
UKPIPS
(A company limited by guarantee)

UNAUDITED
TRUSTEES' REPORT AND FINANCIAL STATEMENTS
FOR THE PERIOD ENDED 28 FEBRUARY 2013

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**REFERENCE AND ADMINISTRATIVE DETAILS OF THE COMPANY, ITS TRUSTEES AND ADVISERS
FOR THE PERIOD ENDED 28 FEBRUARY 2013**

Trustees Margaret Anne Fuller, Trustee (appointed 7 August 2012)
Elizabeth Mary Macartney, Trustee (appointed 20 April 2012)
Geoffrey Oliver Peter Moore, Trustee (appointed 20 April 2012)

Company registered number 7957558

Charity registered number 1148789

Registered office 32 Avon Street
Evesham
Worcestershire
WR11 4LQ

Accountants Brian Cook Associates
Chartered Accountants
Marine House
151 Western Road
Haywards Heath
West Sussex
RH16 3LH

UKPIPS
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TRUSTEES' REPORT
FOR THE PERIOD ENDED 28 FEBRUARY 2013

The Trustees (who are also directors of the charity for the purposes of the Companies Act) present their annual report together with the financial statements of UKPIPS (the company) for the period ended 28 February 2013. The Trustees confirm that the Annual report and financial statements of the company comply with the current statutory requirements, the requirements of the company's governing document and the provisions of the Statement of Recommended Practice (SORP) "Accounting and Reporting by Charities" issued in March 2005.

Structure, governance and management

a. CONSTITUTION

The company is registered as a charitable company limited by guarantee. It is constituted under a Memorandum of Association dated 20/2/2012 and is a registered charity number 1148789.

The principal object of the company is to promote and protect the physical and mental health of sufferers of Primary Antibody Deficiency and other Primary Immune Deficiencies, in the United Kingdom through the provision of support, education and practical advice.

b. METHOD OF APPOINTMENT OR ELECTION OF TRUSTEES

The management of the company is the responsibility of the Trustees who are elected and co-opted under the terms of the Articles of Association.

Objectives and Activities

a. POLICIES AND OBJECTIVES

The Charity's objectives are:

- To provide information and support for patients (and their carers, partners and family) with a Primary Antibody Deficiency and other Primary Immune Deficiencies, residing permanently or temporarily in the United Kingdom
- To establish a volunteer medical panel comprising appropriate experts
- To advance the education of the general public and medical community in all areas relating to a Primary Antibody Deficiency and other Primary Immune Deficiencies
- To promote the social and medical welfare of people with a Primary Antibody Deficiency and other Primary Immune Deficiencies
- To encourage research into Primary Antibody Deficiency and other Primary Immune Deficiencies
- To champion recognition and representation
- To expand activities from time to time in any way that may be consistent with the foregoing in order to bring benefit to the community of people in the UK with a Primary Antibody Deficiency and other Primary Immune Deficiencies.

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TRUSTEES' REPORT (continued)
FOR THE PERIOD ENDED 28 FEBRUARY 2013

b. ACTIVITIES FOR ACHIEVING OBJECTIVES

UKPIPS has identified the following activities to promote the achievement of these objectives:

- The establishment of UKPIPS as a limited company and a charity
- The development of a UKPIPS community of patients and their carers, partners and family
- The establishment of a presence on the internet and social networking sites
- The production and publication of information leaflets providing information about Primary Antibody Deficiency and other Primary Immune Deficiencies and a community newsletter
- An awareness raising project which involves visits to immunology centres around the UK to promote the charity to medical staff and patients
- The establishment of a volunteer medical panel and a volunteer panel of other experts to provide appropriate and reviewed information to the UKPIPS community, the general public and the medical community
- The encouragement of fund-raising activities to provide funds for the charity
- The representation of the needs of patients with a Primary Antibody Deficiency and other Primary Immune deficiencies to hospital trusts, NHS England and to Members of Parliament and Government Ministers.

Achievements and performance

a. GOING CONCERN

After making appropriate enquiries, the trustees have a reasonable expectation that the company has adequate resources to continue in operational existence for the foreseeable future. For this reason they continue to adopt the going concern basis in preparing the financial statements. Further details regarding the adoption of the going concern basis can be found in the Accounting Policies.

b. REVIEW OF ACTIVITIES

- UKPIPS was incorporated on 21st February 2012 and registered as a charity on 3rd September 2012. The Articles of Association of UKPIPS Ltd sets out the objectives and governance of the organisation. It is an entirely volunteer organisation and has no paid employees at the present time.
- The need for a formal organisation to represent patients with a PAD and other PIDs became apparent in January 2012, from telephone conversations and discussions on internet forums. From this a steering group evolved which enabled the formation of UKPIPS Ltd. The steering group recognised that the community of PID patients, carers and their families would appreciate a place where they could discuss issues with others. UKPIPS' priorities therefore included the development of a website, forum and Twitter account to provide this support. We are grateful for the expertise and generosity of volunteers in setting these up and continuing to maintain them.

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TRUSTEES' REPORT (continued)
FOR THE PERIOD ENDED 28 FEBRUARY 2013

- From these initiatives, a community of c. 420 people has grown up and UKPIPS keeps them updated on developments via a newsletter and information on the website and social networks.
- 5 leaflets have been produced over the year providing information about Primary Antibody Deficiency and other Primary Immune Deficiencies. In order for these to be available in NHS outlets it is necessary for UKPIPS to develop an information production system and to be accredited to the Information Standard. Work is underway to be audited and to achieve this quality mark.
- The Co-ordinator has visited c.20 Immunology centres during the year, talking to patients, nurse specialists and doctors. A helpline has been set up where people can obtain support and help, and this has been well used by members of the Community. An average of 3 people per week is asking for help and support.
- The major event to raise awareness of UKPIPS' objectives, work and future developments took place in November, when we held a meeting for the UKPIPS community, interested medical specialists and pharmaceutical companies. We were very grateful for the donations that made this successful event possible. At least 50 people were present and it was good to meet and discuss the way forward.
- The second important activity was the educational meeting on 4th February 2013 for practitioners, GPs and nurse specialists at which we were greatly honoured to have the presence of Prof. Etzioni, President of ECID and an eminent specialist in the treatment of children with PID. Other speakers included Dr Siobhan Burns, Great Ormond & Royal Free Hospitals, Mr John Dempster, Clinical Nurse Specialist Barts & London, Dr Sadia Noorani, Birmingham City Hospital, who worked with UKPIPS to arrange the event. This event was attended by over 100 people and invitations were sent to over 8 MPs and 56 GPs, thus increasing awareness of PIDs amongst this community.
- A volunteer medical panel, consisting of both nurse specialists and doctors, has been established. They provide UKPIPS directors and community with advice and guidance, as well as authoring leaflets and providing a review panel for our publications. Volunteers also offer their professional expertise to review publications and to provide professional guidance on matters such as employment and benefits. UKPIPS is very grateful to them all for their willingness to support the UKPIPS community and the directors in this way.
- Over the year there have been several occasions when the Co-ordinator has responded to consultation documents put out by the Government or NHS England on behalf of UKPIPS. This has included contributions to the "Draft Service Specification for Paediatric Immunology", the "Draft Service Specification for Specialised Immunology: Clinical Services", the "Anonymising of Data in the NHS", the "NHS Payment System", and the "External Review on Screening for Severe Combined Immune Deficiency". The UKPIPS Community also wrote a template letter in support of the proposition for neonatal screening for SCID, which generated in the region of 80 responses from the UKPIPS community. It is important to represent the needs of patients with PAD in this way and through our affiliation to such groups as Rare Disease UK and Genetic Alliance. Volunteers and trustees also attended Rare Disease Day events in Cardiff, Edinburgh and London in February.
- The Co-ordinator has been in consultation with and made visits to three NHS Hospital Trusts, whose provision of services for patients with a PAD fall below the level regarded as acceptable by UKPIN. As a result of this work, 5 new nursing posts have been assigned to the care of PAD patients within these hospital trusts. Discussions were also initiated with the department of Health about the funding of these services. UKPIPS wrote to over 50 MPs in East Anglia, bringing to their attention the needs of those living with a PID in their constituencies. The Co-ordinator also initiated correspondence with the Department of Work and pensions about the needs of PID patients when being assessed for benefits. This resulted in increased awareness in Government circles about those living with these conditions.

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TRUSTEES' REPORT (continued)
FOR THE PERIOD ENDED 28 FEBRUARY 2013

c. FUNDRAISING ACTIVITIES/INCOME GENERATION

Income generation has been on a small scale this year and limited to the sale of Christmas cards and to the donations provided by members of our community.

Financial review

a. RESERVES POLICY

It is the policy of the trustees to maintain a level of reserves sufficient to cover three months anticipated expenditure. At 31 March 2013 the level of reserves was consistent with this policy.

b. PRINCIPAL FUNDING

Our funding comes from donations from members of the UKPIPS community and support from pharmaceutical companies.

Plans for the future

a. FUTURE DEVELOPMENTS

UKPIPS is developing a business plan for 2013 -15. The objective is "to consolidate the progress achieved so far, and to launch a number of new projects". In the coming year we plan to achieve the following:

- Awareness Project phase 2 – to build on the work that has already been done and to visit the majority of immunology clinics in England. This has been the major focus of the Co-ordinator and will continue in the future.
- UKPIPS presence in Scotland – to assess the need to provide people with a PAD or PID in Scotland with the same level of support as others within the UK. This may involve registration of the charity in Scotland and the development of a branch in Scotland
- Community meetings – To hold one or more meetings in different regions to enable the community to meet in person and to provide networking, information and other support
- Information Standard: To achieve the Information Standard, recognized by the NHS, to ensure that our information production system is accredited as a quality process that meets the Standard. Therefore our information will be available for use by health and social care organisations
- Development of a UKPIPS server and email addresses to improve the security and effectiveness of our electronic systems
- Strategies for volunteers and fund-raising to ensure that we have the people and financial resources to maintain and develop our objectives and plans.

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MEMBERS' LIABILITY

The Members of the company guarantee to contribute an amount not exceeding £1 to the assets of the charity in the event of winding up.

In preparing this report, the Trustees have taken advantage of the small companies exemptions provided by section 415A of the Companies Act 2006.

This report was approved by the Trustees on 19 September 2013 and signed on their behalf by:

Margaret Anne Fuller, Trustee

Elizabeth Mary Macartney, Trustee

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**CHARTERED ACCOUNTANTS' REPORT TO THE TRUSTEES ON THE PREPARATION OF THE
UNAUDITED STATUTORY FINANCIAL STATEMENTS OF UKPIPS
FOR THE PERIOD ENDED 28 FEBRUARY 2013**

In order to assist you to fulfil your duties under the Companies Act 2006, we have prepared for your approval the financial statements of UKPIPS for the period ended 28 February 2013 which comprise the Statement of financial activities, the Balance sheet and the related notes from the company's accounting records and from information and explanations you have given to us.

As a member firm of the Institute of Chartered Accountants in England and Wales (ICAEW), we are subject to its ethical and other professional requirements which are detailed at icaew.com/regulations.

This report is made solely to the Trustees in accordance with the terms of our engagement letter dated 9 September 2013. Our work has been undertaken solely to prepare for your approval the financial statements of UKPIPS and state those matters that we have agreed to state to them in this report in accordance with AAF 2/10 as detailed at icaew.com/compilation. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than UKPIPS and its Trustees for our work or for this report.

It is your duty to ensure that UKPIPS has kept adequate accounting records and to prepare statutory financial statements that give a true and fair view of the company's assets, liabilities, financial position and net incoming resources. You consider that UKPIPS is exempt from the statutory audit requirement for the period.

We have not been instructed to carry out an audit or review of the financial statements of UKPIPS. For this reason, we have not verified the accuracy or completeness of the accounting records or information and explanations you have given to us and we do not, therefore, express any opinion on the statutory financial statements.

Brian Cook Associates

Chartered Accountants

Marine House
151 Western Road
Haywards Heath
West Sussex
RH16 3LH

24 September 2013

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STATEMENT OF FINANCIAL ACTIVITIES
(incorporating income and expenditure account)
FOR THE PERIOD ENDED 28 FEBRUARY 2013

	Note	Restricted funds 2013 £	Unrestricted funds 2013 £	Total funds 2013 £
INCOMING RESOURCES				
Incoming resources from generated funds:				
Voluntary income	2	5,364	4,699	10,063
Activities for generating funds	3	-	338	338
TOTAL INCOMING RESOURCES		5,364	5,037	10,401
RESOURCES EXPENDED				
Costs of generating funds:				
Costs of generating voluntary income	4	-	214	214
Charitable activities	6	4,827	1,971	6,798
Governance costs	5	-	815	815
TOTAL RESOURCES EXPENDED		4,827	3,000	7,827
NET INCOME BEFORE TRANSFERS		537	2,037	2,574
Transfers between Funds	10	138	(138)	-
NET MOVEMENT IN FUNDS FOR THE YEAR		675	1,899	2,574
<i>Total funds at 21 February 2012</i>		-	-	-
TOTAL FUNDS AT 28 FEBRUARY 2013		675	1,899	2,574

The notes on pages 10 to 14 form part of these financial statements.

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REGISTERED NUMBER: 7957558

BALANCE SHEET
AS AT 28 FEBRUARY 2013

	Note	£	2013	£
FIXED ASSETS				
Tangible assets	8			104
CURRENT ASSETS				
Stocks			25	
Cash at bank			2,745	
			<u>2,770</u>	
CREDITORS: amounts falling due within one year	9		(300)	
			<u>2,470</u>	
NET CURRENT ASSETS				2,470
NET ASSETS				<u>2,574</u>
CHARITY FUNDS				
Restricted funds	10			675
Unrestricted funds	10			1,899
				<u>2,574</u>
TOTAL FUNDS				<u>2,574</u>

The Trustees consider that the company is entitled to exemption from the requirement to have an audit under the provisions of section 477 of the Companies Act 2006 ("the Act") and members have not required the company to obtain an audit for the period in question in accordance with section 476 of the Act.

The Trustees acknowledge their responsibilities for complying with the requirements of the Companies Act 2006 with respect to accounting records and for preparing financial statements which give a true and fair view of the state of affairs of the company as at 28 February 2013 and of its net incoming resources for the period in accordance with the requirements of sections 394 and 395 of the Act and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the company.

The financial statements have been prepared in accordance with the special provisions relating to companies subject to the small companies regime within Part 15 of the Companies Act 2006 and in accordance with the Financial Reporting Standard for Smaller Entities (effective April 2008).

The financial statements were approved by the Trustees on 19 September 2013 and signed on their behalf, by:

Margaret Anne Fuller, Trustee

Elizabeth Mary Macartney, Trustee

The notes on pages 10 to 14 form part of these financial statements.

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NOTES TO THE FINANCIAL STATEMENTS
FOR THE PERIOD ENDED 28 FEBRUARY 2013

1. ACCOUNTING POLICIES

1.1 Basis of preparation of financial statements

The financial statements have been prepared under the historical cost convention, with the exception of investments which are included at market value, and in accordance with the Financial Reporting Standard for Smaller Entities (effective April 2008). The financial statements have been prepared in accordance with the Statement of Recommended Practice (SORP), 'Accounting and Reporting by Charities' published in March 2005, applicable accounting standards and the Companies Act 2006.

1.2 Company status

The company is a company limited by guarantee. The members of the company are the Trustees named on page 1. In the event of the company being wound up, the liability in respect of the guarantee is limited to £1 per member of the company.

1.3 Fund accounting

General funds are unrestricted funds which are available for use at the discretion of the Trustees in furtherance of the general objectives of the company and which have not been designated for other purposes.

Restricted funds are funds which are to be used in accordance with specific restrictions imposed by donors or which have been raised by the company for particular purposes. The costs of raising and administering such funds are charged against the specific fund. The aim and use of each restricted fund is set out in the notes to the financial statements.

1.4 Incoming resources

All incoming resources are included in the Statement of financial activities when the company is legally entitled to the income and the amount can be quantified with reasonable accuracy.

Donated services or facilities, which comprise donated services, are included in income at a valuation which is an estimate of the financial cost borne by the donor where such a cost is quantifiable and measurable. No income is recognised where there is no financial cost borne by a third party.

Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

Income tax recoverable in relation to investment income is recognised at the time the investment income is receivable.

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NOTES TO THE FINANCIAL STATEMENTS
FOR THE PERIOD ENDED 28 FEBRUARY 2013

1. ACCOUNTING POLICIES (continued)

1.5 Resources expended

All expenditure is accounted for on an accruals basis and has been included under expense categories that aggregate all costs for allocation to activities. Where costs cannot be directly attributed to particular activities they have been allocated on a basis consistent with the use of the resources.

Support costs are those costs incurred directly in support of expenditure on the objects of the company and include project management carried out at Headquarters. Governance costs are those incurred in connection with administration of the company and compliance with constitutional and statutory requirements.

1.6 Tangible fixed assets and depreciation

Tangible fixed assets are stated at cost less depreciation. Depreciation is provided at rates calculated to write off the cost of fixed assets, less their estimated residual value, over their expected useful lives on the following bases:

Office equipment - 25% reducing balance

2. VOLUNTARY INCOME

	Restricted funds 2013 £	Unrestricted funds 2013 £	Total funds 2013 £
Donations	-	2,075	2,075
Grants	5,364	2,624	7,988
	<hr/>	<hr/>	<hr/>
Voluntary income	5,364	4,699	10,063
	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>

3. FUNDRAISING INCOME

	Restricted funds 2013 £	Unrestricted funds 2013 £	Total funds 2013 £
Christmas cards	-	338	338
	<hr/>	<hr/>	<hr/>

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NOTES TO THE FINANCIAL STATEMENTS
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4. COSTS OF GENERATING VOLUNTARY INCOME

	Restricted funds 2013 £	Unrestricted funds 2013 £	Total funds 2013 £
Cost of cards	-	214	214

5. GOVERNANCE COSTS

	Restricted funds 2013 £	Unrestricted funds 2013 £	Total funds 2013 £
Accountancy	-	780	780
Depreciation of office equipment	-	35	35
	-	815	815

6. SUPPORT COSTS

	£
Motor expenses	3,140
Office supplies	607
Website	298
Travel	147
Accommodation and subsistence	869
Postage	151
Sundry expenses	91
Event cost	1,495
	<u>6,798</u>

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NOTES TO THE FINANCIAL STATEMENTS
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7. NET INCOME

This is stated after charging:

	Period ended 28 February 2013 £
Depreciation of tangible fixed assets: - owned by the charity	35
Accountancy	780
	815

During the period, no Trustees received any remuneration.
During the period, no Trustees received any benefits in kind.
During the period, no Trustees received any reimbursement of expenses.

8. TANGIBLE FIXED ASSETS

	Office equipment £
Cost	
At 21 February 2012	-
Additions	139
At 28 February 2013	139
Depreciation	
At 21 February 2012	-
Charge for the period	35
At 28 February 2013	35
Net book value	
At 28 February 2013	104

9. CREDITORS:
Amounts falling due within one year

	2013 £
Accruals and deferred income	300

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**NOTES TO THE FINANCIAL STATEMENTS
FOR THE PERIOD ENDED 28 FEBRUARY 2013**

10. STATEMENT OF FUNDS

	Brought Forward £	Incoming resources £	Resources Expended £	Transfers in/out £	Carried Forward £
Unrestricted funds					
General Funds - all funds	-	5,037	(3,000)	(138)	1,899
Restricted funds					
Awareness project	-	4,689	(4,827)	138	-
Birmingham meeting	-	675	-	-	675
	-	5,364	(4,827)	138	675
Total of funds	-	10,401	(7,827)	-	2,574

SUMMARY OF FUNDS

	Brought Forward £	Incoming resources £	Resources Expended £	Transfers in/out £	Carried Forward £
General funds	-	5,037	(3,000)	(138)	1,899
Restricted funds	-	5,364	(4,827)	138	675
	-	10,401	(7,827)	-	2,574

11. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	Restricted funds 2013 £	Unrestricted funds 2013 £	Total funds 2013 £
Tangible fixed assets	-	104	104
Current assets	675	2,095	2,770
Creditors due within one year	-	(300)	(300)
	675	1,899	2,574