THE PRIMARY IMMUNODEFICIENCY ASSOCIATION (A COMPANY LIMITED BY GUARANTEE)

FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 DECEMBER 2010

Registered Charity No. 1107233

Company Registration No. 05230438

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LEGAL AND ADMINISTRATIVE INFORMATION

A Moore **Trustees**

J Drabwell R McNairney D Webster K Hennessy

C Hughan **Company Secretary**

Chairman D Webster

Chief Executive C Hughan

Charity no 1107233

Company no 05230438

Registered office and Alliance House Principal address

12 Caxton Street

London SW1H OQS

Auditors Ward Williams

Park House

25-27 Monument Hıll

Weybridge

Surrey KT13 8RT

Bankers

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

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REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 DECEMBER 2010

Report of the Trustees

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The Trustees have pleasure in presenting their Report and Statement of Financial Activities for the year ended 31 December 2010

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 year, were

Dr David Webster, MD, FRCP, FRCPath - Chairman Mr Andrew Moore, FCA, MA (Oxon) - Treasurer Mrs Jose Drabwell Mrs Kathryn Hennessy Mrs Rae McNairney Mr John Rixon (Resigned 26 April 2010)

The Chief Executive Officer of the PiA is Christopher Hughan In 2010 there were a further four employees (all full-time)

The Auditors of the PiA are

Ward Williams Park House, 25-27 Monument Hill Weybridge Surrey KT13 8RT

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 DECEMBER 2010

The Principal Bankers of the PiA are

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

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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

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 DECEMBER 2010

For the past fifteen years the PiA, along with three other Founder (Partner) Charities and annually invited guest charities, has been a participant in the national Jeans for Genes Campaign. Jeans for Genes Limited raises funds through commercial activities for its parent undertaking, Jeans for Genes Campaign, a registered Charity. PiA's Chief Executive, Christopher Hughan, is a Director and Trustee of Jeans for Genes Campaign Limited and Jeans for Genes Limited and Ray Dias (formerly PiA's Honorary Treasurer and Trustee) is an independent Trustee and Honorary Treasurer of Jeans for Genes Campaign Limited

However, in March 2010 the trademark holder of Jeans for Genes, the Chronic Granulomatous Disorder Research Trust (CGDRT), gave notice to the three other Partner Charities, including PiA, that at the end of the current five-year Partner Charity Agreement in March 2011 they would not be renewing the Partnership Agreement. They also stated that the Jeans for Genes Partner Charity structure that had existed in one form or another for fifteen years would also end in March 2011. However, recognising the financial difficulties the loss of such substantial income would create with the two smaller Partner Charities in particular, PiA and The Society for Mucopolysaccharide Diseases (MPS), CGDRT agreed initially to a transitional financial arrangement whereby the three other Partner Charities, Great Ormond Street Hospital Children's Charity (GOSHCC), MPS and PiA, would receive a declining percentage of the gross income from the Jeans for Genes Campaign over a further three-year period. This would allow the smaller Partner Charities in particular to build income from other sources and/or cut costs without having an immediate and substantial 'hole' in their finances which would have a dramatic impact on their operating ability-certainly at the same level of activity

At the end of December 2010, without warning, CGDRT withdrew this agreed transitional arrangement at the point of signing by all four Partner Charities. As the PiA has been dependent, for a substantial - if declining - part of its income, on the continuation and success of the Jeans for Genes Campaign this will put the finances of PiA under great pressure in 2011. Even with necessary cost and activity cutting measures the immediate loss of this income is likely to impact significantly on the reserves of the Charity that have been built to a reasonable level in the previous five years.

The Trustees reviewed other risks to which the PiA is exposed on a regular basis and are satisfied that internal controls are in place to mitigate these, taking into account the size of the Charity and the nature of its operations

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

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 DECEMBER 2010

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 future activities and setting the grant-making policy for the year

The Trustees consider each of the above objectives to be of equal importance, and the work carried out during the year 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.

Achievements and Performance

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Treatment, Outreach & Advocacy

In 2010 PiA was an integral member of the editing and writing panels responsible for producing two new Consensus Documents dealing with the diagnosis and treatment of primary immunodeficiencies. One of the documents, being produced in conjunction with the Royal College of Physicians, contains definitive guidelines for the 'gold standard' management and treatment of Primary Antibody Deficiencies (PAD). This has now been completed and has been widely circulated throughout the clinical immunology community as well as being available on all the relevant websites for easy reference.

The other, a 'lay' guide to primary immunodeficiencies, is targeted primarily at Health Service Managers and Commissioners, as well as those in the primary care sector and other medical professionals not coming into regular contact with PID and PID patients. Other key audiences for this publication include Government, specifically the Department of Health and those parliamentarians with an active interest in health issues, and health writers and broadcasters. It is hoped that this publication will be launched early in 2011

Over the year, Chief Executive, Chris Hughan, actively represented the interests of PiA members/patients in a number of situations that threatened the continuity and quality of patient treatments and care

P1A had discussions with the Department of Health about its demand management plan and usage guidelines for IVIg and SCIg treatment, to ensure the treatments and interests of PID patients continue to be prioritised, especially with regard to planned future revisions of the guidelines P1A also had talks with the Department's Commercial Medicines Unit - the body responsible for NHS treatment procurement processes - to reflect the patient perspective in the forthcoming new procurement 'auction' for supplies of IVIg and SCIg products in England

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 DECEMBER 2010

The Chief Executive and Chairman attended and played an active role in a number of key medical meetings, workshops and conferences, where they represented the views and interests of PID patients, including, regular meetings of the Steering Committee of UK PIN (the national professional association for Immunologists and Specialist Immunology Nurses), 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 representing the clinical aspect of Immunology), 29th Congress of the European Academy of Allergy and Clinical Immunology in London, and the European Society for Immunodeficiencies (ESID) biennial International Meeting in Istanbul in October

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

Patient Support

A number of regional events were organised and held in 2010, including Regional Patient Days in the West Country (Plymouth), Sheffield and London Chris Hughan, the Chief Executive, and Dr David Webster, the PiA Chair, attended and spoke at most of these events. These meetings continue to prove very popular with patients and their families and, despite declining revenues through Jeans for Genes it is hoped that a more modest programme will be planned for 2011

Following a decision to move the P1A Annual Meeting around the UK - to allow patients from other parts of the country to attend - the first "on the road" Annual Meeting was held in November at the Hilton Hotel in Sheffield Speakers covered a broad range of topics including, the value of home visits by immunology nurse specialists, the benefits of physiotherapy, and making the transition from paediatric to adult PID units less daunting for the patient. The keynote presentation, "Shaping the future of PID services in the UK" was given by Consultant Immunologist and Chair of UK PIN, Dr Phil Wood, and provoked considerable interest with all the patients and others present. Dean Howson, a Sheffield patient, gave a very emotional and moving account of his own experiences living with a PID and the impact it has had on his life and those around him. P1A also used the meeting to launch a new initiative for Subcutaneous and Hereditary Angioedema (HAE) patients attending A&E Departments with acute swellings and a range of new materials designed to help them receive the appropriate treatment in a timely manner - a problem many have faced in the past. The new HAE A&E Emergency Packs for Patients and Clinicians will be introduced in 2011.

For younger PID patients PiA organised two successful three-day Canal Boat holidays on the Kennet and Avon Canal in late Summer – events closely supervised by trained PiA volunteers and local experts. These events give children with PID an opportunity to mix with others with similar disorders, engage in enjoyable and challenging pursuits and build their self-confidence and self-esteem in a non-threatening environment.

P₁A staff attended meetings of IVIg manufacturers in the UK to put the patient perspective to staff and senior executives. As a result of these visits and other activities P₁A is increasingly involved in the consultation process leading to new product launches and marketing of IVIg, HAE treatments and even in the production of relevant literature by the various pharmaceutical companies

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 DECEMBER 2010

Although the PiA's Welfare and Benefits Adviser, Jenny Jackson, retired in 2009, PiA continues to provide an advisory service on where to obtain information on benefits such as Disability Living Allowance and Attendance Allowance and information is downloadable from the PiA website or can be sent as hard copy to those members not on the Internet. In late 2010 and with the support of Shire Pharmaceuticals, PiA and its Jeans for Genes Partner Charity, the Society for Mucopolysaccharide Diseases (MPS) jointly employed a new Advocacy and Support Officer, Alison Wilson Alison, who is based in Belfast but operating throughout Ireland, is a qualified genetics counsellor, and her role is to visit PiA and MPS patients in the home or hospital setting to understand their requirements and how these can best be met - and then take appropriate action

Five membership mailings were sent out to members/patients and their families during the year, some of which included copies of PiA's popular newsletter, InSight Updated member information and fundraising packs were two new publications produced during the year PiA will embark on a major review and updating of all its literature and other information sources in 2011/2012

The P₁A website continued to be popular with members and other visitors and received a record number of 'hits' during the year. The website, which is due for redesign and upgrading in 2011/2012, was monitored, supervised and updated by P₁A staff member, Helen Edwards

Medical and Research

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A continuing decline in Jeans for Genes income meant that once again investment in new research was very limited, although current projects continued to receive significant funding

In an interesting development, and one that might herald an expansion of services to PID patients in the future, PiA agreed to part fund a 'pilot' project being undertaken at London's Royal Free Hospital Recent PiA research has discovered that the psychological aspects of long-term chronic illness, such as PID, have been largely overlooked - resulting in many patients suffering frequent bouts of depression, fatigue and anxiety. In order to address this issue and take a more holistic approach to treating patients, the Royal Free is piloting a PiA-supported programme of Cognitive Behavioural. Therapy with specially screened and selected patients, conducted by a qualified Clinical Psychologist. It is hoped that if this 'pilot' is successful it may be rolled-out nationally and adopted as an integral element in the treatment mix offered to PID patients.

Following a successful questionnaire drop in 2009, with a record number of PID patients responding, the PiA supported "Is it PID?" Campaign, moved into its next phase of education through the establishment of an online clinical network of physicians, nurse specialists and researchers interested in PID and the production of specific guides on PID and its diagnosis, treatment and management - aimed at other hospital specialists who might see PID patients (such as Respiratory Physicians, Paediatricians, Gastroenterologists and ENT Surgeons) PiA is represented on the panel of specialists overseeing the development of the Campaign and analysing its effectiveness

Progress continues on the UK Registry of PID Patients, a major undertaking for which PiA has committed £107,445 over three years. Concern over the lack of reliable and accurate statistics on the number of PID patients in the UK, as well as allied information about their diagnosis, treatment and management, has been an issue for PiA since its foundation and several attempts have been made in the past to quantify this data and information - with little success. PiA took the initiative again in 2008 and established a UK PID Registry with the help and guidance of UK PIN and the Royal College of Nursing, Allergy and Immunology Specialist Nurses Group

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 DECEMBER 2010

P1A funded the purchase and installation of the UK servers for the Registry, based at UCL in London, along with associated equipment, software development, IT technical support and an expert and highly trained documenter - who visits the various PID Centres throughout the UK to help enter anonymised patient data on the servers, once the normal ethical and patient clearances have been obtained. At the end of 2010 there were approximately 1,500 UK patients and their details entered on the database and a great deal of existing information had been updated. It is hoped that this number will increase significantly over the next few years and that ultimately all PID patients will be included.

Promising progress has been made on the other ongoing research projects being funded in whole or part by PiA including, an international research study on familial links in Common variable immunodeficiency disorders (CVID), being conducted by Professor Bodo Grimbacher and his team at the Royal Free Hospital in London - through a £165,000 grant over three years provided by GlaxoSmithKline (GSK) and work on developing a ground-breaking gene therapy treatment for Wiskott-Aldrich Syndrome through a Research Fellowship grant of £270,220 over four years made by PiA to Dr Siobhan Burns and her team at London's Institute of Child Health

In February PiA was delighted to provide funding for the International XLP Symposium - the first meeting of its kind in the world - held at the Institute of Child Health in London X-linked lymphoproliferative syndrome, also known as Duncan's Syndrome, is a rare (1 in 1,000,000) and potentially fatal disease that affects only boys. The XLP Symposium was organised as a joint collaboration between the XLP Research Trust, the PiA and the Institute of Child Health and was attended by leading XLP scientists and researchers from France, Japan, Australasia, USA and the UK. It was so successful another meeting is planned for 2012.

PiA was also delighted to be the primary host and sponsor of the Public Engagement Day at the 2010 British Society Gene Therapy Scientific Meeting held in Surrey Entitled 'Journeys in the Genetic Jungle' the public day was aimed at encouraging 'A' level science students to pursue scientific careers Pegging Gene Therapy as the future for medicine, a series of presentations outlined the exciting developments in this area (including the successful gene therapy programme for x-linked Severe Combined Immunodeficiency (x-SCID) children) and the future potential for curing some of the world's killer diseases PiA also had a stand at the exhibition, held on the same day

The Chair of the PiA's Medical Advisory Panel (MAP) is Dr Aarnoud Huissoon. He is a Consultant Immunologist at Birmingham Heartlands Hospital. Dr Hilary Longhurst, Consultant Immunologist at Barts and The London NHS Trust, is the Vice-Chair. The Board, which advises PiA on a range of topical and longer-term medical issues, includes three specialist immunology nurses, Sister Fran Ashworth of Sheffield's Northern General Hospital, Sister Janet Burton of Oxford's John Radcliffe Hospital and Sister Lucia Russell of Newcastle General Hospital

Fundraising

In fundraising terms the year was yet another 'mixed bag' On the positive side, in a very difficult economic environment, the Charity's total income was up on the previous year. However this included an extraordinary payment from Jeans for Genes to reflect the sale of the assets of the company (including the staff and goodwill) to the trade mark holder, CGDRT; and other payments to the Partner Charities at the end of the fifteen-year agreement, and a quarter's residual payment from the end of the Big Lottery Grant.

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 DECEMBER 2010

Pharmaceutical company support income was much higher than the previous year despite highly competitive market conditions PiA's excellent relationship with these companies yielded significant funds and a commitment to engage in a broader spectrum of projects over the year under review PiA partnered the pharma companies in joint Patients Days, literature production, practical materials which can be used by patients to improve their quality of life and ensure they receive the treatment they should expect, research studies and other projects in 2010, ensuring at the same time that any cooperation did not compromise the independent position of the Charity and its freedom to challenge the pharmaceutical companies as and when this might be necessary PiA is grateful for the continued support of the pharmaceutical companies and the contribution they make to facilitate the work of the Charity

P₁A was very appreciative of its members and supporters who were, once again, generous in their support of the Charity at a time when all Charities are showing a marked decline in most income streams. Donation income was much in line with previous years and support provided through member fundraising events was also significant. In 2011 P₁A hopes that more members will, once again, organise events to raise funds for the Charity

There was a steady growth in members making donations to PiA through standing orders and direct debits and the Charity hopes that more members will use this convenient method to give regularly to PiA and its work over the coming years. It remains the case that the average donation per member remains stubbornly around £16 per year, although a dedicated group of supporters give considerably more than this Legacy and bequest income remains disappointingly low to non-existent, despite an ongoing campaign to encourage more of our friends and supporters to remember the Charity in their wills

Jeans for Genes (J4G) income was somewhat misleading in 2010 because in addition to the net amount distributed to all the Partner Charities, which, disappointingly, had declined for the third year in a row, other amounts were paid to the Partner Charities by trade mark holder, CGDRT, to coincide with the end of the agreement, the transfer of undertaking and the closing of the Jeans for Genes Campaign and Limited companies. These included, an agreed sum for the sale of the assets and transfer of the undertaking (including staff and premises) to CGDRT, a share of the reserves left in the Jeans for Genes Campaign company, an agreed amount to compensate for any related donated income accruing in the Jeans for Genes bank accounts post 31 March 2011, and an agreed payment to cover office and other overheads while the staff and operation were in the transitional phase.

The Charity had six runners in the London Marathon raising money for PiA and teams of runners in the BUPA and Adidas events - also raising much needed funds for our work. The Charity was also delighted when three cyclists raised funds for the Charity when completing the London-Paris cycle challenge.

The Christmas Draw was once again a fundraising success and the sale of Christmas cards and related merchandise was showing a small increase on the previous year, mainly through additional donations. A review of the Christmas card selection and marketing was conducted in early 2010 to provide a more appealing selection of cards at attractive price points and we believe this was appreciated by our members and supporters. Card sales overall benefitted through additional sites negotiated with nationwide charity shop organisation, Cards for Good Causes, and we hope this positive trend continues in 2011.

The Trustees and PiA staff thank PiA members and supporters for all their hard work and fundraising efforts in 2010 and look forward to their continued and much valued support in 2011

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 DECEMBER 2010

Staff

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There were no changes in staff in 2010 and the Charity owes a debt of gratitude to all the staff and volunteers for their dedication and hard work during a turbulent and pressured year

Financial Review

Results

Total income was slightly higher than in the previous year at £381,656 (2009: £368,954), although this includes a payment by Jeans for Genes of £187,341 plus £1,656 in logo fees and loan interest Stripping out this payment the total income for 2010 is just under £200,000. As Jeans for Genes income ceases in 2010 this means that revenues through other sources will have to increase very significantly and overheads will need to be cut if PiA is to continue as a viable concern in 2011 and beyond.

Income in other areas has held up remarkably well in very testing economic conditions and a highly competitive charitable environment

Member donations and fundraising events contributed a creditable £45,339 against £46,164 in 2009 and sales from Christmas cards and the Annual Draw amounted to £18,812 against £18,277 in 2009 - a marginal increase

Corporate and Trust income was very disappointing at £5,763 (2009 £11,712) and reflected the overall decline in this sector's charitable giving. Despite an ongoing legacy campaign, legacies and bequests to PiA were virtually non-existent in 2010 at £250 (2009 £5,300).

P₁A generated £19,519 from its programme of organised fundraising events, including the London Marathon and BUPA and Adidas runs. This was significantly lower than the £36,662 in 2009 but this included the proceeds from a P₁A co-ordinated London - Paris cycle ride.

One particularly bright spot was the income from pharmaceutical company 'partners' who contributed £84,000 to supporting PiA's activities - just under £20,000 more than in 2009 (£64,831)

Costs were kept under strict control and were £86,914 lower than in 2009 Further cost reductions will be made in 2011

PiA had a deficit of £40,237 on the general fund for the year (2009 £61,442 deficit)

Reserves Policy

The Board has established a policy whereby the unrestricted funds not committed that are held by the PiA should be between three and nine months of total expenditure, excluding research grants Free reserves of £100,117 at 31 December 2010 represents around three months of operational expenditure

Investment Policy

Under its Memorandum & Articles of Association the PiA has the power to make any investment

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 DECEMBER 2010

that the Trustees feel is appropriate In the year under review PiA no longer holds any such investments and bank deposits are classed as current assets as appropriate

Plans for Future Periods

In 2011 the Charity will build on its fundraising successes and will seek additional funding from existing and new sources as well as higher profile participation in events such as the London Marathon and other such runs. Every effort will be made to raise additional funds to fill the large funding gap created by the ending of the Jeans for Genes Campaign.

During 2011 the PiA Trustees will review the financial situation created by the loss of Jeans for Genes on an ongoing basis and if there appears, at any time, to be insufficient additional new income, reserves or revenue from cost-cutting measures to allow the Charity to operate as a viable longer-term operation they will take steps to curtail severely the scope of the Charity's activities and reduce its overheads, or, if this is insufficient, consider closing down the Charity

Dependent on income, a more limited programme of patient support activities and events will be run in 2011, including regional patient days working in partnership with local PID Centres Canal boat holidays for younger children will be considered but will be dependent on response and funds being available

PiA will step up its advocacy campaigns on behalf of its members, collectively and individually, and will monitor changes in Health Service provision in all regions to ensure that the rights of PID patients are preserved and protected. It plans to launch the 'lay' guide to PID for Health Service Managers and Commissioners and Government at a Parliamentary Reception early in 2011 and will ensure all HAE members/patients and clinical immunologists in the UK receive the new A&E Emergency Packs - including the proposed new Medical Alert Card

The Charity will continue to offer its members a free membership, support and advisory service, including benefits and welfare advice and information and materials to help PID patients cope with significant moments of change in their lives

P1A will continue to work with leading medical professionals to produce guidelines on the best forms of treatment for PID patients and with the pharmaceutical companies on the development and marketing of new treatments for all PID patients, including Hereditary Angioedema

The Charity will continue to invest in its ongoing programme of research and seek significant external funding for additional research to its own programme – such as the GSK award

P1A will use the coming year to examine closely the range of services it provides its members and with the help and input of the members themselves will seek to rationalise, prioritise, develop and promote those services that are most valued by people with PID. Costs will be reduced wherever prudent but without damaging the valued services P1A provides its members and the wider PID community.

Although the environment in the charitable sector continues to be highly competitive and the economic conditions in the UK increasingly challenging, the Trustees believe PiA should continue to provide children and adults with primary immunodeficiencies the required level of advisory, educational, advocacy and support services to meet its charitable obligations and objectives

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 DECEMBER 2010

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

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 year ended 31 December 2010, which comprise the statement of financial activities, the balance sheet, and the related notes on pages 14 to 25. 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 11, 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 (APB'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' Annual 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 December 2010 and of its incoming resources and application of resources, including its income and expenditure, for the year 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),
- have been prepared in accordance with the requirements of the Companies Act 2006

Emphasis of matter

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. The charity has lost its major source of income and unless this is replaced in the near future the charity will not have sufficient reserves to continue its activities. This, along with the matters explained in note 1a, indicate the existence of a material uncertainty which may cast significant doubt about the charitable company's ability to continue as a going concern. The financial statements do not include the adjustments that would result if the charitable company was unable to continue as a going concern.

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

Park House 25-27 Monument Hill Weybridge Surrey KT13 8RT

Chartered Accountants Statutory Auditor

STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31 DECEMBER 2010

Note	General Funds	Unrestricted Research	Restricted Research	Total 2010	General Funds	Unrestricted Research	Restricted Research	Total 2009
INCOMING RESOURCES Incoming resources from generated	£	£	£	£	£	£	£	£
funds Voluntary income 6	277.024		10.554	202 520	220 526		62 038	201.664
Voluntary income 6 Pharmaceutical Company donations 7	277,024 84,000	-	10,554	287,578 84,000	229,526 64,831	-	02 038	291,564 64,831
Investment income 8	604	-	-	604	3,138	-	-	3,138
myesanen meome s								
	361,628	-	10,554	372,182	297,495	-	62,038	359,533
Other incoming resources	9,474	-	-	9,474	9,421	-	-	9,421
TOTAL INCOMING RESOURCES	371,102		10,554	381,656	306,916		62,038	368 954
RESOURCES EXPENDED Costs of generated funds Fundraising Charitable activities 9a	13,744 383,983	- 36,435	982	14,726 465,126	8,937 322,058	- 95,153	5,958 126,293	14,895
		·	44,708	•	1		126,293	543,504
Governance Costs 10	11,741	-	-	11,741	20,108	-	-	20,108
TOTAL RESOURCES EXPENDED	409,468	36,435	45,690	491,593	351,103	95,153	132,251	578,507
Net (resources expended)/ incoming								
resources before transfers	(38,366)	(36,435)	(35,136)	(109,937)	(44,187)	(95,153)	(70,213)	(209,553)
Transfers between funds 9b	(1,871)	-	1,871	<u>-</u>	(17,255)		17,255	-
NET MOVEMENT IN FUNDS	(40,237)	(36,435)	(33,265)	(109,937)	(61,442)	(95,153)	(52,958)	(209,553)
FUNDS BROUGHT FORWARD AT 1 JANUARY 2010 14	140,354	92,644	69,070	302,068	201,796	187,797	122,028	511,621
					ļ ———			
FUNDS CARRIED FORWARD AT 31 DECEMBER 2010 14	100,117	56,209	35,805	192,131	140,354	92,644	69,070	302,068
								

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

BALANCE SHEET AT 31 DECEMBER 2010

FIXED ASSETS Tangible assets	Note 11	£	£ 7,227	2009 £ 17,260
CURRENT ASSETS Stock Debtors Cash at bank and in hand Funds on deposit	12	1,631 129,509 17,280 149,279	207 (00	1,631 114,756 15,861 247,838
CREDITORS AMOUNTS FALLING DUE WITHIN ONE YEAR TOTAL ASSETS LESS CURRENT LIABILITIE	13 S		297,699 304,926 (112,795) 192,131	380,086
FUNDS General fund Unrestricted Research Fund Restricted Research Fund	14 14 14		100,117 56,209 35,805 192,131	140,354 92,644 69,070 302,068

The financial statements on pages 14 to 25 were approved by the trustees on 23/9/11 and signed on their behalf by

A. Moore Director

Company Registration No. 05230438

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2010

1 ACCOUNTING POLICIES

(a) Basis of accounting

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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. The five-year partnership agreement expired in March 2011 and the J4G trademark holder. The Chronic Granulomatous Disorder Research Trust (CGDRT), had no wish to renew it. The Charity, along with the other partner charities, tried negotiating a transitional income arrangement with CGDRT/J4G to protect it against the sudden and significant further income loss in the next few years, and an agreement appeared close. However at the end of December 2010, without warning, CGHRT withdrew this agreed transitional agreement at the point of signing by all four partner charities.

As a result the reserves of the Charity have been placed under great pressure in 2011, and although cost and activity cutting measures have been implemented as much as possible the immediate loss of the J4G income means that there remains the very real possibility that the Charity may have to be wound up in the near future, although the Charity continues to pursue all options available and continues to look for additional income streams

On this basis there is significant doubt about the Charity's ability to continue as a going concern. The financial statements do not include the adjustments that would result if the Charity was unable to continue as a going concern.

(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

NOTES TO THE FINANCIAL STATEMENTS (continued) FOR THE YEAR ENDED 31 DECEMBER 2010

(c) Resources expended

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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 year 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

(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

NOTES TO THE FINANCIAL STATEMENTS (continued) FOR THE YEAR ENDED 31 DECEMBER 2010

2 TRUSTEES' REMUNERATION AND REIMBURSED EXPENDITURE

The trustees were not entitled to and received no remuneration from the Charity during the year Trustees were reimbursed expenses from the Charity for meetings and activities that they attended, these amounts totalled £2,587 (2009 £3,177)

3 EMPLOYEES' REMUNERATION

The average number of employees during the year was 5 (2009 6) The total costs of the employees including temporary staff is as follows

	2010	2009
	£	£
Salary costs	184,632	182,817
Employers NIC	19,977	18,576
Pension contributions	13,748	11,461
Recruitment/training costs	1,031	863
		
	219,388	213,717
		===

The number of employees whose emoluments as defined for taxation purposes amounted to over £60,000 in the year was as follows

	2010 Number	2009 Number
£60,001 - £70,000	1 =	1 =

4 PENSION COST

The Charity contributes towards employees' personal pension schemes The contributions for the year amounted to £13,748 (2009 £11,461) £1,074 (2009 £1,097) was outstanding as at the year-end

5 NET MOVEMENT IN FUNDS

This is stated after charging	2010 £	2009 £
Depreciation Auditors' remuneration	13,883 6,600	13,467 4,075
	20,483	17,542

NOTES TO THE FINANCIAL STATEMENTS (Continued) FOR THE YEAR ENDED 31 DECEMBER 2010

		INCOM	

	General Fund	Unrestricted Research	Restricted Research	2010 Total	General Fund	Unrestricted Research	Restricted Research	2009 Total
	£	£	£	£	£	£	£	£
Membership subscriptions and donations Members fundraising	31,296	-	-	31,296	32,009	-	-	32 009
activities	14,043	-	-	14,043	14,155	-	-	14,155
Annual draw and Christmas card sales Corporate and trust donations	18,812	-	-	18,812	18,277	-	-	18,277
and fundraising	5,763	-	-	5,763	11,712	-	-	11,712
Legacy individuals	250	-	-	250	5,300	-	-	5,300
PiA organised events	19,519	-	-	19,519	36,662	-	-	36,662
Big Lottery Fund grant	-	-	10,554	10,554	-	-	62,038	62,038
Jeans for Genes	187,341	•	-	187,341	111,411	-	-	111,411
	277,024		10,554	287,578	229,526 ====	-	62,038	291,564 ====

PHARMACEUTICAL COMPANY DONATIONS

	General Fund	Unrestricted Research	Restricted Research	2010 Total	General Fund	Unrestricted Research	Restricted Research	2009 Total
	£	£	£	£	£	£	£	£
Grifols UK	5,000	_	-	5,000	1,250	-	•	1,250
Baxter	16,000	-	-	16,000	11,250	-	-	11,250
Bio-Products Laboratory	15,500	-	-	15,500	1,250	-	-	1,250
CSL Behring	15,000	-	-	15,000	16,250	-	-	16,250
Octapharma	1,500	-	-	1,500	1,250	-	-	1,250
Bio-test	10,000	-	-	10,000	1,250	-	-	1,250
Jerini	-	-	-	-	100	-	-	100
Synergy	1,000	-	-	1,000	-	-	-	-
Convatec	1,500	-	-	1,500	-	-	-	-
Binding Site Group	5,000	-	-	5,000	-	-	-	-
Swedish Orphan Bio Int	1,500	-	-	1,500	-	-	-	-
Shire	12,000	-	-	12,000	32,231	•	-	32,231
	84,000			84,000	64,831		-	64,831
								

8 INVESTMENT INCOME

	General Fund	Unrestricted Research	Restricted Research	2010 Total	General Fund	Unrestricted Research	Restricted Research	2009 Total
	£	£	£	£	£	£	£	£
Bank interest	604	-	-	604	3,138	-	-	3,138
				===	===			_

NOTES TO THE FINANCIAL STATEMENTS (Continued) FOR THE YEAR ENDED 31 DECEMBER 2010

9a CHARITABLE ACTIVIT	FIVITIES	AC	Æ	BI	TA	RI	HA	Cl	9a
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9a CHARLLA	DLE AC	HALLES		_				
	General	Unrestricted	Restricted	2010	General	Unrestricted	Restricted	2009
DIRECT CHARTIABLE	Fund	Research	Research	Total	Fund	Research	Research	Total
EXPENDITURE	£	£	£	£	£	£	£	£
Meeting costs	13,427	-	1,990	15,417	4,538	-	15,063	19,601
Insight expenses	15,040	-	519	15,559	5,029	-	1,257	6,286
Regional days costs	2,577	-	286	2,863	2,035	-	3,052	5,087
Jeans for Genes costs	12,712	-	-	12,712	623	-	-	623
Other projects	6,489	-	90	6,579	6,644	-	2,423	9,067
Volunteer expenses	445	-	•	445	-	-	•	-
Research expenditure - note 9b		36,435	33,265	69,700		95,153	52,958	148,111
	50,690	36,435	36,150	123,275	18,869	95,153	74,753	188,775
SUPPORT COSTS								
Staff costs								
Support staff wages	171,574	-	5,215	176,789	145,530	-	29,413	174,943
Admin staff wages	27,673	-	147	27,820	25,602	-	848	26,450
Staff pensions	13,451	-	297	13,748	9,749	-	1,712	11,461
Staff recruitment & training	1,031	-	-	1,031	863	-	-	863
Staff welfare	1,816	-	•	1,816	1,240			1,240
	215,545		5,659	221,204	182,984	-	31,973	214,957
Rent and services								
Rent and rates	49,938	-	1,064	51,002	40,489	-	6,095	46,584
Office insurance	833	-	-	833	918	-	-	918
light and heat	1,494	-	42	1,536	1,566	-	310	1,876
[elephone	3.575	-	336	3,911	1,814	-	1,928	3,742
Cleaning	4,581	-	-	4,581	3,879	-	-	3,879
Repairs and maintenance	567	-	-	567	506	•	•	506
	60,988		1,442	62,430	49,172	-	8,333	57,505
Other expenses								
Printing, post and stationery	6,660	_	137	6,797	9,960	-	1,121	10,811
Advertising	278	_	10	288	440	-	110	550
Computer costs	10,106	_	585	10,691	6,533	_	4,270	10,803
Equipment hire	9,092	-	563	9,655	5,697	-	3,068	8,765
egal fees	- 7	-	-	-	5,045	-	-	5,045
Consultancy	9,562	_	162	9,724	23,990	•	2,665	26,655
Payroll service costs	559	-		559	580	-	_,	580
Bank charges	1,348	-	_	1,348	1,095	_	_	1,095
Currency Exchange variance	20	_	-	20		_	_	
Subscriptions	2,515	-	-	2,515	2,724	-	_	2,724
Sundry expense	2,737	-	-	2,737	1,772	_	-	1,772
Office equipment depreciation	13,883	-	-	13,883	13,467	•	-	13,467
	56,760	-	1,457	58,217	71,033		11,234	82,267
FOTAL CHARI FABLE						_		
ACTIVITIFS	383,983	36,435	44,708	465,126	322,058	95,153	126,293	543,504
		20.43.7						

NOTES TO THE FINANCIAL STATEMENTS (Continued) FOR THE YEAR ENDED 31 DECEMBER 2010

9b RESEARCH FUNDS

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	Balance 31.12 09	Receipts in year	Allocations	Expenditure in year	Balance 31.12.10
Unrestricted research funds	£	£	£	£	£
Jeans for Genes - unallocated	39,937	-	(27,500)	(4,606)	7,831
PhD Studentship	-	-	10,000	-	10,000
CBT Locum	-	-	12,500	-	12,500
XLP International	-	-	5,000	(1,226)	3,774
PID Register	23,249	-	-	(12,702)	10,547
Intercalated Degrees	6,500	-	-	-	6,500
Jolles – NIMR/RFH	11,303	_	-	(11,301)	2
AMS Project	11,655		-	(6,600)	5,055
Unrestricted research funds	92,644		<u>-</u>	(36,435)	56,209
Restricted research funds					
and other restricted grants					
BCH	10,269	-	-	-	10,269
GlaxoSmithKline	58,801	-	-	(33,265)	25,536
Big Lottery Fund	-	10,554	1,871	(12,425)	-
Restricted research funds					
and other restricted grants	69,070 ———	10,554	1,871	(45,690)	35,805
		_			
Total Funds	161,714	10,554	1,871	(82,125)	92,014

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 £	2010 Total £	General Fund £	Unrestricted Research £	Restricted Research £	2009 Total £
Trustees insurances	1,572	-	-	1,572	1,316	-	_	1,316
Trustees expenses	2,587	-	-	2,587	3,177	-	-	3,177
Audit fee	6,600	-	-	6,600	4,075	-	-	4,075
Legal fees	982	-	-	982	11,540	-	-	11,540
	11,741	_	-	11,741	20,108	-	-	20,108
	===		=		==	==	===	_

NOTES TO THE FINANCIAL STATEMENTS (Continued) FOR THE YEAR ENDED 31 DECEMBER 2010

11 FIXED ASSETS

	Fixtures,
	Fittings and
	Equipment
COST	£
As at 1 January 2010	40,402
Additions during year	3,850
Total as at 31 December 2010	44,252
DEPRECIATION	
As at 1 January 2010	23,142
Charged in year	13,883
Total as at 31 December 2010	37,025
NET BOOK VALUE	
31 December 2010	7,227
31 December 2009	17,260

12 **DEBTORS**

	2010	2009
	£	£
Other debtors Prepayments and accrued income	4,610 124,899	2,425 112,331
	129,509	114,756

Jeans for Genes

The Jeans for Genes Day is held in October and as at the year-end the amount still to be received regarding the campaign was £98,299 (2009 £49,589) and this is included in prepayments and accrued income

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NOTES TO THE FINANCIAL STATEMENTS (Continued) FOR THE YEAR ENDED 31 DECEMBER 2010

13 CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2010	2009
	£	£
Taxation & social security	5,827	5,526
Accruals	70,907	54,376
Deferred income	572	11,364
Other creditors	35,489	24,012
	112,795	95,278
		

Incoming resources that have been deferred are as follows,

2011 Virgin London Marathon donations

572

572

Deferred income relates to income that has been received prior to the year end that relates to performance and specific deliverables that has not been achieved at the year end. As such the Charity accounts for the income as it earns the right to consideration by its performance

At 1 January 2010	
The Publishery 2010	11,364
Transfer to the SOFA	(11,364)
Additional deferred income	572
At 31 December 2010	572

14 FUNDS

101105	General Funds	Unrestricted Research	Restricted Research	Total	
	£	£	£	£	
At 1 January 2010	140,354	92,644	69,070	302,068	
Net movement in funds	(40,237)	(36,435)	(33,265)	(109,937)	
At 31 December 2010	100,117	56,209	35,805	192,131	

NOTES TO THE FINANCIAL STATEMENTS (Continued) FOR THE YEAR ENDED 31 DECEMBER 2010

15 FINANCIAL COMMITMENTS

At 31 December 2010, the Charity had annual commitments under a non-cancellable operating lease as follows

	Land and	Land and buildings		
	2010	2009		
	£	£		
Expiry date	35,000	35,000		
2 to 5 years				
·	35,000	35,000		

The above lease expires in November 2013

16 **CONTROL**

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

17 RELATED PARTIES TRANSACTIONS

Jeans for Genes

Since 1996 a Jeans for Genes (JGC) campaign has been held on an annual basis to raise money for research. An agreement was drawn up between the parties involved, as shown below

Both Jeans for Genes Limited (JGL) and JGC receive income from donations generated by the appeal Any income received from JGL and JGC after deductions of all relevant costs, expenses, liabilities and other distributions, will result in the net proceeds being paid to each of the charities

The current five-year partnership agreement expired in March 2011 and the J4G trademark holder, The Chronic Granulomatous Disorder Research Trust (CGDRT), had no wish to renew it Therefore the Charity will no longer receive the J4G distributions mentioned above in future years (See note 1a)

Chris Hughan (Chief Executive of PiA) is also a director of JGL and a trustee of JGC A total of £187,341 is receivable from the campaign for the year (2009 £111,411) During the year, PiA loaned £37,500 (2009 £25,000) to JGC at an interest rate of 2% above Barclays Bank base rate per annum. The loan was fully repaid in October 2010

Participants of the Jeans for Genes Campaign are as follows

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

And

NOTES TO THE FINANCIAL STATEMENTS (Continued) FOR THE YEAR ENDED 31 DECEMBER 2010

17 RELATED PARTIES TRANSACTIONS (Continued)

Jeans for Genes

4 2 %

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 SWIH OQS
(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)

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)