

**THE PRIMARY IMMUNODEFICIENCY ASSOCIATION
(A COMPANY LIMITED BY GUARANTEE)**

FINANCIAL STATEMENTS

**FOR THE PERIOD FROM 1 JANUARY 2011
TO 31 MARCH 2012**

Registered Charity No. 1107233

Company Registration No. 05230438



THE PRIMARY IMMUNODEFICIENCY ASSOCIATION

LEGAL AND ADMINISTRATIVE INFORMATION

Trustees	A. Moore J. Drabwell R McNairney (Resigned 13 February 2012) D Webster K Hennessy (Resigned 13 February 2012)
Company Secretary	C Hughan
Chairman	D Webster
Chief Executive	C Hughan (Resigned 14 April 2011)
Charity no	1107233
Company no	05230438
Registered office and Principal address	Alliance House 12 Caxton Street London SW1H 0QS
Auditors	Ward Williams Belgrave House 39-43 Monument Hill Weybridge Surrey KT13 8RN
Bankers	The Royal Bank of Scotland 3 rd Floor, Cavell House 2a Charing Cross Road London WC2H 0NN

THE PRIMARY IMMUNODEFICIENCY ASSOCIATION

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THE PRIMARY IMMUNODEFICIENCY ASSOCIATION

REPORT OF THE TRUSTEES FOR THE PERIOD ENDED 31 MARCH 2012

Report of the Trustees

The Trustees present their Report and Statement of Financial Activities for the fifteen months ended 31 March 2012

The Accounts have been prepared in accordance with the accounting policies set out in note 1 to the Accounts and comply with the Charity's Memorandum and Articles of Association, applicable law and the requirements of the Statement of Recommended Practice, "Accounting and Reporting by Charities" issued in 2005

Structure, Governance and Management

Constitution

The Primary Immunodeficiency Association ('PiA') was established originally under a Trust Deed dated 14 March 1990 and registered as a charitable Unincorporated Association with the Charity Commission (number 803217). In accordance with a resolution, passed unanimously at the PiA AGM on 20 May 2006, PiA changed its constitution and legal status from an Unincorporated Association to a charitable Company limited by Guarantee (Registered in England and Wales under company number 5230438). PiA remains a Registered Charity (number 1107233) and all the activities, contracts, assets and liabilities of the previous Association have been transferred to the new Charity. It is governed by a Memorandum & Articles of Association, adopted on 4 December 2004 and approved by the Charity Commission.

Trustees, Staff and Professional Advisers

The Trustees, who are also the directors for the purpose of company law, who served during the fifteen months, were

Dr David Webster, MD, FRCP, FRCPath - Chairman

Mr Andrew Moore, FCA, MA (Oxon) - Treasurer

Mrs Jose Drabwell

Mrs Kathryn Hennessy (Resigned 13 February 2012)

Mrs Rae McNairney (Resigned 13 February 2012)

The Chief Executive Officer of the PiA was Christopher Hugan. In 2011 there were a further three employees (all full-time). All staff, including the CEO, had left the company by 31 December 2011.

The Auditors of the PiA are.

Ward Williams

Belgrave House, 39-43 Monument Hill

Weybridge

Surrey KT13 8RN

THE PRIMARY IMMUNODEFICIENCY ASSOCIATION

REPORT OF THE TRUSTEES FOR THE PERIOD ENDED 31 MARCH 2012

The Principal Bankers of the PIA are

Royal Bank of Scotland
3rd Floor, Cavell House
2a Charing Cross Road
London WC2H 0NN

Governance and Risk Assessment

None of the Trustees has any beneficial interest in the company. All of the Trustees are members of the company and guarantee to contribute £1 in the event of a winding up.

The nomination of a new Trustee can be proposed by any existing Trustee or by a candidate who is a member of the Charity putting his or her name forward for consideration. The Trustees can also co-opt Trustees at any time.

Election to the Board is for an initial period of three years. At the end of this term Trustees may offer themselves for a further term of three years. Following six years in the post Trustees would normally retire from the Board. However, in exceptional circumstances, Trustees may be elected to remain on the Board on a year-by-year basis up to a maximum of nine years, at which time they must retire.

Training and induction for new Trustees is provided as necessary.

The PIA is administered by a Trustee Board of not less than three or more than nine members, including the Chairman and Honorary Officers. These unpaid Trustees serve alongside the Chief Executive and other paid staff, on a day-to-day basis. Sub-committees are established as and when necessary.

The Board meets not less than four times a year, in addition to the Annual General Meeting. A strategy-planning meeting is held each year to carry out an in-depth view of activities and to plan for several years ahead.

The PIA has a Medical Advisory Panel, membership of which is at the invitation of the Trustee Board (through the Chief Executive). The Chairman of this Panel is an ex officio member of the Board. The functions of the Medical Advisory Panel include providing guidance and advice to the PIA on medical and associated matters, patient related issues and approving the medical content of all materials published by the PIA.

THE PRIMARY IMMUNODEFICIENCY ASSOCIATION

REPORT OF THE TRUSTEES FOR THE PERIOD ENDED 31 MARCH 2012

In last year's annual report the PiA Trustees expressed deep concerns for the financial future of PiA in 2011 and beyond. This followed the unanticipated and unexpected withdrawal by the Jeans for Genes (J4G) trademark holder, the Chronic Granulomatous Disorder Research Trust (CDGRT), of a previously agreed three-year transitional fee arrangement – designed to lessen the anticipated financial impact of the end of the J4G partnership agreement (also ended by CGDRT) and the consequent loss of substantial J4G revenue to the three other founding and Partner charities involved for over 15 years in the J4G campaign, including PiA.

Despite instigating severe cost-cutting measures, including the loss of staff, and increasing fundraising efforts in a number of areas throughout 2011, the additional revenue generated was insufficient to meet the considerable shortfall caused by the loss of J4G income and the transitional fee arrangement. As a result – and facing the unacceptable reality of trading in an insolvent position early in 2012 – the PiA Trustees very reluctantly took the decision at their Board meeting on 2 December 2011 to close the Charity and its operations on 31 December 2011. After serving UK PID (primary immune deficiencies) patients and the wider PID community for over 21 years this decision was not taken lightly and was only reached after all other possibilities and alternatives were examined in depth and given active consideration.

All PiA members had been informed previously of the possibility of PiA's closure in a number of mailings, leading articles in *Insight* and at a number of patient meetings – including reports at the 2010 and 2011 Annual Meetings. However, they were notified formally by mail, in *Insight* and on the PiA website early in January 2012.

It is anticipated that the Charity will be closed formally by late 2012 and removed from Companies House and Charity Commission records soon after. The former Chief Executive, Chris Hugan, was appointed by the Trustees to oversee the closure of the Charity and it is hoped that the Charity will close without any outstanding liabilities or debts.

The Trustees would like to express their sincere thanks to all the PID members and their families who have supported the Charity since its formation in 1990 and who have enabled PiA to, undertake vital investment in breakthrough research to treat patients, implement important advocacy and other programmes to protect and enhance the funding, treatment and management of PID patients, help develop the network of specialist PID treatment centres throughout the UK that diagnose and treat PID patients; provide continuous information, counselling and benefits services to child and adult PID patients, and raise general awareness of the needs of PID patients in an increasingly competitive healthcare environment.

The Trustees would also like to thank the medical professionals who have worked closely with the Charity since its foundation and who have given so much of their valuable time to PiA events, expert panels, conferences, publications, patient meetings and fundraising events – and to the pharmaceutical companies for their invaluable support and involvement in a wide range of activities and projects over the years.

THE PRIMARY IMMUNODEFICIENCY ASSOCIATION

REPORT OF THE TRUSTEES FOR THE PERIOD ENDED 31 MARCH 2012

Objectives and Activities for Public Benefit

The objectives of the PiA, which are set out in its Memorandum & Articles of Association, are to:

- Protect and preserve the good health of persons suffering from primary immune deficiencies (PID) (and the members of their immediate families)
- Advance education of these conditions within the medical profession, among patients and their families, and the general public
- Promote improvements in diagnosis and provision for medical treatment
- Encourage and support appropriate research into the diagnosis and treatment of these conditions and any other issues affecting the health of patients with these primary immune deficiencies and publish the useful results where appropriate

The Trustees see these objects as being one charitable activity for public benefit and confirm that they have referred to the guidance contained in the Charity Commission's general guidance on public benefit when reviewing the Charity's aims and objectives and in planning past activities and setting grant-making policies

The Trustees consider each of the above objectives to be of equal importance, and the work carried out during the fifteen months under review in achieving them can be seen in the following report, "Achievements and Performance"

Applications for research grants are advertised in recognised research journals relevant to the field of immunology. All previous grant applicants are also invited to apply. Association of Medical Research Charities (AMRC) policies are rigorously followed in the review and assessment process, using an independent external peer review group. Final decisions are made by the Trustees based on available funding and on the recommendations of the Research Grants Review Panel based on the advice received. Successful applicants are then notified and their projects monitored on a regular basis.

The rigour of PiA's peer review based research grant program was recognised by the Association of Medical Research Charities which not only commended PiA in its 2010/2011 audit but also issued the Charity the AMRC certificate of best practice.

Achievements and Performance

Treatment, Outreach & Advocacy

In its final period of operation PiA continued its involvement in a number of important initiatives to raise the profile of primary immunodeficiencies with key audiences and these initiatives and other projects are reflected in the following reports.

2011 saw the completion of the 'lay' guide to primary immunodeficiencies, targeted primarily at Health Service Managers and Commissioners. Produced under the editorial guidance of clinical immunologist, Dr Matthew Helbert, and reviewed by a number of leading clinical immunologists and immunology nurse specialists, the PiA sponsored guide was launched at a special reception at the House of Commons in May 2011.

THE PRIMARY IMMUNODEFICIENCY ASSOCIATION

REPORT OF THE TRUSTEES FOR THE PERIOD ENDED 31 MARCH 2012

Over the period Chief Executive, Chris Hughan, and Chairman, Dr David Webster, represented the interests of PiA members and patients in a number of situations that threatened the continuity and quality of patient care.

PiA continued to have an active dialogue with the Department of Health about its demand management plan and usage guidelines for IVIg and SCIg treatments to ensure the treatments and interests of PID patients continued to be prioritised

As result of this work and proactive consultation the revised version of the guidelines retained priority status for the treatment of PID patients, even in times of product shortages

Further discussions with the Department's Commercial Medicines Unit – the body responsible for NHS treatment procurement processes – ensured that from the PID patient's perspective cost was not the only factor in the procurement process and consideration was also given to patient treatment preference and choice

The PiA Chief Executive, Chairman and Trustees attended and played an active role in a number of key medical meetings, workshops and conferences throughout 2011, where they represented the views and interests of PID patients including, regular meetings of the steering committee of UK PIN (the national professional body for clinical immunologists and immunology nurse specialists), the UK PIN sub-committee overseeing the operation and development of the UK PID Registry, BSI-CIAS (the clinical immunology and allergy sub-committee of the British Society for Immunology), the Scottish Paediatric Allergy and Immunology Network, the Scottish National Plasma Product Expert Advisory Group, and at the biennial UK PIN Forum meeting for the primary immunodeficiency medical community in Liverpool in December 2011

In May 2011 PiA held a successful inaugural Parliamentary event at the House of Commons, supported by pharmaceutical partner, Baxter. The event was used as a platform to explain to parliamentarians with an interest in health issues the needs of PID patients and to promote early diagnosis and new-born screening. It was attended by a broad cross-section of patients, clinicians, specialist nurses, PiA staff and Trustees, parliamentarians from both Houses and representatives from related healthcare organisations and charities, including the Genetic Alliance and the SHCA.

In addition to representing the interests of PID patients on all these committees, professional groups and at key events, PiA also dealt with an increasing number of individual problems with treatment sourcing and funding encountered by PID patients.

Patient Support

Because of budget restrictions and the requirement to cut costs, fewer patient meetings were held in 2011. However, in line with PiA's previous decision to hold its Annual Meeting away from its traditional London venue, the final PiA annual meeting in 2011 was held in Birmingham. Organised in conjunction with Dr Aarn Huissoon and Dr Scott Hackett and their respective adult and paediatric PID teams at Heartlands Hospital, Birmingham, the September meeting drew one of the largest ever attendances for a PiA Annual Meeting - with over 200 PID patients and their guests enjoying a series of excellent presentations and the opportunity to meet representatives from the treatment providers and fellow patients in a relaxed environment.

THE PRIMARY IMMUNODEFICIENCY ASSOCIATION

REPORT OF THE TRUSTEES FOR THE PERIOD ENDED 31 MARCH 2012

A broad range of topics included the importance of proper transition arrangements for young adults transitioning from paediatric to adult PID clinics and a fascinating insight into a pilot cognitive behavioural therapy programme for PID patients at London's Royal Free Hospital. In addition there was a vigorous debate about the financial position of PiA and the options available to either continue or close down.

The keynote presentation was given by John Murray, Chief Executive of the Strategic Healthcare Alliance, who outlined some of the major changes being made to the commissioning process for rare disorders such as PID and HAE and the importance of ensuring that future treatments for these disorders are protected in a volatile commissioning environment.

Regrettably, because of budgetary constraints PiA had to cancel its annual three-day canal boat holidays for younger PID patients. Over the years these events, along with the longer activity holidays for older children, have given youngsters with a range of primary immunodeficiencies the chance to be independent and resourceful – in the process building their self-confidence and self-esteem in a non-threatening and closely supervised fun environment. We hope that any successor organisation to PiA will consider such programmes as an important part of what they can offer children and young adults often socially and psychologically marginalised by their disorders.

The PiA Chief Executive and staff attended meetings of IVIg/SCIg manufacturers to put the PID patient perspective to staff and senior executives. This ensured the interests of patients were reflected in resultant provider activity, including new product launches and patient literature.

During the period under review PiA staff continued to provide an advisory service to patients and families on benefits such as Disability Living Allowance and Attendance Allowance and relevant information was downloadable from the PiA website. Following the closure of PiA it is planned that some of this and other information will continue to be available from a special patient access section of the UK PIN website (www.ukpin.org.uk).

Five membership mailings were sent out to members/families during the 15 months, some of which included PiA's newsletter, Insight.

Medical and Research

No new research was undertaken because of the economic environment and the need to cut back costs because of the J4G revenue loss. However a number of important projects funded by PiA either reached their natural conclusion or significant milestones in their progress.

PiA continued to fund the UK Registry of PID patients for a third year – a major undertaking initiated by PiA in 2008 and organised under the overall supervision of UK PIN.

The Registry is now one of the most successful in Europe and contains detailed anonymised information on UK PID patients, their disorders, treatments and management. It will play an important role in the development of future treatments and treatment guidelines, help identify important research projects and encourage participation, shape future service provision for PID patients, help in the promotion of early diagnosis and treatment intervention, and provide important information on diagnostic and treatment provision in key UK centres. This important work will continue under the guidance and supervision of UK PIN – working in collaboration with ESID (the European Society for Immunodeficiencies).

THE PRIMARY IMMUNODEFICIENCY ASSOCIATION

REPORT OF THE TRUSTEES FOR THE PERIOD ENDED 31 MARCH 2012

Other P1A funded research projects that reached their natural conclusion included an important international study on the familial links in Common Variable Immunodeficiency Disorders (CVID) conducted by Professor Bodo Grimbacher and his team at London's Royal Free Hospital and ground-breaking work on gene therapy treatment for Wiskott-Aldrich Syndrome, conducted at the Institute of Child Health by Dr Siobhan Burns and her team

The P1A Trustees would like to pay special thanks to the chair of the P1A Medical Advisory Panel, Dr Aarn Huissoon, the Vice Chair, Dr Hilary Longhurst, and all the consultant immunologists and immunology nurse specialists who have been members of the Panel over the years for their invaluable advice, counsel and guidance on a range of PID related issues. They would also like to thank members of P1A's Research Review Panel for guiding the Charity in its selection of key research projects to fund

Fundraising

As has already been stated, the request to raise substantial additional funds as well as dramatically cut costs was a predominant feature of the Charity's final 15 months of operation

P1A was deeply appreciative of all its members and supporters who were generous in their support of the Charity, especially at such a critical time. Overall income from members and supporters increased over the previous year – both from donations and fundraising events

Donations from Foundations, Trusts and Corporations continued to reflect the increasingly difficult and highly competitive charitable fundraising and economic environment and were disappointingly low.

Conversely, grants from the Charity's pharmaceutical industry partners were at a record level and the Charity thanks the pharmaceutical industry for its much valued support to P1A over many years

The Charity had a team of runners in the London Marathon and Adidas events, raising much-needed funds for P1A. Members and supporters also took part in other marathons and running events throughout the UK and P1A thanks them for the sponsorship money they raised

Sales of Christmas cards directly through our members and supporters and through the Cards for Good Causes outlets were significantly lower than the previous year, reflecting the overall drop in Christmas card sales across the charitable sector and in the wider community

Annual draw ticket sales stayed steady and matched previous years. P1A is grateful to all its members and supporters who purchased the Charity's Christmas cards and draw tickets

Staff

The Charity owes a deep debt of gratitude to all the staff and volunteers for their dedication and hard work during a turbulent and extraordinarily difficult year and for showing great loyalty to P1A and the important mission of the Charity even when, in the case of the staff, their own jobs were in peril and eventually eliminated

THE PRIMARY IMMUNODEFICIENCY ASSOCIATION

REPORT OF THE TRUSTEES FOR THE PERIOD ENDED 31 MARCH 2012

Financial Review

Results

Although the financial statements reflect a fifteen month period to 31 March 2012 virtually no income was received past the date of the closure of the Charity being 31 December 2011

Total income for the fifteen month period of £244,109 was significantly lower than in the previous twelve months (2010 £381,656) but almost all of this reduction could be attributed to the loss of the Jeans for Genes income - which in the previous year had accounted for £187,341 out of this total. Stripping out this Jeans for Genes contribution, PIA income in the Charity's final year of operation was around £50,000 higher than the previous year's comparable non-J4G income and reflected the considerable fundraising efforts made by the CEO and staff to bridge the financial gap caused by the sudden loss of the J4G revenues.

Member donations and fundraising events contributed a highly creditable £66,991 against £45,339 in 2010. Sales from Christmas cards and the Annual Draw amounted to a somewhat disappointing £17,930 against £18,812 in 2010, a drop attributable in large part to the general move away from sending traditional Christmas cards because of high postage costs, the overall economic climate and electronic card alternatives.

Corporate and Trust income was very disappointing at £7,890 although this was a slight increase on the previous year's result (2010 £5,763). Again, this reflected the overall decline in this sector's charitable giving. Despite an ongoing legacy campaign, legacies and bequests to PIA were still disappointingly low at £2,000 (2010 £250).

PIA generated £8,338 from its programme of organised fundraising events, including the London Marathon and Adidas runs. This was significantly lower than the £19,519 in 2010 and, despite an active promotional campaign, reflected a disappointing response by members and supporters to the offer of available places in both events.

Once again the Charity's pharmaceutical 'partners' were particularly supportive and grants totalling £133,503 (including £23,000 restricted grant) were made to support PIA's work and final period of operations. This was £49,500 more than the previous year (2010 £84,000) and was a record for the Charity.

As a result of the loss of J4G revenues and despite additional income and further cost cutting measures PIA had a deficit of £93,889 on the General Fund for the period under review (2010 £40,237 deficit). With a cumulative deficit of £185,903 when including Unrestricted and Restricted Research Funds and Reserves barely covering this amount the Trustees made the decision that the Charity would run the likely risk of moving into an insolvent position early in 2012 - a position that was neither acceptable nor viable. As a result of this position, and with considerable reluctance, they decided to close the Charity on 31 December 2011.

THE PRIMARY IMMUNODEFICIENCY ASSOCIATION

REPORT OF THE TRUSTEES FOR THE PERIOD ENDED 31 MARCH 2012

Statement of Trustees' responsibilities

The Trustees (who are also directors of The Primary Immunodeficiency Association for the purposes of company law) are responsible for preparing the Trustees' Report 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 net income and expenditure, of the charitable company for the year. 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 the Charities SORP,
- make judgements and estimates that are reasonable and prudent,
- state whether applicable UK accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in operation

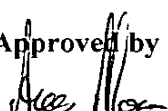
The Trustees are responsible for keeping adequate accounting records that disclose with reasonable accuracy at any time the financial position of the charitable company and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding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

Statement of disclosure to auditor

In so far as the Trustees are aware

- (a) there is no relevant audit information of which the charitable company's auditors is unaware, and
- (b) the Trustees have taken all the steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditor is aware of that information

Approved by the Board of Trustees on4/10/12..... and signed on its behalf by:


A. Moore
Director

REPORT OF THE AUDITORS TO THE TRUSTEES OF THE PRIMARY IMMUNODEFICIENCY ASSOCIATION

Independent Auditors' Report to the Trustees of The Primary Immunodeficiency Association

We have audited the financial statements of The Primary Immunodeficiency Association for the period ended 31 March 2012, which comprise the statement of financial activities, the balance sheet, and the related notes on pages 12 to 23. The financial reporting framework that has been applied in their preparation is applicable law and Financial Reporting Standard for Smaller Entities (effective April 2008) (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 auditor's 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 its 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 Trustees' Responsibilities Statement set out on page 9, 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 Trustees' Report to identify material inconsistencies with the audited financial statements. 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 March 2012 and of its incoming resources and application of resources, including its income and expenditure, for the period then ended,

**REPORT OF THE AUDITORS TO THE TRUSTEES OF
THE PRIMARY IMMUNODEFICIENCY ASSOCIATION**

Opinion on financial statements (Continued)

- 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

Emphasis of matter – Going concern

In forming our opinion on the financial statements, which is not modified, we have considered the adequacy of the disclosure made in note 1a to the financial statements concerning the charitable company's ability to continue as a going concern. Following the loss of the Charity's major revenue source in the previous period and despite the best efforts of the Charity to raise substantial additional funds and dramatically reduce costs, the trustees decided at their board meeting on 2 December 2011 to close the Charity on 31 December 2011. The Charity is currently in the final stages of being wound up, and it is anticipated that the Charity will be closed formally by late 2012 and removed from Companies House and Charity Commission records soon after. The accounts have therefore correctly been prepared on this basis.

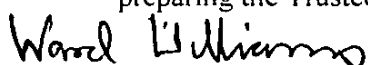
Opinion on other matter prescribed by the Companies Act 2006

In our opinion the information given in the trustees' Annual report for the financial year for which the financial statements are prepared is consistent with the financial statements.

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 in preparing the Trustees' Annual Report



**Craig Tribe (Senior Statutory Auditor)
For and on behalf of Ward Williams**

**Chartered Accountants
Statutory Auditor**

**Belgrave House
39-43 Monument Hill
Weybridge
Surrey KT13 8RN**

9/10/12

THE PRIMARY IMMUNODEFICIENCY ASSOCIATION

STATEMENT OF FINANCIAL ACTIVITIES FOR THE PERIOD ENDED 31 MARCH 2012

	Note	Period from 1 January 2011 to 31 March 2012				Year ended 31 December 2010			
		General Funds	Unrestricted Research	Restricted Research	Total 2012	General Funds	Unrestricted Research	Restricted Research	Total 2010
		£	£	£	£	£	£	£	£
INCOMING RESOURCES									
Incoming resources from generated funds									
Voluntary income	6	103,149	-	-	103,149	277,024	-	10,554	287,578
Pharmaceutical Company donations	7	110,503	-	23,000	133,503	84,000	-	-	84,000
Investment income	8	335	-	-	335	604	-	-	604
		<u>213,987</u>	<u>-</u>	<u>23,000</u>	<u>236,987</u>	<u>361,628</u>	<u>-</u>	<u>10,554</u>	<u>372,182</u>
Other incoming resources		7,122	-	-	7,122	9,474	-	-	9,474
TOTAL INCOMING RESOURCES		<u>221,109</u>	<u>-</u>	<u>23,000</u>	<u>244,109</u>	<u>371,102</u>	<u>-</u>	<u>10,554</u>	<u>381,656</u>
RESOURCES EXPENDED									
Costs of generated funds									
Fundraising		5,479	-	-	5,479	13,744	-	982	14,726
Charitable activities	9a	328,715	9,631	57,397	395,743	383,983	36,435	44,708	465,126
Governance Costs	10	28,790	-	-	28,790	11,741	-	-	11,741
TOTAL RESOURCES EXPENDED		<u>362,984</u>	<u>9,631</u>	<u>57,397</u>	<u>430,012</u>	<u>409,468</u>	<u>36,435</u>	<u>45,690</u>	<u>491,593</u>
Net (resources expended)/ incoming resources before transfers		(141,875)	(9,631)	(34,397)	(185,903)	(38,366)	(36,435)	(35,136)	(109,937)
Transfers between funds	9b	47,986	(46,578)	(1,408)	-	(1,871)	-	1,871	-
NET MOVEMENT IN FUNDS		<u>(93,889)</u>	<u>(56,209)</u>	<u>(35,805)</u>	<u>(185,903)</u>	<u>(40,237)</u>	<u>(36,435)</u>	<u>(33,265)</u>	<u>(109,937)</u>
FUNDS BROUGHT FORWARD									
At 1 January 2011	14	100,117	56,209	35,805	192,131	140,354	92,644	69,070	302,068
FUNDS CARRIED FORWARD									
At 31 March 2012	14	<u>6,228</u>	<u>-</u>	<u>-</u>	<u>6,228</u>	<u>100,117</u>	<u>56,209</u>	<u>35,805</u>	<u>192,131</u>

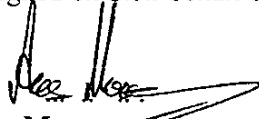
The Statement of Financial Activities also complies with the requirements for an income and expenditure account under the Companies Act 2006

THE PRIMARY IMMUNODEFICIENCY ASSOCIATION

BALANCE SHEET AT 31 MARCH 2012

	Note	31/3/2012	31/12/2010
		£	£
FIXED ASSETS			
Tangible assets	11	-	7,227
CURRENT ASSETS			
Stock		-	1,631
Debtors	12	3,741	129,509
Cash at bank and in hand		7,561	17,280
Funds on deposit		-	149,279
		<u>11,302</u>	<u>297,699</u>
		11,302	304,926
CREDITORS AMOUNTS FALLING DUE WITHIN ONE YEAR	13	(5,074)	(112,795)
TOTAL ASSETS LESS CURRENT LIABILITIES		<u>6,228</u>	<u>192,131</u>
FUNDS			
General fund	14	6,228	100,117
Unrestricted Research Fund	14	-	56,209
Restricted Research Fund	14	-	35,805
		<u>6,228</u>	<u>192,131</u>

The financial statements on pages 12 to 23 were approved by the Trustees on 4/10/12 and signed on their behalf by


A. Moore
Director

Company Registration No. 05230438

THE PRIMARY IMMUNODEFICIENCY ASSOCIATION

NOTES TO THE FINANCIAL STATEMENTS FOR THE PERIOD ENDED 31 MARCH 2012

1 ACCOUNTING POLICIES

(a) Basis of accounting

The Accounts are prepared under the historical cost convention and in accordance with the Statement of Recommended Practice, "Accounting and Reporting by Charities" issued in 2005 (SORP 2005), the Financial Reporting Standard for Smaller Entities (effective April 2008) and the Companies Act 2006

Historically the Charity's major source of revenue has been from the Jeans for Genes (J4G) campaign. Following the expiration of the five-year partnership agreement in March 2011 and subsequent loss of income, the Charity ran the likely risk of moving into an insolvent position early in 2012 - a position that the Trustees deemed was neither acceptable nor viable. This was despite the best efforts of the Charity to raise substantial additional funds and dramatically reduce costs. As a result of this position, and with considerable reluctance, the Trustees decided at their board meeting on 2 December 2011 to close the Charity on 31 December 2011.

The Charity is currently in the final stages of being wound up, and it is anticipated that the Charity will be closed formally by late 2012 and removed from Companies House and Charity Commission records soon after.

(b) Incoming resources

All incoming resources are included in the Statement of Financial Activities ("SOFA") when the Charity is entitled to the income and the amount can be quantified with reasonable accuracy. The following specific policies are applied to particular categories of income:

- Grants, donations, gifts and legacies are included in the SOFA as they are received. Grants, where entitlement is not conditional on the delivery of a specific performance by the Charity, are recognised when the Charity becomes unconditionally entitled to the grant.
- Cash collected at special fundraising events is included in the SOFA before deducting the expenditure incurred directly in staging the event.
- The value of voluntary help is not included in the accounts.
- Bank interest is included in the SOFA on receipt.
- Incoming resources from grants, where related to performance and specific deliverables, are accounted for as and when the Charity earns the right to consideration by its performance.

THE PRIMARY IMMUNODEFICIENCY ASSOCIATION

NOTES TO THE FINANCIAL STATEMENTS (continued) FOR THE PERIOD ENDED 31 MARCH 2012

(c) **Resources expended**

All expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all costs related to the category. Fundraising costs are those costs incurred in seeking voluntary contributions.

Charitable activities comprise expenditure on the Charity's day to day administration, plus projects that the Charity and third parties have designated funds for. This includes expenditure on research grants, which are approved by the Trustees on annual basis and allocated to specific funds in the next financial year.

Governance costs are those incurred in connection with the constitutional and statutory requirements of the Charity.

(d) **Operating leases**

Rentals applicable to operating leases where substantially all of the benefits and risks of ownership remain with the lessor are charged to the SOFA.

(e) **Pensions**

The Charity operates a defined contribution scheme for the benefit of its employees. Pension contributions are charged to the SOFA in the period they are payable.

(f) **Irrecoverable Value Added Tax**

The Charity is not registered for Value Added Tax. All irrecoverable Value Added Tax is included within the expense heading in which the expense is incurred.

(g) **Tangible fixed assets**

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life:

Office equipment	33 33% on cost
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(h) **Funds**

The funds are determined on the basis of the entity making the donation, i.e. some donors stipulate that the donation is for a certain research project and as such is part of the research fund.

Restricted research funds comprise of funds that have been specifically designated by the entity making the donation and should be used by the Charity in accordance with the terms set out by the donor.

Unrestricted research funds comprise of funds that were not received for a specific research project, but have since been allocated by the Trustees to research.

General funds comprise of funds that can be spent at the discretion of the Trustees for any purpose of the Charity. These funds have not been allocated to research and are used by the Charity to cover its day-to-day costs.

THE PRIMARY IMMUNODEFICIENCY ASSOCIATION

NOTES TO THE FINANCIAL STATEMENTS (continued) FOR THE PERIOD ENDED 31 MARCH 2012

2 TRUSTEES' REMUNERATION AND REIMBURSED EXPENDITURE

The Trustees were not entitled to and received no remuneration from the Charity during the period. Trustees were reimbursed expenses from the Charity for meetings and activities that they attended, these amounts totalled £2,757 (2010: £2,587)

3 EMPLOYEES' REMUNERATION

The average number of employees during the period was 3 (2010: 5). The total costs of the employees including temporary staff are as follows

	2012 £	2010 £
Salary costs	151,684	184,632
Employers NIC	17,119	19,977
Pension contributions	10,348	13,748
Redundancy costs	7,400	-
Temporary Staff	169	-
Recruitment/training costs	-	1,031
	<u>186,720</u>	<u>219,388</u>

The number of employees whose emoluments as defined for taxation purposes amounted to over £75,000 (£60,000 pro-rated) in the period was as follows

	2012 Number	2010 Number
£75,001 - £87,500 (Pro-rated £60,001 - £70,000)	-	1
	<u>=</u>	<u>=</u>

4 PENSION COST

The Charity contributes towards employees' personal pension schemes. The contributions for the period amounted to £10,348 (2010: £13,748). £Nil (2010: £1,074) was outstanding as at the period-end.

5 NET MOVEMENT IN FUNDS

	2012 £	2010 £
This is stated after charging		
Depreciation	-	13,883
Auditors' remuneration	6,000	6,600
	<u>6,000</u>	<u>20,483</u>

THE PRIMARY IMMUNODEFICIENCY ASSOCIATION

NOTES TO THE FINANCIAL STATEMENTS (Continued)
FOR THE PERIOD ENDED 31 MARCH 2012

6 VOLUNTARY INCOME

	General Fund	Unrestricted Research	Restricted Research	2012 Total	General Fund	Unrestricted Research	Restricted Research	2010 Total
	£	£	£	£	£	£	£	£
Membership subscriptions and donations	46,743	-	-	46,743	31,296	-	-	31,296
Members fundraising activities	20,248	-	-	20,248	14,043	-	-	14,043
Annual draw and Christmas card sales	17,930	-	-	17,930	18,812	-	-	18,812
Corporate and trust donations and fundraising	7,890	-	-	7,890	5,763	-	-	5,763
Legacy individuals	2,000	-	-	2,000	250	-	-	250
PiA organised events	8,338	-	-	8,338	19,519	-	-	19,519
Big Lottery Fund grant	-	-	-	-	-	-	10,554	10,554
Jeans for Genes	-	-	-	-	187,341	-	-	187,341
	<u>103,149</u>	<u>-</u>	<u>-</u>	<u>103,149</u>	<u>277,024</u>	<u>-</u>	<u>10,554</u>	<u>287,578</u>

7 PHARMACEUTICAL COMPANY DONATIONS

	General Fund	Unrestricted Research	Restricted Research	2012 Total	General Fund	Unrestricted Research	Restricted Research	2010 Total
	£	£	£	£	£	£	£	£
Gnifols UK	10,000	-	-	10,000	5,000	-	-	5,000
Baxter	21,000	-	23,000	44,000	16,000	-	-	16,000
Bio-Products Laboratory	14,000	-	-	14,000	15,500	-	-	15,500
CSL Behring	15,750	-	-	15,750	15,000	-	-	15,000
Octapharma	3,253	-	-	3,253	1,500	-	-	1,500
Bio-test	12,000	-	-	12,000	10,000	-	-	10,000
ViroPharma SPRL	2,000	-	-	2,000	-	-	-	-
Synergy	-	-	-	-	1,000	-	-	1,000
Convatec	1,500	-	-	1,500	1,500	-	-	1,500
Binding Site Group	5,000	-	-	5,000	5,000	-	-	5,000
Swedish Orphan Bio Int	-	-	-	-	1,500	-	-	1,500
Shire	26,000	-	-	26,000	12,000	-	-	12,000
	<u>110,503</u>	<u>-</u>	<u>23,000</u>	<u>133,503</u>	<u>84,000</u>	<u>-</u>	<u>-</u>	<u>84,000</u>

8 INVESTMENT INCOME

	General Fund	Unrestricted Research	Restricted Research	2012 Total	General Fund	Unrestricted Research	Restricted Research	2010 Total
	£	£	£	£	£	£	£	£
Bank interest	335	-	-	335	604	-	-	604

THE PRIMARY IMMUNODEFICIENCY ASSOCIATION

NOTES TO THE FINANCIAL STATEMENTS (Continued)
FOR THE PERIOD ENDED 31 MARCH 2012

9a CHARITABLE ACTIVITIES

	General	Unrestricted	Restricted	2012	General	Unrestricted	Restricted	2010
DIRECT CHARTIABLE	Fund	Research	Research	Total	Fund	Research	Research	Total
EXPENDITURE	£	£	£	£	£	£	£	£
Meeting costs	2,429	-	10,269	12,698	13,427	-	1,990	15,417
Insight expenses	15,011	-	-	15,011	15,040	-	519	15,559
Regional days costs	-	-	-	-	2,577	-	286	2,863
Jeans for Genes costs	393	-	-	393	12,712	-	-	12,712
Other projects	6,776	-	-	6,776	6,489	-	90	6,579
Volunteer expenses	959	-	-	959	445	-	-	445
Parliamentary reception costs	-	-	21,609	21,609	-	-	-	-
Donation of marathon places	1,763	-	-	1,763	-	-	-	-
Research expenditure - note 9b	-	9,631	25,519	35,150	-	36,435	33,265	69,700
	<u>27,331</u>	<u>9,631</u>	<u>57,397</u>	<u>94,359</u>	<u>50,690</u>	<u>36,435</u>	<u>36,150</u>	<u>123,275</u>
SUPPORT COSTS								
Staff costs								
Support staff wages	140,832	-	-	140,832	171,574	-	5,215	176,789
Admin staff wages	27,971	-	-	27,971	27,673	-	147	27,820
Staff redundancy costs	7,400	-	-	7,400	-	-	-	-
Staff pensions	10,348	-	-	10,348	13,451	-	297	13,748
Temporary staff	169	-	-	169	-	-	-	-
Staff recruitment & training	-	-	-	-	1,031	-	-	1,031
Staff welfare	1,659	-	-	1,659	1,816	-	-	1,816
	<u>188,379</u>	<u>-</u>	<u>-</u>	<u>188,379</u>	<u>215,545</u>	<u>-</u>	<u>5,659</u>	<u>221,204</u>
Rent and services								
Rent and rates	49,909	-	-	49,909	49,938	-	1,064	51,002
Office insurance	1,161	-	-	1,161	833	-	-	833
Light and heat	1,299	-	-	1,299	1,494	-	42	1,536
Telephone	3,549	-	-	3,549	3,575	-	336	3,911
Repairs, maint. & cleaning	4,605	-	-	4,605	5,148	-	-	5,148
	<u>60,523</u>	<u>-</u>	<u>-</u>	<u>60,523</u>	<u>60,988</u>	<u>-</u>	<u>1,442</u>	<u>62,430</u>
Other expenses								
Printing, post and stationery	6,361	-	-	6,361	6,660	-	137	6,797
Advertising	570	-	-	570	278	-	10	288
Computer costs	12,788	-	-	12,788	10,106	-	585	10,691
Equipment hire	13,914	-	-	13,914	9,092	-	563	9,655
Office Clearance costs	3,706	-	-	3,706	-	-	-	-
Consultancy	173	-	-	173	9,562	-	162	9,724
Payroll service costs	715	-	-	715	559	-	-	559
Bank charges	1,706	-	-	1,706	1,348	-	-	1,348
Currency Exchange variance	-	-	-	-	20	-	-	20
Subscriptions	1,397	-	-	1,397	2,515	-	-	2,515
Sundry expense	3,925	-	-	3,925	2,737	-	-	2,737
Office equipment depreciation	-	-	-	-	13,883	-	-	13,883
Loss on disposal of fixed assets	7,227	-	-	7,227	-	-	-	-
	<u>52,482</u>	<u>-</u>	<u>-</u>	<u>52,482</u>	<u>56,760</u>	<u>-</u>	<u>1,457</u>	<u>58,217</u>
TOTAL CHARITABLE ACTIVITIES	<u>328,715</u>	<u>9,631</u>	<u>57,397</u>	<u>395,743</u>	<u>383,983</u>	<u>36,435</u>	<u>44,708</u>	<u>465,126</u>

THE PRIMARY IMMUNODEFICIENCY ASSOCIATION

NOTES TO THE FINANCIAL STATEMENTS (Continued)
FOR THE PERIOD ENDED 31 MARCH 2012

9b RESEARCH FUNDS

	Balance 01.01.11	Receipts in period	Allocations	Expenditure in period	Balance 31.03.12
Unrestricted research funds	£	£	£	£	£
Jeans for Genes - unallocated	7,831	-	(7,831)	-	-
PhD Studentship	10,000	-	(10,000)	-	-
CBT Locum	12,500	-	(12,500)	-	-
XLP International	3,774	-	(3,774)	-	-
PID Register	10,547	-	(4,716)	(5,831)	-
Intercalated Degrees	6,500	-	(6,500)	-	-
Jolles – NIMR/RFH	2	-	(2)	-	-
AMS Project	5,055	-	(1,255)	(3,800)	-
Unrestricted research funds	56,209	-	(46,578)	(9,631)	-
Restricted research funds and other restricted grants					
BCH	10,269	-	-	(10,269)	-
GlaxoSmithKline	25,536	-	(17)	(25,519)	-
UK MP Reception	-	23,000	(1,391)	(21,609)	-
Restricted research funds and other restricted grants	35,805	23,000	(1,408)	(57,397)	-
Total Funds	92,014	23,000	(47,986)	(67,028)	-

Each year research grants are approved by the Trustees in December and then communicated to those concerned with conditions attached for acceptance. Once the final acceptances are received the allocation is made in the next financial year.

10 GOVERNANCE COSTS

	General Fund £	Unrestricted Research £	Restricted Research £	2012 Total £	General Fund £	Unrestricted Research £	Restricted Research £	2010 Total £
Trustees insurances	1,134	-	-	1,134	1,572	-	-	1,572
Trustees expenses	2,757	-	-	2,757	2,587	-	-	2,587
Audit fee	6,000	-	-	6,000	6,600	-	-	6,600
Legal fees	5,001	-	-	5,001	982	-	-	982
Consultancy	13,898	-	-	13,898	-	-	-	-
	28,790	-	-	28,790	11,741	-	-	11,741

THE PRIMARY IMMUNODEFICIENCY ASSOCIATION

NOTES TO THE FINANCIAL STATEMENTS (Continued)
FOR THE PERIOD ENDED 31 MARCH 2012

11 FIXED ASSETS

	Fixtures, Fittings and Equipment £
COST	
As at 1 January 2011	44,252
Cost on Disposal	(44,252)
	<u>-</u>
Total as at 31 March 2012	<u>-</u>
DEPRECIATION	
As at 1 January 2011	37,025
Depreciation on Disposal	(37,025)
	<u>-</u>
Total as at 31 March 2012	<u>-</u>
NET BOOK VALUE	
31 March 2012	<u>-</u>
31 December 2010	<u><u>7,227</u></u>

12 DEBTORS

	2012 £	2010 £
Other debtors	-	4,610
Prepayments and accrued income	3,741	124,899
	<u>3,741</u>	<u>129,509</u>
	<u><u>3,741</u></u>	<u><u>129,509</u></u>

Jeans for Genes

The Jeans for Genes Day is held in October. As noted in Note 1a above, nothing was receivable in the period to the Charity from the campaign following the expiration of the 5 year partnership agreement in March 2011. Therefore as at the period end nothing was outstanding regarding the campaign (2010 £98,299 included in Prepayments and accrued income)

THE PRIMARY IMMUNODEFICIENCY ASSOCIATION

NOTES TO THE FINANCIAL STATEMENTS (Continued)
FOR THE PERIOD ENDED 31 MARCH 2012

13 CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2012 £	2010 £
Taxation & social security	-	5,827
Accruals	4,227	70,907
Deferred income	-	572
Other creditors	847	35,489
	<u>5,074</u>	<u>112,795</u>

Deferred income related to income that had been received prior to the period end that related to performance and specific deliverables that had not been achieved at the period end. As such the Charity accounted for the income as it earned the right to consideration by its performance.

The movement in deferred income is as follows	£
At 1 January 2011	572
Transfer to the SOFA	(572)
Additional deferred income	-
At 31 March 2012	<u>-</u>

14 FUNDS

	General Funds £	Unrestricted Research £	Restricted Research £	Total £
At 1 January 2011	100,117	56,209	35,805	192,131
Net movement in funds	(93,889)	(56,209)	(35,805)	(185,903)
At 31 March 2012	<u>6,228</u>	<u>-</u>	<u>-</u>	<u>6,228</u>

THE PRIMARY IMMUNODEFICIENCY ASSOCIATION

NOTES TO THE FINANCIAL STATEMENTS (Continued) FOR THE PERIOD ENDED 31 MARCH 2012

15 FINANCIAL COMMITMENTS

At 31 March 2012, the Charity had annual commitments under a non-cancellable operating lease as follows

	Land and buildings	
	2012	2010
	£	£
Expiry date		
2 to 5 years	-	35,000
	<u>-</u>	<u>35,000</u>
	<u>-</u>	<u>35,000</u>

The above lease expires in November 2013. The Charity closed its offices at 31 December 2011 and the landlords (Alliance House Foundation) kindly agreed to terminate the existing lease agreement that was in place at no additional cost.

16 CONTROL

The Charity is controlled jointly by the Trustees. There is no ultimate controlling party.

17 RELATED PARTIES TRANSACTIONS

During the period the Charity paid Communications Management Limited (CML) consultancy fees totalling £10,000 for the services of the former PIA CEO and Director and Shareholder of CML, Christopher Hughan. These fees, agreed in advance by the PIA Trustees, were for Mr Hughan's time and services involved in the day-to-day running, administration and winding up of the Charity including extensive negotiations with the Charity's creditors and covered a five month period between his departure from PIA on 31 October 2011 to 31 March 2012. Reimbursable expenses totalling £2,332 were also paid to Mr Hughan to cover necessary costs incurred in the administrative and winding up process.

Jeans for Genes

Since 1996 a Jeans for Genes Campaign (JGC) has been held on an annual basis to raise money for research into children's genetic disorders and support activities to help these children and their families. Up to 2006 annual agreements were drawn up and signed between the four founding charity parties involved, as shown below. In 2006 a five-year agreement was signed, replacing the annual agreements.

Both JGC and its trading subsidiary, Jeans for Genes Limited (JGL) received income from donations and sales generated by the Campaign. After deductions of all relevant overheads, costs, expenses, liabilities and other distributions, net income received through JGC and JGL was paid to each of the four founding charities.

The previous five-year partnership agreement expired in March 2011 and the J4G trademark holder, The Chronic Granulomatous Disorder Research Trust (CGDRT), decided not to renew it or replace it with any other annual or transitional agreement with its former founding charity partners, despite initially agreeing to do so. Therefore PIA no longer received the J4G distributions mentioned above (See note 1a).

THE PRIMARY IMMUNODEFICIENCY ASSOCIATION

NOTES TO THE FINANCIAL STATEMENTS (Continued) FOR THE PERIOD ENDED 31 MARCH 2012

17 RELATED PARTIES TRANSACTIONS (Continued)

Chris Hughan was also previously a director of JGL and a Trustee of JGC. A total of £Nil was received from the Campaign for the period (2010: £187,341). During the period, PIA loaned £Nil (2010: £37,500) to JGC.

Former participants in the Jeans for Genes Campaign were as follows:

The Chronic Granulomatous Disorder Research Trust ("CGDRT")
Seafields, Shootersway Lane, Berkhamsted, Herts HP4 3NP
(Charity no 1003425)

and

The Society for Mucopolysaccharide Diseases ("MPS")
46 Woodside Road, Amersham, Bucks HP6 6AJ
(Charity no 287034)

and

The Primary Immunodeficiency Association ("PIA")
Alliance House, 12 Caxton Street, London SW1H 0QS
(Charity no 1107233)

and

Great Ormond Street Hospital Children's Charity ("GOSHCC")
Great Ormond Street, London WC1N 3JH
(Charity no 235825)

(hereinafter jointly referred to as "the Charities")

(each of the above have nominated a person to be a member of JGC)

and

Jeans for Genes Campaign ("JGC")
40-41 Queen Square, London WC1N 3AJ (Charity no 1062206)

and

Jeans for Genes Ltd ("JGL") 40-41 Queen Square, London WC1N 3AJ
(Company no 03073588)

and

Great Ormond Street International Promotions Limited ("GOSIPL")
(Company no 2265303)