REGISTERED COMPANY NUMBER: 09273983 (England and Wales) REGISTERED CHARITY NUMBER: 1164466



REPORT OF THE TRUSTEES AND FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 OCTOBER 2016 FOR

UNITED KINGDOM PRIMARY IMMUNODEFICIENCY NETWORK

WEDNESDAY

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08/03/2017 COMPANIES HOUSE #212

Hartley Fowler LLP Statutory Auditors Chartered Accountants 44 Springfield Road Horsham West Sussex RH12 2PD

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REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 OCTOBER 2016

The trustees who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31 October 2016. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard for Smaller Entities (the FRSSE) (effective 1 January 2015).

OBJECTIVES AND ACTIVITIES

Objectives and aims

The main objective of UK PIN is to advance care for primary immunodeficiency. The workstreams include:

- 1. development of best practice guidance.
- 2. clinical leadership of the QPIDS accreditation scheme run through the Royal College of Physicians Accreditation Unit.
- 3. maintenance of the UK PID registry and annual reporting combined with MDSAS.
- 4. advancement of education in primary immunodeficiency.
- 5. enhancement of communication and networking of professionals working in the field of PID.

The charity seeks to achieve its objectives by aiming to improve patient care through networking, standardisation of care based on evidence and enhanced understanding of disease.

Significant activities

During the year, the following significant activities took place:

- 1. partnership agreement with BSI to develop evidence based guidance for PID.
- 2. contribution to national patient information.
- 3. majority of PID centres registered and preparing for accreditation.
- 4. maintenance of patient registry.
- 5. partnership agreement with MDSAS with the aim of producing combined annual report.
- 6. successful biennial UKPIN meeting.
- 7. development of new website with enhanced functionality for networking.
- 8. publication of quarterly eNewsletter to membership.
- 9. membership database review.

Public benefit

The activities of the charity are for the public benefit as the accreditation scheme, the development of guidelines and registry enhances understanding and standardises management of immunodeficiency diseases.

ACHIEVEMENT AND PERFORMANCE

Charitable activities

Incoming resources for the period totalled £229,351 (2015: £284,180).

Resources expended of £235,182 (2015: £210,275), resulting in net outgoing resources in the period of £5,831 (2015: net incoming resources of £73,905).

The balance sheet appears healthy with a net assets position of £68,074 (2015: £73,905).

FINANCIAL REVIEW

Principal funding sources

The principle funding source so far has been pharmaceutical funding and the attendance at the biennial UK PIN Conference. In addition UK PIN will introduce membership fees to ensure the charity becomes less reliant on money generated by pharmaceutical funding. The charity is also considering other mechanisms of funding the registry project including but not limited to NIHR.

Reserves policy

The charity's policy is to set aside funds for special purposes or as reserves against future expenditure, and also to enable smooth running of the charity.

FUTURE PLANS

The charity aims to introduce UK PIN membership fees in the near future to support management costs and to generate funds for guidelines development. The charity has a strategic forward plan with the broad aim of advancing care for PID patient based on the specific workstreams details in the charity's aims.

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 OCTOBER 2016

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

The charity is controlled by its governing document, articles of association, and constitutes a limited company, limited by guarantee, as defined by the Companies Act 2006.

Recruitment and appointment of new trustees

There will be 3 to 15 trustees who will be elected by the membership following nomination.

Each year there will be a call to the membership for nominations followed by membership vote. Each year one third of trustees will retire (not in the calendar year of incorporation or the calendar year following incorporation) and the positions will be filled by elected members. Trustees may be appointed without election if there is no contest or where trustees from specific professional groups are required.

Organisational structure

The steering committee (board of trustees) meets quarterly and decisions are agreed on by open vote. The sub-committees report into the steering committee and the reports are approved during steering committee meetings. Any decisions outside of the steering committee meetings will either be resolved by the directors agreeing or by an electronic vote by all of the trustees.

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Company number

09273983 (England and Wales)

Registered Charity number

1164466

Registered office

C/o MCI UK Ltd Durford Mill Petersfield Hampshire GU31 SAZ

Directors

Mr M Buckland Consultant - resigned 19/11/15

Immunologist

Dr J Edgar Medical Doctor - resigned 19/11/15
Dr C Bethune Medical Practitioner - appointed 19/11/15
Dr R Jain Doctor - resigned 19/11/15
- appointed 19/11/15

Dr T Garcez Medical Doctor - appointed 19/11/15
Dr D Kumararatne - resigned 19/11/15

Auditors

Hartley Fowler LLP Statutory Auditors Chartered Accountants 44 Springfield Road Horsham West Sussex RH12 2PD

COMMENCEMENT OF ACTIVITIES

The charity commenced trading on 21st October 2014.

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 OCTOBER 2016

STATEMENT OF TRUSTEES RESPONSIBILITIES

The trustees (who are also the directors of United Kingdom Primary Immunodeficiency Network for the purposes of company law) are responsible for preparing the Report of the Trustees and the 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 charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that period. In preparing those financial statements, the trustees are required to

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charity SORP;
- make judgements and estimates that are reasonable and prudent:
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in business.

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

In so far as the trustees are aware:

- there is no relevant audit information of which the charitable company's auditors are unaware; and
- the trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditors are aware of that information.

AUDITORS

The auditors, Hartley Fowler LLP, will be proposed for re-appointment at the forthcoming Annual General Meeting.

This report has been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small companies.

REPORT OF THE INDEPENDENT AUDITORS TO THE MEMBERS OF UNITED KINGDOM PRIMARY IMMUNODEFICIENCY NETWORK

We have audited the financial statements of United Kingdom Primary Immunodeficiency Network for the year ended 31 October 2016 on pages six to twelve. The financial reporting framework that has been applied in their preparation is applicable law and the Financial Reporting Standard for Smaller Entities (effective January 2015) (United Kingdom Generally Accepted Accounting Practice applicable to Smaller Entities).

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

Respective responsibilities of trustees and auditors

As explained more fully in the Statement of Trustees Responsibilities set out on page three, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view.

Our responsibility is to audit and express an opinion on the financial statements in accordance with applicable law and International Standards on Auditing (UK and Ireland). Those standards require us to comply with the Auditing Practices Board's Ethical Standards for Auditors.

Scope of the audit of the financial statements

An audit involves obtaining evidence about the amounts and disclosures in the financial statements sufficient to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or error. This includes an assessment of: whether the accounting policies are appropriate to the charitable company's circumstances and have been consistently applied and adequately disclosed; the reasonableness of significant accounting estimates made by the trustees; and the overall presentation of the financial statements. In addition, we read all the financial and non-financial information in the Report of the Trustees to identify material inconsistencies with the audited financial statements and to identify any information that is apparently materially incorrect based on, or materially inconsistent with, the knowledge acquired by us in the course of performing the audit. If we become aware of any apparent material misstatements or inconsistencies we consider the implications for our report.

Opinion on financial statements

In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 October 2016 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice applicable to Smaller Entities; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

Opinion on other matter prescribed by the Companies Act 2006

In our opinion the information given in the Report of the Trustees for the financial year for which the financial statements are prepared is consistent with the financial statements.

REPORT OF THE INDEPENDENT AUDITORS TO THE MEMBERS OF UNITED KINGDOM PRIMARY IMMUNODEFICIENCY NETWORK

Matters on which we are required to report by exception

We have nothing to report in respect of the following matters where the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate accounting records have not been kept or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; or
- the trustees were not entitled to prepare the financial statements in accordance with the small companies regime and take advantage of the small companies exemption from the requirement to prepare a Strategic Report or in preparing the Report of the Trustees.

Matthew Cleghorn ACA (Senior Statutory Auditor)
For and on behalf of Hartley Fowler LLP
Statutory Auditors
Chartered Accountants
44 Springfield Road
Horsham
West Sussex
RH12 2PD

nator 6th March 2017

STATEMENT OF FINANCIAL ACTIVITIES (INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT) FOR THE YEAR ENDED 31 OCTOBER 2016

INCOME AND ENDOWMENTS FROM	Notes	Year Ended 31/10/16 Unrestricted fund £	Period 21/10/14 to 31/10/15 Total funds
Activities for generating funds Investment income	2 3	229,351	284,178 2
Total		229,351	284,180
EXPENDITURE ON Cost of generating funds Charitable activities Governance Costs Administrative expenditure	4 5	140,402 8,609 86,171	20,036 13,599 176,640
Total		235,182	210,275
NET INCOME/(EXPENDITURE)		(5,831)	73,905
RECONCILIATION OF FUNDS			
Total funds brought forward		73,905	
TOTAL FUNDS CARRIED FORWARD		68,074	73,905

BALANCE SHEET AT 31 OCTOBER 2016

•					,
				2016 Unrestricted fund	2015 Total funds
	Notes		ב	£	£
CURRENT ASSETS Debtors Cash at bank	10			49,000 79,238	183,713 177,911
	, .			128,238	361,624
CREDITORS Amounts falling due within one year	11			(60,164)	(287,719)
NET CURRENT ASSETS				_68,074	73,905
TOTAL ASSETS LESS CURRENT LIABILITIE	s		,	68,074	73,905
NET ASSETS		. •		68,074	73,905
FUNDS Unrestricted funds	12			68,074	73,905
TOTAL FUNDS		•		68,074	<u>73,905</u>

These financial statements have been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small charitable companies and with the Financial Reporting Standard for Smaller Entities (effective January 2015).

Dr R Jain -Director

The notes form part of these financial statements

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 OCTOBER 2016

1. ACCOUNTING POLICIES

Basis of preparing the financial statements

The financial statements of the charitable company have been prepared in accordance with the Charities SORP (FRSSE) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard for Smaller Entities (the FRSSE) (effective 1 January 2015)', the Financial Reporting Standard for Smaller Entities (effective January 2015) and the Companies Act 2006. The financial statements have been prepared under the historical cost convention.

Exemption from preparing a cash flow statement

Exemption has been taken from preparing a cash flow statement in accordance with the Financial Reporting Standard for Smaller Entities (effective January 2015).

Income

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

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.

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 particular restricted purposes.

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

2. ACTIVITIES FOR GENERATING FUNDS

	Deposit account interest	Year Ended 31/10/16 £	Period 21/10/14 to 31/10/15 £
3.	INVESTMENT INCOME		
	Conference income	Year Ended 31/10/16 £ 229,351	21/10/14 to 31/10/15 £ 284,178

NOTES TO THE FINANCIAL STATEMENTS - CONTINUED FOR THE YEAR ENDED 31 OCTOBER 2016

4. COST OF GENERATING FUNDS

Costs of generating voluntary income

•		Period
•		21/10/14
	Year Ended	to
	31/10/16	31/10/15
	£	£
Venue Hire	48,915	2,117
Travel costs	22,031	6,554
Website	29,344	1,893
Executive Secretariat	40,112	9,472
	140,402	20,036

5. CHARITABLE ACTIVITIES COSTS

	Support costs	Totals
	(See note 6)	
	£	. £
Governance Costs	8,609	8,609
Administrative expenditure	<u>86,171</u>	86,171
	94,780	94,780

6. SUPPORT COSTS

·	Support Costs
Governance Costs Administrative expenditure	8,609 86,171
	94,780

Support costs, included in the above, are as follows:

NOTES TO THE FINANCIAL STATEMENTS - CONTINUED FOR THE YEAR ENDED 31 OCTOBER 2016

6. SUPPORT COSTS - continued

Support Costs

•	,			Period
				21/10/14
			Year Ended	to
			31/10/16	31/10/15
	Governance	Administrative		
	Costs	expenditure	Total activities	Total activities
	£	£	£	£
Auditors' remuneration	4,000	-	4,000	4,000
Bank charges	3,094	-	3,094	117
Legal fees	1,515	-	1,515	9,482
Wages	· -	47,167	47,167	112,152
Committee expenses	-	8,552	8,552	20,183
Awards and gifts	-	886	886	-
Secretariat Fees	-	26,984	26,984	12,860
Postage and stationery	-	985	985	1,209
Telephone	-	1,597	1,597	236
Accreditation				30,000
	<u>8,609</u>	86,171	94,780	190,239

7. NET INCOME/(EXPENDITURE)

Net income/ (expenditure) is stated after charging/ (crediting):

TRUSTEES' REMUNERATION AND BENEFITS

	Period
	21/10/14
Year Ended	to
31/10/16	31/10/15
£	£
<u>4,000</u>	<u>4,000</u>

Auditors' remuneration

8.

There were no trustees' remuneration or other benefits for the year ended 31 October 2016 nor for the period ended 31 October 2015.

Trustees' expenses

During the year, the following expenses were reimbursed to trustees:

Trustees	Reason	Reimbursed (£)	Year End Creditor (£)
Ms C.Bethune	Directors Expenses	126	-
Dr R.Jain	None in the year	-	-
Dr T.Garcez	Directors Expenses	120	-
Dr J. Edgar	Directors Expenses	406	- .

NOTES TO THE FINANCIAL STATEMENTS - CONTINUED FOR THE YEAR ENDED 31 OCTOBER 2016

9.	STAFF COSTS			
	Wages and salaries		Year Ended 31/10/16 £ 47,167	Period 21/10/14 to 31/10/15 £ 112,152
	The average monthly number of employees during the year was as	s follows:		
	Registry Staff		Year Ended 31/10/16 3	Period 21/10/14 to 31/10/153
	No employees received empluments in excess of £60,000.			
10.	DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR			
	Trade debtors Other debtors		2016 £ 49,000 ——————————————————————————————————	2015 £ 167,570 16,143 183,713
11.	CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR			
	Trade creditors VAT Accruals and deferred income Accrued expenses		2016 £ 21,261 3,282 20,833 14,788	2015 £ 9,478 38,074 170,718 69,449 287,719
12.	MOVEMENT IN FUNDS			
	Unrestricted funds General fund	At 1/11/15 £ 73,905	Net movement in funds £ (5,831)	At 31/10/16 £ 68,074
	TOTAL FUNDS	73,905	<u>(5,831</u>)	68,074

NOTES TO THE FINANCIAL STATEMENTS - CONTINUED FOR THE YEAR ENDED 31 OCTOBER 2016

12. MOVEMENT IN FUNDS - continued

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds
Unrestricted funds General fund	229,351	(235,182)	(5,831)
TOTAL FUNDS	229,351	(235,182)	<u>(5,831</u>)

13. CAPITAL COMMITMENTS

The company has committed to paying MCI Secretariat £10,500 (2015: £21,000) in monthly instalments, over the next 6 (2015: 12) months after the period ended 31 October 2016.

14. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 October 2016.