The Trustees are responsible for directing the Charity's activities and for overseeing the management of the affairs of the Charity, they actively manage the organisation. They have contracted the British Society for Immunology to provide secretariat services to the Charity.

The Trustees meets quarterly and decision are agreed on by open vote. The sub committees report into the Steering Committee and the reports are approved during the steering committee meetings. Any decisions outside the steering committee meetings will either be resolved by the trustees agreeing or by an electronic vote by all trustees.

As part of their induction process, Trustees spend some time with the Chair who gives a full introduction together with the history of the Charity and key information they require to fulfil their duties as Trustee.

The success of the Charity belongs in part to the people who generously volunteer their time to add their experience to our activities, we thank you all.

#### **Financial Performance**

Income fell in 2022 without a UKPIN meeting. The final costs for the registry were paid before it became financially independent from the UKPIN during the year.

The main cost this year was the transfer of UKPIN funds to the BSI following the merger in December. This pushed the deficit for the year to £172k (2021: surplus £42k).

#### Reserves policy

The Charity operates a reserves policy requiring a minimum of two years budgeted non-meeting annual costs to be retained as free reserves. The Trustees consider that this level will provide enough funds to respond to any unexpected events.

At 31 December 2022, free reserves stood at £4k (2020: £172k). This is considered to be sufficient to cover all outstanding liabilities as at the year end.

#### Risk management

Good risk management is fundamental to the continued work and sustainability of the Charity. We identify and mange risks that could adversely impact the achievement of our strategic purpose and determine the calculated risks we need to take to succeed.

The Charity operates a formal framework for the management of risk, taking the view that risk can be positive (opportunity) or negative (threat). The Charity operates a risk register incorporating strategic, operational and compliance risks, which are informed by the Charity's strategic objectives, performance, voice of our stakeholders, regulatory environment and analysis of the external environment.

The Steering Committee delegates day-to-day responsibility for risk management to the Directors, who are responsible for identifying and evaluating risks to their areas and activities implementing appropriate controls for ongoing mitigation and monitoring.

The Steering Committee reviews the Charity's strategic and compliance risks annually.

#### **Fundraising statement**

Although the Charity does not actively fundraise from members, occasional donations are received. The Charity applies best practice in the tone of its communications and the accuracy of its data to minimise the pressures on supporters. The Charity applies best practice to protect supporters' data, never sells or swaps it and ensures that communication preferences can be changed at any time. The Charity commits to react to and investigate any complaints received, to learn from them and improve its service. During the year, the Charity received no complaints about its fundraising activities.

#### Future plans

The charitable activities of UKPIN have been transferred to the BSI. The BSI have created the BSI Clinical Immunology Professional Network (BSI-CIPN).

#### Trustees' responsibilities

The Trustees are responsible for preparing the Trustees' report and financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

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 Charity and of the income and expenditure of the Charity for that period. In preparing these financial statements, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable to the United Kingdom and Republic of Ireland; and
- make judgements and estimates that are reasonable and prudent;
- state whether applicable United Kingdom Accounting Standards have been followed, subject to any
  material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume the charity will continue in operation.

The Trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the Charity and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the Charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

#### Each of Trustees confirm that:

- so far as the Trustee is aware, there is no relevant information of which the Charity's independent examiner is unaware; and
- the Trustee has taken all steps that he/she ought to have taken as a Trustee in order to make himself/herself aware of any relevant audit information and to establish that the Charity's independent examiner is aware of that information.

This confirmation is given and should be interpreted in accordance with the provisions of s418 of the Companies Act 2006.

The Trustees are responsible for the maintenance and integrity of corporate and financial information included on the Charlty's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

Approved by the Trustees and signed on their behalf by:

Fleelly 31/3/23

Fiona Culley Director Date:

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# Independent Examiner's Report to the Trustees of the United Kingdom Primary Immunodeficiency Network ('the Company')

I report to the charity trustees on my examination of the accounts of the Company for the period ended 31 December 2022.

#### Responsibilities and basis of report

As the charity's trustees of the Company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5) (b) of the 2011 Act.

#### **Independent Examiner's Statement**

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

- accounting records were not kept in respect of the Company as required by section 386 of the 2006 Act; or
- 2) the accounts do not accord with those records; or
- 3) the accounts do not comply with the accounting requirements of section 396 of the 2006 Act 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; or
- 4) the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities.

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.

Moore Krighten Jaka LLP

**Neil Finlayson** 

For and on behalf of Moore Kingston Smith LLP

**Chartered Accountants** 

9 Appold Street London EC2A 2AP

**Date:** 27 April 2023

# Statement of Financial Activities Period to 31 December 2022

	Note	General funds	Restricted funds	Total 2022	Total 2021
		€,000	£'000	€'000	£'000
Income from:					
Donations	2	45	· -	45	35
Charitable activities:	3		•		
Conference		-	•	-	181
Membership		. 9	-	9	5
Sponsorship		1	-	1	-
Total income		55	<u>-</u>	55	221
Expenditure on:					
Charitable activities					
Conference		0	-	-	100
Guidance		0	-	•	4
Membership		44	-	44	26
Registry		8	•	8	49
Transfer to BSI		171	4	175	-
Total expenditure	4	223	4	227	. 179
Net (expenditure)/income		(168)	(4)	(172)	42
Reconciliation of funds:					
Funds brought forward		172	4	176	134
Funds carried forward		4		4	176

There are no recognised gains or losses other than those recognised above. All activities are continuing.

The notes on pages 10 to 17 form part of these financial statements

		Total	Total
	Notes	2022	2021
		£'000	£'000
Current assets			
Debtors	8	3	18
Cash at bank and in hand		5	129
	<u>-</u>	8	147
Liabilities			•
Creditors: amounts falling due			
within one year	9	(4)	(25)
Net assets		4	122
Funds			•
Unrestricted funds			
General funds	13	4	172
Restricted funds	12	•	4
Total		4	176

For the financial year in question the company was entitled to exemption under section 477 of the Companies Act 2006 relating to small companies.

No members have required the company to obtain an audit of its accounts for the year in question in accordance with section 476 of the Companies Act 2006.

The directors acknowledge their responsibility for complying with the requirements of the Act in respect to accounting records and for the preparation of accounts.

These accounts have been prepared in accordance with the provisions applicable to companies subject to the small companies regime.

These accounts were approved by the Board and authorised for issue on 23/3/23 and were signed on its behalf by:

Fiona Culley Director

United Kingdom Primary Immunodeficiency Network, Company Limited by Guarantee Company Registration Number 09273983 (England and Wales)

The notes on pages 10 to 17 form part of these financial statements

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#### 1 Accounting policies

The principle accounting policies adopted, judgements and key sources of estimation uncertainty in the preparation of the financial statements are as follows:

#### **Basis of preparation**

The financial statements are prepared on a going concern basis, under the historical cost convention modified to include the recognition of listed investments measured at fair value, which is consistent with the prior year. The financial statements have been prepared in accordance with the Statement of Recommended Practice: Accounting and Reporting by Charities ("The SORP"), the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS 102) and the Charities Act 2011.

The United Kingdom Primary Immunodeficiency Network ("The Charity") meets the definition of a public benefit entity under FRS 102.

#### **General information**

The Charity is a charitable company incorporated in England and Wales (company number 09273983) and is a charity registered in England and Wales (charity number 1164466) The Charity's registered address is 9 Appold Street, London EC2A 2AP. In December 2022 It became a wholly owned subsidiary of the British Society for Immunology, a charitable company (Charity number 1043255) (Company number 03005933) (England and Wales)).

#### Critical accounting judgements and key sources of estimation uncertainty

The preparation of financial statements requires the sue of certain critical accounting estimates. It also requires management to exercise its judgement in the process of applying the Charity accounting policies. In the application of the accounting policies, Trustees are required to make judgements, estimates and assumptions about the carrying value of assets and liabilities that are not readily apparent from other sources. The estimates and underlying assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised if the revision only affects that period, or in the period of revision and future periods if the revision affected current and future periods.

In the view of the Trustees, no assumptions concerning the future or estimation uncertainty affecting assets or liabilities at the balance sheet date are likely to result in a material adjustment to their carrying amounts in the next financial year.

#### Going concern

The Trustees have assessed whether the use of the going concern assumption is appropriate in preparing these financial statements. The directors have made this assessment in respect to a period of one year from the date of approval of these financial statements.

Following the merger with the British Society for Immunology (BSI) in December 2022, the charity transferred its charitable activities and assets to the BSI. The charity has retained funds to cover all outstanding liabilities, therefore the trustees consider the charity to be going concern.

#### Income

All income is recognised once the Charity has entitlement to income, it is probable that income will be received and the amount of income receivable can be measured reliably. Income of the Charity is, where applicable, included net of Value Added Tax (VAT) and is allocated to the period to which it relates, carrying forward that part of the income relating to future accounting periods.

#### **Expenditure**

Liabilities are recognised as soon as there is a legal or constructive obligation committing the Charity to that expenditure, it is probable that settlement will be required and the amount of obligation can be measured reliably. Expenditure is recognised on an accruals basis as a liability is incurred, inclusive of VAT, which cannot be recovered.

Expenditure is allocated to a particular activity where the cost relates directly to that activity. The cost of overall direction and administration of each activity, known as "support costs" and comprising the overhead costs of the central function is apportioned to each activity.

Support costs also include governance costs, which comprise organisational administration and compliance with constitutional and statutory requirements. The allocation of support and governance costs is analysed in notes 5 and 6.

#### **Financial instruments**

The Charity has chosen to adopt Section 11 of FRS 102 in respect of financial instruments.

#### I) Financial assets

Basic financial assets, including trade and other receivables, cash and bank balances, are initially recognised at transaction value and subsequently measured at amortised cost. Other financial assets, including investments, are initially measured at fair value. Financial assets are derecognised when:

- a) the contractual rights to the cash flows of the asset expire or are settled, or
- b) substantially all the risks and rewards of the ownership of the asset are transferred to another party or
- c) despite having retained some significant risks and rewards of ownership, control of the asset has been transferred to another party who has the practical ability to unilaterally sell the asset to an unrelated third party without imposing additional restrictions.

Cash at bank and cash in hand includes cash and short-term highly liquid investments with a short maturity of three months or less.

#### II) Financial liabilities

Basic financial liabilities, including trade and other payables, are initially recognised at transaction price. Trade payables are obligations to pay for goods or services that have been acquired in the ordinary course of business from suppliers. Accounts payable are classified as current liabilities if payment is due within one year or less. If not, they are presented as non-current liabilities. Financial liabilities held at amortised cost comprise all creditors except social security and other taxes and provisions.

#### **Provisions**

Provisions are recognised where the Charity has a present legal or constructive 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. Provisions are measured at the present value or the expenditures expected to be required to settle the obligation.

#### **Fund accounting**

Unrestricted funds are those funds available to the Charity for general purposes. They include funds designated by the Trustees for particular purposes where their use remains at the discretion of the Trustees. It is the policy of the Trustees to retain in unrestricted funds, amounts which in their judgement, can help to mitigate the short-term effects of income volatility; and retain as long-term investment funds to generate sufficient income to meet current and future operational activities of the Charity.

Restricted funds are those funds available to the Charity restricted to a specific purpose or are subject to particular donor imposed conditions. Further information is available in the reserves section of the Trustees' report.

#### 2 Income from donations

	Unrestricted funds £'000	Restricted funds £'000	2022 Total Funds £'000	2021 Total Funds £'000
Donations	45	•	45	35
Total	45	•	45	35

#### 3 Income from charitable activities

			2022	2021
	Unrestricted	Restricted	Total	Total
	funds	funds	Funds	Funds
	£'000	£'000	£'000	£'000
Conference		-	0	181
Membership	9	-	9	5
Sponsorship	1		1	
Total	10		. 10	186

#### 4 Total expenditure

<del>-</del>				
			2022	2021
	Unrestricted	Restricted	Total	Tota
	funds	funds	Funds	Fund
	£'000	£'000	£'000	£'00(
Conference	-	-	-	100
Guidance	-	-	-	4
Membership	44	-	44	26
Registry	8	-	8	49
Transfer to BSI	171	4	175	
Total	223	4	227	179
Allocation of support costs to charitable activities:		Direct	Support	2022
••		costs	costs	Tota
		£'000	£,000	€'000
Membership		_	44	44
Registry		. 8	•	8
Total		8	44	52
Support costs are as follows:			2022	202:
			£'000	£'000
Independent examiners' remuneration			2	2
Accountancy fees			-	:
Committee expenses			•	:
Professional fees			9	-
Secretariat fees			30	30
Website			2	2
Total			44	36
Allocation of support costs to charitable activities:		Direct	Support	2021
		costs	costs	Tota
		£'000	£'000	£'000
Conference		96	4	100
Guidance			4	4
Membership		-	26	26
Registry		47	2	49
Total .	•	143	36	179

#### 5 Governance Costs

	2022	2021
	€,000	£'000
Auditor's remuneration - audit	2	;
Auditor's remuneration - other	-	1
Total	2	3
6 Net income  This is stated after charging:	Total	Total
illis is stated diter thalging.	, 2022 £'000	2021 £'000
Auditor's remuneration - audit	2	2

The company has no employees as its day to day operations are conducted by the employees of the British Society for Immunology. During the period ended 31 December 2022, a secretariat fee to include staff, office and IT costs) of £30,000 (2021: £30,000) was charged by the British Society for Immunology to the Charity.

The total renumeration (including taxable benefits and employer's pension contributions) of the key management personnel for the year was £nil (2021: £nil).

The Charity does not employ staff.

No renumeration was paid to the trustees during the period to 31 December 2022 (2021: none). Expenses totalling £nll (2021: £nil) were reimbursed to nil trustees (2020: nil).

#### 8 . Debtors

	2022 €′000	2021 £'000
Other debtors	-	68
VAT recoverable	3	15
Total	3_	83

#### 9 Creditors: amounts falling due within one year

		2022	2021
			£'000
		7,000	1 000
		•	15
		4	10
	· _	4	25
<del></del>	· · · · · · · · · · · · · · · · · · ·	_ <del></del>	
At 1			At 31
			December
2022	Income	Costs	2022
£'000	£'000	£'000	£,000
4	-	(4)	
4		4	0
At 1			At 31
January			December
2022	Income	Costs	2022
£'000	£'000	£,000	£'000
4	-	•	4
4	0	<del></del>	4
	£'000  4  At 1  January 2022 £'000	January 2022 Income £'000 £'000  4 -  At 1 January 2022 Income £'000 £'000	At 1 January 2022 Income Costs E'000 £'000 £'000  4 - (4)  At 1 January 2022 Income Costs £'000 £'000

#### **Visiting Scholar and Jonathan Sherrard Awards**

Funds to support UKPIN members for periods training in other academic or clinical centres to further their knowledge of primary immuno deficiences.

#### 11 Analysis of net assets between funds

Total Funds	4	0	4
Current liabilities	(4)		(4)
Current assets	8	-	8
	£'000	£'000	€,000
	Unrestricted funds	Restricted funds	Total funds
			2022

•			2021
	Unrestricted funds	Restricted funds	Total funds
	£,000	£'000	£,000
Current assets	197	4	201
Current liabilities	(25)	<u> </u>	(25)
Total Funds	172	4	176

#### 12 Share capital

The company is limited by guarantee and therefore has no share capital. Each member's liability is limited to £1.

#### 13 Ultimate control and related party transactions

The company is controlled by and is a wholly owned subsidiary of the British Society for Immunology, (Charity registration number 1043255) and a Company Limited by Guarantee incorporated in the UK (Company registration number 03009533), whose registered office is located at 9 Appold Street, London, EC2A 2AP.

The financial statements do not include a disclosure of transactions between the British Society for Immunology and UKPIN. As a 100% controlled subsidiary undertaking, UKPIN is exempt from the requirement to disclose such transactions under section 33.1A of FRS 102.

There were no further related party transactions during the financial period (2021: none).

# Trustees

Position	Office holder	Date of appointment / resignation
Chair	Dr Sinisa Savic	Resigned December 2022
Treasurer	Dr Catherine Stroud	Resigned December 2022
Honorary Secretary	Dr Suzy Elcombe	Resigned December 2022
Trustee	Mrs Sarah Denman	Resigned December 2022
Trustee	Dr Lisa Devlin	Resigned December 2022
Trustee	Miss J Edmonds	Resigned December 2022
Trustee	Dr Shuayb Elkhalifa	Resigned July 2022
Trustee	Dr Kimberly Gilmour	Resigned December 2022
Trustee	Dr Alex Richter	Resigned December 2022
Trustee	Dr Ravishankar Sargur	Resigned December 2022
Trustee	Dr Austen Worth	Resigned December 2022
Trustee	Dr Patrick Yong	Resigned December 2022
Trustee	Dr Manisha Ahuja	Resigned December 2022
Trustee	Dr Claire Stockdale	Resigned December 2022
Chair	Dr Fiona Culley	Appointed December 2022
Trustee	Otto Balsiger	Appointed December 2022
Trustee	Dr Doug Brown	Appointed December 2022
Trustee	Paul Harding	Appointed December 2022
Trustee	James Lowe	Appointed December 2022

#### Principal professional advisers

Bankers Lloyds Bank 14/16 Cockspur Street London EC2V 6DL External independent examiners Moore Kingston Smith LLP 9 Appold Street London EC2A 2AP