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

### FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 DECEMBER 2009

Registered Charity No. 1107233

Company Registration No. 05230438

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# LEGAL AND ADMINISTRATIVE INFORMATION

Trustees A Moore
J Drabwell

R McNairney
D Webster
K Hennessy

Company Secretary C Hughan

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 Hill

Weybridge

Surrey KT13 8RT

Bankers The Royal Bank of Scotland

3<sup>rd</sup> Floor, Cavell House 2a Charing Cross Road London WC2H 0NN

# **CONTENTS**

	Page
Trustees' report	1 - 11
Auditors' report	12 - 13
Statement of financial activities	14
Balance sheet	15
Notes to the accounts	16 - 25

### REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 DECEMBER 2009

## Report of the Trustees

The Trustees have pleasure in presenting their Report and Statement of Financial Activities for the year ended 31 December 2009

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

Mr John Rixon (Resigned 26 April 2010)

The Chief Executive Officer of the PiA is Christopher Hughan In 2009 there were a further six employees (four full-time and two part-time)

The Auditors of the PiA are

Mrs Rae McNairney

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

The previous auditors were Pinkney Keith Gibbs (PKG) PKG merged with Ward Williams on 4 January 2010

### REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 DECEMBER 2009

The Principal Bankers of the PiA are

Royal Bank of Scotland 3<sup>rd</sup> 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

### REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 DECEMBER 2009

The PiA is, with three other founder charities and annually invited guest charities, 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.

The PiA is dependent, for a substantial part of its income, on the continuance and success of the Jeans for Genes Campaign. The PiA Trustees and Chief Executive continue to look at ways to mitigate this dependence whilst, at the same time, building up the level of free reserves.

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

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"

#### REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 DECEMBER 2009

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**

### Treatment, Outreach & Advocacy

PiA continued to work as 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, will contain definitive guidelines for the 'gold standard' management and treatment of Primary Antibody Deficiencies (PAD). The other document, a guide to primary immunodeficiencies, is targeted at Health Service Managers and Commissioners, as well as those in the primary care sector and other medical professionals not coming into contact with PID patients on a regular basis. Both of these important publications are in progress and PiA will work closely with the editorial teams to ensure these important guidelines are distributed widely to all relevant UK medical and healthcare professionals and other key audiences, such as Government

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

Following its success in ensuring that, even in times of shortages, English PID patients are prioritised for IVIg and SCIg treatment under usage guidelines and a demand management plan issued by the Department of Health, PiA was invited by the Scottish NHS authorities to participate in a similar review of Ig usage in Scotland. As a result of PiA being actively involved in this process the IVIg and SCIg usage guidelines and demand management launched in Scotland also prioritise Scottish PID patients for IVIg and SCIg treatment, even in times of treatment shortages

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 Pan London PID Consortium (Clinical Immunologists and Specialist Immunology Nurses from centres across London), 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), the inaugural IPOPI Global Leaders Conference in London in late October, and the UK PIN biennial International PID Forum in Bath in November

#### REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 DECEMBER 2009

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 2009, including Regional Patient Days in the West Country (Plymouth), Birmingham, London, Liverpool and Oxford 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 it is hoped that an expanded programme will be planned for 2010, covering additional centres. Smaller, more informal meetings of medical professionals, PiA and patients are also being considered in areas where there are fewer PID patients or a larger meeting is not warranted.

At the Annual Meeting in September keynote speakers covered all aspects of PID, including an update on the successful "Is it PID? Campaign, the NHS perspective on commissioning PID services and treatments, international support for PID and new and emerging treatments for PID, including Hereditary Angioedema (HAE) Three well-attended workshops discussed HAE, managing complications in Antibody Deficiency Disorders and the management of rarer PID disorders

For younger PID patients PiA organised two successful three-day Canal Boat holidays in late Summer and in July a group of young adults travelled to Center Parcs in Sherwood Forest for a week-long activity holiday – both events being closely supervised by trained PiA volunteers and local experts. These events give children and young adults 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.

PiA 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 PiA is increasingly involved in the consultation process leading to new product launches and marketing of IVIg, subcutaneous and Hereditary Angioedema (HAE) treatments and even in the production of relevant literature by the various pharmaceutical companies

PiA's Welfare & Benefits Adviser, Jenny Jackson, and Volunteers and Activities Coordinator, John Satchell, continued to provide valuable advisory and counselling services to PiA members until their retirement from the charity in the Autumn These services are now part of a comprehensive review of all services and activities provided by PiA to determine which should be prioritised and continue to be provided to PiA members in the current challenging economic environment. In the meantime advice is still being provided on benefits such as Disability Living Allowance (DLA) and Attendance Allowance (AA) and information is downloadable from the PiA website or can be sent as hard copy to those members not on the Internet

Four 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 An updated member information pack and useful tips for young PID patients attending University 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 2010/2011

### REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 DECEMBER 2009

The PiA 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 2010/2011, is currently monitored, supervised and updated by PiA staff member, Helen Edwards

### Medical and Research

Owing to a substantial reduction in overall PiA income - mainly due to rapidly declining Jeans for Genes income - investment in major new research programmes was not possible in 2009 However, in addition to PiA's ongoing investment in several high profile studies a number of low entry cost initiatives were taken in partnership with other organisations

PiA was a very active partner and participant in the "Is it PID? Campaign - an initiative coordinated by leading medical communications company, Oyster Healthcare Communications, and involving leading UK Immunology Consultants, Immunology Specialist Nurses and other medical professionals. The Campaign is aimed at reducing significantly the damaging and distressing diagnosis lag-times for PID patients by educating and informing other hospital specialists (such as Respiratory Physicians, Gastroenterologists, Paediatricians and ENT Specialists) about PID - thereby encouraging more and quicker referrals to Consultant Immunologists PiA's members participated in the Campaign by completing questionnaires aimed at determining the current average wait times for a PID diagnosis - and providing a benchmark against which the success of the Campaign will ultimately be measured

Progress has been painstaking 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

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 2009 there were approximately 1,200 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

### REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 DECEMBER 2009

As Jeans for Genes distributed income was at a new record low in 2009 and because of PiA's existing research commitments and new initiatives, the Trustees felt it would not be fiscally prudent to offer additional substantial research grants in the year ahead. However, every effort will be made in 2010/2011 to obtain research funding from other (than J4G) sources, such as that provided by GSK.

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 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. There are likely to be further additions to the MAP in 2010, as well as the establishment of a Specialist Immunology Nurses Advisory Panel for the first time.

### **Fundraising**

In fundraising terms the year was another 'mixed bag'. On the positive side the Charity received the final year's tranche of its first major Lottery Grant but unfortunately this additional revenue and other gains were effectively cancelled out by much lower than anticipated Jeans for Genes distributed income

The Lottery Grant – an award from the Big Lottery Fund under its "Reaching Communities" programme – was in the final year of the three years and was awarded to help PiA develop its volunteer base, local support groups, youth and other PID 'community' involvement and volunteer related activities PiA also benefitted from the final year of a three-year grant from BBC's "Children In Need" Campaign to help with PID children related activities such as the Canal Boat and Activity Centre holidays

Pharmaceutical income was 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 years ahead. PiA will partner 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 does not compromise the independent position of the Charity and its freedom to challenge the pharma companies as and when this might be necessary

PiA was very appreciative of its members and supporters who were, once again, very generous in their support of the Charity Donation income was much in line with previous years and support provided through member fundraising events was also significant. In 2010 PiA 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. 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

### REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 DECEMBER 2009

Jeans for Genes (J4G) income reached a new low in 2009, which was a major disappointment after the considerable investment in infrastructure building, including a new J4G database and redesigned and upgraded website that had been made by the four partner charities including PiA, in 2008 Certainly the economic situation did not help the campaign in a difficult year and explains a substantial drop in involvement and giving by small to medium size companies - very active donors in past campaigns. It is hoped that income from J4G will improve in 2010 but continuing pressures on donors in a difficult period ahead is only likely to result in slow growth at best. PiA Chief Executive, Chris Hughan, who is also a J4G Trustee, continues to work closely with the J4G team to maximise the involvement of PiA and help revitalise the J4G campaign for 2010/11

The Charity had seven 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. In July, PiA member, Diane Hammond and her daughter, Rachel, were granted the opportunity to stand on the fourth plinth in Trafalgar Square - which they did and then used the occasion to communicate the seriousness of primary immunodeficiencies and genetic disorders generally and how people can help PID patients by joining PiA and supporting the work it undertakes

Although the Christmas Draw was once again a fundraising success the sale of Christmas cards and related merchandise was somewhat flat and disappointing, resulting in a below budget drop in overall income. A review of the Christmas card selection and marketing was conducted for 2010 to provide a more appealing selection of cards at attractive price points. Additional sites for card sales were also negotiated with nationwide charity shop organisation, Cards for Good Causes, and we hope this will produce increased sales of PiA Christmas cards and other Christmas merchandise in 2010 and beyond

The Trustees and PiA staff thank PiA members and supporters for all their hard work and fundraising efforts in 2009 and look forward to their continued and much valued support in 2010

#### Staff

Long-serving PiA staff members, Jenny Jackson and John Satchell, left the Charity during the year through retirement and newcomer, Helen Edwards, was recruited to the fundraising and member and volunteer development team later in the year. There were no other significant staff changes during the year.

### REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 DECEMBER 2009

### **Financial Review**

#### Results

Total income was significantly lower than in the previous year at £368,954 (2008 £429,723) Although very disappointing, the result is far more satisfactory when the very significant drop in income from PiA's historic major source of revenue, Jeans for Genes is taken into consideration Jeans for Gene's revenue was £113,343 against £181,180 in 2008, a drop of £67,837 This followed a drop of £90,837 the previous year - a reduction in J4G contributed income of £158,674 in two years. Despite the re-organisation of the fundraising initiatives following the appointment of a new J4G Chief Executive in 2006 and subsequent infrastructure investment by the four partner charities, donation income was well down – as were the number of fundraising coordinators participating in the campaign

Every effort is being made by the J4G management and staff, as well as the J4G Trustees, to turn around the four year decline in J4G generated partner charity income but it is anticipated that only modest gains at best are likely in 2010 and 2011. There are also serious doubts about the future of the original charity partnership, and thus PiA's involvement, following the announcement by the J4G trademark holder, the Chronic Granulomatous Disorder Research Trust ("CGDRT"), that it has no wish to renew the current five-year partnership agreement when it expires in March 2011. If no new partnership agreement emerges from current discussions - the likely outcome - then PiA and the other partner charities will try and negotiate a transitional income arrangement with CGDRT / J4G to protect the Charity against sudden and significant further income loss in the next few years. This will allow for other revenue streams to be built up in the interim and protect PiA's important support and advocacy role on behalf of PID patients throughout the UK

P1A continued its successful 'challenge' fundraising events in the year and, along with revenue from running events, this generated £36,662 of gross income The Charity also received £62,038 in Big Lottery funding during the year Pharmaceutical income at £64,831 was higher than the previous year and member/supporter donations and member fundraising totalled £32,009 and £14,155 respectively

Costs were kept under strict control and were £13,000 less that the amount budgeted

As a result of a further significant downturn in J4G income, PiA had a deficit of £61,442 on the general fund for the year (2008 £2,793)

## **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 £140,354 at 31 December 2009 represents over three months of operational expenditure

### REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 DECEMBER 2009

### **Investment Policy**

Under its Memorandum & Articles of Association the PiA has the power to make any investment 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 2010 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. A decision on participation in another 'challenge' event will depend to a large extent on potential participant reaction.

Dependent on income a comprehensive programme of patient support activities and events will be run in 2010, including an increased number of regional patient days and Canal Boat and Sherwood Forest activity holidays for younger PID patients

PiA will continue to advocate aggressively 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

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

PiA 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

Dependent on the level of Jeans for Genes revenues in 2010, PiA will consider another round of research funding towards the end of 2010. In the meantime the Charity will continue to invest in its substantial, ongoing programme of PID research, fund a number of strategically important new initiatives, such as the Intercalated Degree Bursary Awards and the UK PID Register, and seek significant funding for additional research from its own fundraising programme – such as the GSK award

PiA 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

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 will 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 2009

### 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 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 on and signed on its behalf by:

24 September ZUIO

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 year ended 31 December 2009, which comprise the statement of financial activities, the balance sheet, and the related notes on pages 14 to 25 These financial statements have been prepared under the accounting policies set out in pages 16 to 17 and the Financial Reporting Standard for Smaller Entities (effective April 2008)

This report is made solely to the charitable company's members, as a body, in accordance with Sections 495 and 496 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

The trustees' (who are also the directors of The Primary Immunodeficiency Association for the purposes of company law) responsibilities for preparing the trustees' Annual Report and the Financial Statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice) and for being satisfied that the financial statements give a true and fair view are set out in the Statement of Trustees' Responsibilities

Our responsibility is to audit the Financial Statements in accordance with relevant legal and regulatory requirements and International Standards on Auditing (UK and Ireland)

We report to you our opinion as to whether the Financial Statements give a true and fair view, have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice and have been prepared in accordance with the Companies Act 2006. We also report to you whether in our opinion the information given in the trustees' Annual Report is consistent with the financial statements.

In addition we report to you if, in our opinion, the charity has not kept proper accounting records, if the financial statements are not in agreement with the accounting records and returns, if we have not received all the information and explanations we require for our audit, or if certain disclosure of trustees' remuneration specified by law are not made

We read the trustees' Annual Report and consider the implications for our report if we become aware of any apparent misstatements within it

### Basis of audit opinion

We conducted our audit in accordance with International Standards on Auditing (UK and Ireland) issued by the Auditing Practices Board. An audit includes examination, on a test basis, of evidence relevant to the amounts and disclosures in the financial statements. It also includes an assessment of the significant estimates and judgements made by the trustees in the preparation of the financial statements, and of whether the accounting policies are appropriate to the charitable company's circumstances, consistently applied and adequately disclosed

### REPORT OF THE AUDITORS TO THE TRUSTEES OF

### THE PRIMARY IMMUNODEFICIENCY ASSOCIATION

We planned and performed our audit so as to obtain all the information and explanations which we considered necessary in order to provide us with sufficient evidence to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or other irregularity or error. In forming our opinion we also evaluated the overall adequacy of the presentation of information in the financial statements.

### **Opinion**

### 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 2009 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- the Financial Statements have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice (applicable to smaller entities);
- the Financial Statements have been prepared in accordance with the Companies Act 2006; and
- the information given in the trustees' Annual Report is consistent with the financial statements.

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

**Chartered Accountants Statutory Auditor** 

27 September 2010

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

# STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31 DECEMBER 2009

Note	General Funds	Unrestricted Research	Restricted Research	Total 2009	General Funds	Unrestricted Research	Restricted Research	Total 2008
INCOMING RESOURCES Incoming resources from generated funds	£	£	£	£	£	£	£	£
Voluntary income 6	229,526	_	62,038	291,564	308,171	_	55,252	363,423
Pharmaceutical Company donations 7	64,831	_	-	64,831	31.089	_	33,232	31,089
Investment income 8	3,138	-	-	3,138	22,003	-	-	22,003
	297,495	<del>-</del>	62,038	359,533	361,263		55,252	416,515
Other incoming resources	9,421	-	-	9,421	13,208	-	-	13,208
TOTAL INCOMING RESOURCES	306,916	-	62,038	368,954	374,471		55,252	429,723
RESOURCES EXPENDED Costs of generated funds Fundraising Charitable activities 9a	8,937 322,058	- 95,153	5,958 126,293	14,895 543,504	16,088 328,087	- 115,044	8,662 122,677	24,750 565,808
Governance Costs 10	20,108			20,108	10,243	-		10,243
TOTAL RESOURCES EXPENDED	351,103	95,153	132,251	578,507	354,418	115,044	131,339	600,801
Net (resources expended)/ incoming resources before transfers  Transfers between funds 9b	(44,187) (17,255)	(95,153)	(70,213) 17,255	(209,553)	20,053 (22,846)	(115,044)	(76,087) 22,846	(171,078)
NET MOVEMENT IN FUNDS	(61,442)	(95,153)	(52,958)	(209,553)	(2,793)	(115,044)	(53,241)	(171,078)
FUNDS BROUGHT FORWARD AT 1 JANUARY 2009 14	201,796	187,797	122,028	511,621	204,589	302,841	175,269	682,699
FUNDS CARRIED FORWARD AT 31 DECEMBER 2009 14	140,354	92,644	69,070	302,068	201,796	187,797	122,028	511,621

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 2009**

FIXED ASSETS Tangible assets	Note	£	£ 17,260	2008 £ 16,749
Tungible ussets	11		17,200	10,712
CURRENT ASSETS Stock Debtors Cash at bank and in hand Funds on deposit	12	1,631 114,756 15,861 247,838		2,339 261,795 15,462 333,381
			380,086	612,977
CREDITORS AMOUNTS FALLING DUE WITHIN ONE YEAR	13		397,346 (95,278)	629,726 (118,105)
TOTAL ASSETS LESS CURRENT LIABILITI	ES		302,068	511,621
FUNDS				
General fund	14		140,354	201,796
Unrestricted Research Fund	14		92,644	187,797
Restricted Research Fund	14		69,070	122,028
			302,068	511,621

The financial statements on pages 14 to 25 were approved by the trustees on 44 signed on their behalf by

A. Moore Director

Company Registration No. 05230438

# NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2009

### 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. The current five-year partnership agreement expires in March 2011 and the J4G trademark holder, The Chronic Granulomatous Disorder Research Trust (CGDRT), has no wish to renew it. The charity, along with the other partner charities, is therefore negotiating a transitional income arrangement with CGDRT/J4G to protect it against sudden and significant further income loss in the next few years. This will allow for other income streams to be built up in the interim and protect PiA's important support and advocacy role on behalf of PID patients throughout the UK. On this basis the trustees therefore consider it appropriate to continue to prepare these accounts on a going concern basis.

### (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

# (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

# NOTES TO THE FINANCIAL STATEMENTS (continued) FOR THE YEAR ENDED 31 DECEMBER 2009

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

The Jeans for Genes founder charities (including PiA) received special dispensation in 2008 and 2009 from Jeans for Genes to allocate distributed funds to research or support activity at whatever level they considered prudent and appropriate PiA has not allocated any funds to research this year (PiA did not allocate any funds to research in 2008 either) In prior years where special dispensation had not been received the income was split on the basis of 40% support services, and 60% research (less a research overhead recovery charge) (See note 17)

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 2009

## 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 £ 3,177 (2008 £3,658)

### 3 EMPLOYEES' REMUNERATION

The average number of employees during the year was 6 (2008 7) The total costs of the employees including temporary staff is as follows

	2009	2008
	£	£
Salary costs	182,817	184,821
Employers NIC	18,576	18,434
Pension contributions	11,461	13,009
Recruitment/training costs	863	782
-		—
	213,717	217,046
	=====	

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

	2009 Number	2008 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 £11,461 (2008 £13,009) £1,097 (2008 £1,747) was outstanding as at the year-end

### 5 NET MOVEMENT IN FUNDS

This is stated after charging	2009 £	2008 £
Depreciation Auditors' remuneration	13,467 4,075	8,808 3,450
	17,542	12,258

# NOTES TO THE FINANCIAL STATEMENTS (Continued) FOR THE YEAR ENDED 31 DECEMBER 2009

6	VOLUNTARY INCOM	E.

	General Fund	Unrestricted Research	Restricted Research	2009 Total	General Fund	Unrestricted Research	Restricted Research	2008 Total
	£	£	£	£	£	£	£	£
Membership subscriptions and donations Members fundraising	32,009			32,009	26,408	•	-	26,408
activities	14,155	•	-	14,155	20 127	•	-	20,127
Annual draw and Christmas card sales  Corporate and trust donations	18,277	-	-	18,277	19,022	•	-	19,022
and fundraising	11,712	-	-	11,712	26,110	•	-	26,110
Legacy individuals	5,300	-	-	5,300	4,162	,	-	4,162
PiA organised events	36,662	•	•	36,662	32,342	-	-	32,342
Big Lottery Fund grant	-	-	62,038	62,038	-		55,252	55,252
Jeans for Genes	111,411	-	-	111,411	180,000	-	-	180,000
	229,526		62,038	291,564	308,171		55,252	363,423

### 7 PHARMACEUTICAL COMPANY DONATIONS

	General Fund	Unrestricted Research	Restricted Research	2009 Total	General Fund	Unrestricted Research	Restricted Research	2008 Total
	£	£	£	£	£	£	£	£
Grifols UK	1,250	-	-	1,250	2,500	-	-	2,500
Baxter	11,250	-	_	11,250	_	-	-	-
Bio-Products Laboratory	1,250	-	-	1,250	7,500	-	-	7,500
CSL Behring	16,250	-	-	16,250	12,500	-	-	12,500
Octapharma	1,250	-	-	1,250	2 500	-	-	2,500
B10-test	1,250	-	-	1,250	2 500	-	-	2 500
Jerini	100	-	-	100	3,589	-	-	3,589
Shire	32,231	-	-	32,231	-	-	•	-
	64,831		•	64,831	31,089			31,089

## 8 INVESTMENT INCOME

	General Fund	Unrestricted Research	Restricted Research	2009 Total	General Fund	Unrestricted Research	Restricted Research	2008 Total
	£	£	£	£	£	£	£	£
Bank interest	3,138	-	-	3,138	22,003	-	•	22,003
			====	==		-		====
				1				

# NOTES TO THE FINANCIAL STATEMENTS (Continued) FOR THE YEAR ENDED 31 DECEMBER 2009

	9a CHARITA	BLE AC	TIVITIES				As Restated	i	
Meeting costs		General	Unrestricted	Restricted	2009	General	Unrestricted	Restricted	2008
Meeting costs	DIRECT CHARITABLE	Fund	Research	Research	Total	Fund	Research	Research	Total
Insigh regrouse   5,029   .   1,257   6,286   9,444   .   2,361   11,805   Regional days costs   2,035   .   3,052   5,887   2,094   .   2,560   4,654   4,654   10,250   10	EXPENDITURE	£	£	£	£	£	£	£	£
Insigh regrouse   5,029   .   1,257   6,286   9,444   .   2,361   11,805   Regional days costs   2,035   .   3,052   5,887   2,094   .   2,560   4,654   4,654   10,250   10	•			45.000	40.404				
Regional days costs   2,035   - 3,052   5,887   2,094   - 2,560   4,554   10,250	=	•	-		· 1	*	-		
Chebro ropices   7.267   -   2.433   9.690   7.688   -   2.562   10.250     Volunteer expenses   -   95,153   52,958   148,111   -   115,044   53,241   168,285     Research expenditure - note 9b   -   95,153   52,958   148,111   -   115,044   53,241   168,285     Research expenditure - note 9b   -   95,153   74,753   188,775   26,099   115,044   76,725   217,868     SUPPORT COSTS	• •	•	-			•	•		
Value   Valu	- ·		-				-		•
Research expenditure - note 9b		7,267	-	2,423	9,690		-		
Support Costs   Support staff wages	•	-	-			43	•		
SUPPORT COSTS   Staff cost   Support staff wages   145,530   29,413   174,943   155,973   253,90   181,363   34,40m staff wages   25,602   848   26,459   21,074   818   21,892   31,009   1,712   11,461   13,009   1,712   11,461   13,009   1,712   11,461   13,009   1,712   11,461   13,009   1,712   11,461   13,009   1,712   11,461   13,009   1,712   11,461   13,009   1,712   11,461   13,009   1,712   11,461   13,009   1,712   11,461   13,009   1,712   11,461   13,009   1,712   11,461   13,009   1,712   1,160   1	Research expenditure - note 9b		95,153	52,958	148,111		115,044	53,241	168,285
Staff costs		18,869	95,153	74,753	188,775	26,099	115,044	76,725	217,868
Staff costs	SUPPORT COSTS								
Support staff wages   145,530   29,413   174,943   155,973   25,390   181,363   Admin staff wages   25,602   848   26,450   21,074   818   21,892   13,009									
Admin staff wages   25,602   - 848   26,450   21,074   818   21,892   Staff persions   9,749   - 1,712   11,461   13,009   - 13,009   782   Staff recrutment & training   863   - 863   782   - 782   Staff welfare   1,240   - 1,240   1,160   - 1,160     1,16		145.530	_	29.413	174.943	155 973	_	25 390	181 363
Staff pensions   9,749   - 1,712   11,461   13,009   - 13,009   Staff recruitment & training   863   863   782   1,160     1,160     1,1	••	•	_	•			_	-	
Staff recruitment & training   Staff vertifier			_			-	_		
Staff welfare   1,240		•		1,712	, , , , , , , , , , , , , , , , , , ,	-	_	_	
Rent and services   Rent and rates   40,489   - 6,095   46,584   39,023   - 5,894   44,917				_				_	
Rent and services Rent and rates	Juli Wellale						<u> </u>		
Rent and rates		182,984	-	31,973	214,957	191, <del>99</del> 8	•	26,208	218,206
Computer costs   Comp	Rent and services								
Computer costs   Computer cost	Rent and rates	40,489	-	6,095	46,584	39,023	-	5,894	44,917
Light and heat	Office insurance	918	_	· <u>-</u>	918		-	, -	
Telephone   1,814   - 1,928   3,742   504   - 3,239   3,743	Light and heat	1,566	•	310	1,876		•	293	
Cleaning   3,879   -	Telephone	1,814	-	1,928	3,742		•	3,239	
Repairs and maintenance   506   -   506   -   -   -   -   -   -   -   -   -			-	-	3,879	3,398	_	· -	
Other expenses           Printing, post and stationery         9,690         -         1,121         10,811         5,878         -         2,123         8,001           Advertising         440         -         110         550         601         -         67         668           Computer costs         6,533         -         4,270         10,803         8,069         -         1,599         9,668           Equipment hire         5,697         -         3,068         8,765         6,176         -         3,226         9,502           Legal fees         5,045         -         -         5,045         2,652         -         -         2,652           Consultancy         23,990         -         2,665         26,655         26,264         -         3,203         29,467           Payroll service costs         580         -         -         580         625         -         -         625           Bank charges         1,095         -         -         1,095         1,283         -         -         1,283           Sundry expense         1,772         -         -         1,772         320         -         - <t< td=""><td>Repairs and maintenance</td><td>506</td><td>-</td><td>-</td><td></td><td></td><td>-</td><td>-</td><td></td></t<>	Repairs and maintenance	506	-	-			-	-	
Other expenses           Printing, post and stationery         9,690         -         1,121         10,811         5,878         -         2,123         8,001           Advertising         440         -         110         550         601         -         67         668           Computer costs         6,533         -         4,270         10,803         8,069         -         1,599         9,668           Equipment hire         5,697         -         3,068         8,765         6,176         -         3,226         9,502           Legal fees         5,045         -         -         5,045         2,652         -         -         2,652           Consultancy         23,990         -         2,665         26,655         26,264         -         3,203         29,467           Payroll service costs         580         -         -         580         625         -         -         625           Bank charges         1,095         -         -         1,095         1,283         -         -         1,283           Sundry expense         1,772         -         -         1,772         320         -         - <t< td=""><td>·</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></t<>	·								
Printing, post and stationery 9,690 - 1,121 10,811 5,878 - 2,123 8,001 Advertising 440 - 110 550 601 - 67 668 Computer costs 6,533 - 4,270 10,803 8,069 - 1,599 9,668 Equipment hire 5,697 - 3,068 8,765 6,176 - 3,326 9,502 Legal fees 5,045 - 5,045 2,652 2,652 Consultancy 23,990 - 2,665 26,655 26,264 - 3,203 29,467 Payroll service costs 580 580 625 625 Bank charges 1,095 - 1,095 1,283 - 1,283 Subscriptions 2,724 2,724 3,819 - 3,819 Sundry expense 1,772 - 1,772 320 - 320 Office equipment depreciation 13,467 - 11,234 82,267 64,495 - 10,318 74,813 TOTAL CHARITABLE ACTIVITIES 322,058 95,153 126,293 543,504 328,087 115,044 122,677 565,808		49,172	-	8,333	57,505	45,495	-	9,426	54,921
Printing, post and stationery 9,690 - 1,121 10,811 5,878 - 2,123 8,001 Advertising 440 - 110 550 601 - 67 668 Computer costs 6,533 - 4,270 10,803 8,069 - 1,599 9,668 Equipment hire 5,697 - 3,068 8,765 6,176 - 3,326 9,502 Legal fees 5,045 - 5,045 2,652 2,652 Consultancy 23,990 - 2,665 26,655 26,264 - 3,203 29,467 Payroll service costs 580 580 625 625 Bank charges 1,095 - 1,095 1,283 - 1,283 Subscriptions 2,724 2,724 3,819 - 3,819 Sundry expense 1,772 - 1,772 320 - 320 Office equipment depreciation 13,467 - 11,234 82,267 64,495 - 10,318 74,813 TOTAL CHARITABLE ACTIVITIES 322,058 95,153 126,293 543,504 328,087 115,044 122,677 565,808		_	_				_		<del></del>
Advertising 440 - 110 550 601 - 67 668  Computer costs 6,533 - 4,270 10,803 8,069 - 1,599 9,668  Equipment hire 5,697 - 3,068 8,765 6,176 - 3,326 9,502  Legal fees 5,045 - 5,045 2,652 2,652  Consultancy 23,990 - 2,665 26,655 26,264 - 3,203 29,467  Payroll service costs 580 580 625 625  Bank charges 1,095 1,095 1,283 1,283  Subscriptions 2,724 2,724 3,819 3,819  Sundry expense 1,772 - 1,772 320 - 320  Office equipment depreciation 13,467 13,467 8,808 8,808  TOTAL CHARITABLE  ACTIVITIES 322,058 95,153 126,293 543,504 328,087 115,044 122,677 565,808	•	0.400			10.011	4.070		2 .22	0.001
Computer costs         6,533         -         4,270         10,803         8,069         -         1,599         9,668           Equipment hire         5,697         -         3,068         8,765         6,176         -         3,326         9,502           Legal fees         5,045         -         -         5,045         2,652         -         -         2,652           Consultancy         23,990         -         2,665         26,655         26,264         -         3,203         29,467           Payroll service costs         580         -         -         580         625         -         -         625           Bank charges         1,095         -         -         1,095         1,283         -         -         -         625           Subscriptions         2,724         -         -         2,724         3,819         -         -         -         3,819           Sundry expense         1,772         -         -         13,467         8,808         -         -         -         8,808           TOTAL CHARITABLE         -         -         11,234         82,267         64,495         -         10,318         74,813 <td>•</td> <td>•</td> <td>•</td> <td></td> <td></td> <td>•</td> <td>-</td> <td>•</td> <td></td>	•	•	•			•	-	•	
Equipment hire         5,697         -         3,068         8,765         6,176         -         3,326         9,502           Legal fees         5,045         -         -         5,045         2,652         -         -         2,652           Consultancy         23,990         -         2,665         26,655         26,264         -         3,203         29,467           Payroll service costs         580         -         -         580         625         -         -         625           Bank charges         1,095         -         -         1,095         1,283         -         -         1,283           Subscriptions         2,724         -         -         2,724         3,819         -         -         3,819           Sundry expense         1,772         -         1,772         320         -         -         320           Office equipment depreciation         13,467         -         13,467         8,808         -         -         10,318         74,813           TOTAL CHARITABLE           ACTIVITIES         322,058         95,153         126,293         543,504         328,087         115,044         122,677	<del>-</del>		-				-		1
Legal fees         5,045         -         -         5,045         2,652         -         -         2,652           Consultancy         23,990         -         2,665         26,655         26,264         -         3,203         29,467           Payroll service costs         580         -         -         580         625         -         -         625           Bank charges         1,095         -         -         1,095         1,283         -         -         1,283           Subscriptions         2,724         -         -         2,724         3,819         -         -         3,819           Sundry expense         1,772         -         -         1,772         320         -         -         320           Office equipment depreciation         13,467         -         -         13,467         8,808         -         -         10,318         74,813           TOTAL CHARITABLE           ACTIVITIES         322,058         95,153         126,293         543,504         328,087         115,044         122,677         565,808		•	-			•	-	,	,
Consultancy 23,990 - 2,665 26,655 26,264 - 3,203 29,467  Payroll service costs 580 580 625 625  Bank charges 1,095 1,095 1,283 1,283  Subscriptions 2,724 2,724 3,819 3,819  Sundry expense 1,772 1,772 320 320  Office equipment depreciation 13,467 13,467 8,808 8,808  TOTAL CHARITABLE  ACTIVITIES 322,058 95,153 126,293 543,504 328,087 115,044 122,677 565,808			-	3,068			-	3,326	
Payroll service costs 580 580 625 625  Bank charges 1,095 1,095 1,283 1,283  Subscriptions 2,724 2,724 3,819 3,819  Sundry expense 1,772 - 1,772 320 320  Office equipment depreciation 13,467 - 13,467 8,808 8,808  71,033 - 11,234 82,267 64,495 - 10,318 74,813  TOTAL CHARITABLE  ACTIVITIES 322,058 95,153 126,293 543,504 328,087 115,044 122,677 565,808	<del>-</del>		•	-			-	-	
Bank charges         1,095         -         -         1,095         1,283         -         -         1,283           Subscriptions         2,724         -         -         2,724         3,819         -         -         3,819           Sundry expense         1,772         -         -         1,772         320         -         -         320           Office equipment depreciation         13,467         -         -         13,467         8,808         -         -         -         8,808           -         -         -         -         -         -         -         8,808         -         -         -         8,808           -         -         -         -         -         -         -         -         -         8,808           - <td>•</td> <td></td> <td>-</td> <td>2,665</td> <td></td> <td></td> <td>-</td> <td>3,203</td> <td></td>	•		-	2,665			-	3,203	
Subscriptions         2,724         -         -         2,724         3,819         -         -         3,819           Sundry expense         1,772         -         -         1,772         320         -         -         320           Office equipment depreciation         13,467         -         -         13,467         8,808         -         -         -         8,808           71,033         -         11,234         82,267         64,495         -         10,318         74,813           TOTAL CHARITABLE           ACTIVITIES         322,058         95,153         126,293         543,504         328,087         115,044         122,677         565,808			-	-			-	-	
Sundry expense 1,772 1,772 320 320 Office equipment depreciation 13,467 13,467 8,808 8,808  71,033 - 11,234 82,267 64,495 - 10,318 74,813  TOTAL CHARITABLE ACTIVITIES 322,058 95,153 126,293 543,504 328,087 115,044 122,677 565,808	Bank charges		-	-	The state of the s		-	•	
Office equipment depreciation 13,467 13,467 8,808 8,808  71,033 - 11,234 82,267 64,495 - 10,318 74,813  TOTAL CHARITABLE ACTIVITIES 322,058 95,153 126,293 543,504 328,087 115,044 122,677 565,808	•		-	-			-	-	
71,033 - 11,234 82,267 64,495 - 10,318 74,813  TOTAL CHARITABLE ACTIVITIES 322,058 95,153 126,293 543,504 328,087 115,044 122,677 565,808	Sundry expense	1,772	-	-	1,772		-	-	
TOTAL CHARITABLE ACTIVITIES 322,058 95,153 126,293 543,504 328,087 115,044 122,677 565,808	Office equipment depreciation	13,467	-	-	13,467	8,808	-	-	8,808
ACTIVITIES 322,058 95,153 126,293 543,504 328,087 115,044 122,677 565,808		71,033		11,234	82,267	64,495		10,318	74,813
ACTIVITIES 322,058 95,153 126,293 543,504 328,087 115,044 122,677 565,808	mom. 1 611 . E					<del></del>			
		322 DEP	QE 187	126 202	543 504	328 087	115 044	122 677	564 000
	ACTIVITIES.	344,036	73,133	====	543,504	328,087	====	122,077	

# NOTES TO THE FINANCIAL STATEMENTS (Continued) FOR THE YEAR ENDED 31 DECEMBER 2009

# 9b RESEARCH FUNDS

	Balance 31 12.08	Receipts in year	Allocations	Expenditure in year	Balance 31.12.09
Unrestricted research funds	£	£	£	£	£
Jeans for Genes - unallocated	39,937	•	-	•	39,937
PID Register	56,577	-	-	(33,328)	23,249
Intercalated Degrees	6,500	-	-	•	6,500
Jolles – NIMR/RFH	20,599	-	-	(9,296)	11,303
AMS Project	64,184	-	•	(52,529)	11,655
Unrestricted research funds	187,797	-		(95,153)	92,644
Restricted research funds and other restricted grants					
BCH	10,269	•	-	-	10,269
GlaxoSmithKline	111,759	-	-	(52,958)	58,801
Big Lottery Fund	•	62,038	17,255	(79,293)	-
Restricted research funds				<u> </u>	
and other restricted grants	122,028	62,038	17,255	(132,251)	69,070
<b>2</b> ·· · · ·		<del>,</del>			
		<u></u>			
Total Funds	309,825	62,038	17,255	(227,404)	161,714
		==		<del></del>	

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 £	2009 Total	General Fund £	Unrestricted Research £	Restricted Research £	2008 Total £
Trustees insurances	1,316	-	-	1,316	996	-	-	996
Trustees expenses	3,177	-	-	3,177	3,658	-	-	3,658
Audıt fee	4,075	-	-	4,075	3,450	-	-	3,450
Legal fees	11,540	-	-	11,540	2,139	-	-	2,139
	20,108	-	-	20,108	10,243	-	-	10,243
			===					<del>==</del>

# NOTES TO THE FINANCIAL STATEMENTS (Continued) FOR THE YEAR ENDED 31 DECEMBER 2009

11 FIXED ASSETS	
	Fixtures,
	Fittings and
	Equipment
COST	£
As at 1 January 2009	26,424
Additions during year	13,978
Total as at 31 December 2009	40,402
DEPRECIATION	
As at 1 January 2009	9,675
Charged in year	13,467
Total as at 31 December 2009	23,142
NEW BOOK WATER	
NET BOOK VALUE	18.040
31 December 2009	17,260
21 December 2000	16.740
31 December 2008	16,749
	<del></del>
2 DEBTORS	
2 DEDIORS	2009 2008

# 12

	2009 £	2008 £
Other debtors Prepayments and accrued income	2,425 112,331	7,262 254,533
	114,756 ——	261,795

# Jeans for Genes

The Jeans for Genes Day is held in October and therefore the funds raised and costs relating thereto are not known by the time the financial statements are prepared. The Treasurer has estimated that the amount still to be received will be £49,589 (2008 £186,178) (See note 17)

# NOTES TO THE FINANCIAL STATEMENTS (Continued) FOR THE YEAR ENDED 31 DECEMBER 2009

1.2	CDEDITORS.	A B # COT IN PROCE	DATE TAKE TAKE	WITHIN ONE YEAR
1.3	CKEDITOKS:	AMOUNIS.	FALLING DUE	WILDIN ONE LEAK

	2009	2008
	£	£
Taxation & social security	5,526	3,969
Accruals	54,376	77,832
Deferred income	11,364	11,036
Other creditors	24,012	25,268
	95,278	118,105
	======	

£
10,554
810
11,364

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

The movement in deferred income is as follows	£
At 1 January 2009	11,036
Transfer to the SOFA	(11,036)
Additional deferred income	11,364
At 31 December 2009	11,364

## 14 FUNDS

	General Funds	Unrestricted Research	Restricted Research	Total	
	£	£	£	£	
At 1 January 2009	201,796	187,797	122,028	511,621	
Net movement in funds	(61,442)	(95,153)	(52,958)	(209,553)	
At 31 December 2009	140,354	92,644	69,070	302,068	

# NOTES TO THE FINANCIAL STATEMENTS (Continued) FOR THE YEAR ENDED 31 DECEMBER 2009

### 15 FINANCIAL COMMITMENTS

At 31 December 2009, the Charity had annual commitments under a non-cancellable operating lease as follows

	Land and buildings		
	2009	2008	
	£	£	
Expiry date	35,000	31,000	
2 to 5 years			
	35,000	31,000	
	<del></del>		

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 Each year an agreement is 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 (See note 12)

Chris Hughan (Chief Executive of PiA) is also a director of JGL and a trustee of JGC. It is estimated that a total of £111,411 is receivable from the campaign for the current year (2008 £180,000). During the year, PiA loaned £25,000 (2008 £200,000) to JGC at an interest rate of 2% above the Barclays standard rate per annum. The loan was fully repaid in November 2009.

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 2009

## 17 RELATED PARTIES TRANSACTIONS (Continued)

Jeans for Genes

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 803217)

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)