

COMPANY REGISTRATION NUMBER 2920581

**THE PSP ASSOCIATION
COMPANY LIMITED BY GUARANTEE
FINANCIAL STATEMENTS
SIX MONTH PERIOD ENDED 31 DECEMBER 2009**

Charity Number 1037087

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COMPANY LIMITED BY GUARANTEE
PERIOD ENDED 31 DECEMBER 2009

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MEMBERS OF THE BOARD AND PROFESSIONAL ADVISERS

Registered charity name	The PSP Association
Charity registration numbers	1037087 England & Wales; SC 041199 Scotland
Company registration number	2920581
Registered office and operational address	PSP House 167 Watling Street West Towcester Northants NN12 6BX
Secretary	Gerald Kirby
The Executive Committee Chairman of Trustees:	Brigadier Michael R Koe OBE
Chief Executive (non Trustee):	Mrs Jane Hardy FCIB
Trustees	Mrs F D Chamberlain (formerly Lady Turner) Mr N Down Mr J A Fenwick Mr P B Glithero FCA Mr C R M Kemball Mr R J Koe Mr S R Koe Prof. A J Lees MD, FRCP Mr J D Sutton Mr E T Turner Mr A G Tusa
The Medical Advisory Panel: Chairman:	Prof. A J Lees (UK)
Members:	Prof. Y Agid (France) Prof. L Golbe (USA) Prof. I Litvan (USA) Prof. Dr. W Poewe (Germany/Austria) Prof. N Quinn (UK) Prof. S Reich (USA) Prof. M Rosser (UK)

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Prof. E Tolosa (Spain)
Prof. N Wood (UK)
Prof. D Burn (UK)
Dr. P Damier (France)

Honorary member: Professor J Steele (Canada/Guam)

Associate member: Dr. D Machado (Portugal)

**Medical co-ordinator
Europe:** Dr. P Pramstaller (Italy)

Auditor
Harris & Co
Chartered Accountants
& Statutory Auditor
2 Pavilion Court
600 Pavilion Drive
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NN4 7SL

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TRUSTEES' REPORT

OVERVIEW

The Trustees, who are also Directors for the purposes of company law, have pleasure in presenting their report and the financial statements of the Charity for the period ended 31 December 2009. This report covers the six months period from 1st July to 31st December 2009 as the Charity moves to a calendar year reporting date, as approved by Trustees. **References and administrative details are shown in the schedule of members of the board and professional advisers on pages 1 and 2 of the financial statements.** This Report has been drafted having taken due regard to the Charity Commission's "Charities and Public Benefit -Summary Guidance for Charity Trustees" and demonstrates the public benefit of our Mission, Objectives and Activities, Strategy and Achievements.

CONTENTS. The Trustees' Report consists of four interrelated Sections.

- Section 1 - Statement of Recommended Practice (SORP) Headings
- Structure, Governance and Management**
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- Overview**
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- Section 3 - The Chief Executive's (CEO'S) Report:
- Progressive Supranuclear Palsy (PSP) and the Formation of The PSP Association**
The PSP Association's Mission and Business Plan Statements
Progress Report on Research
Progress Report on Support
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- Section 4 - Treasurer's Report

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Trustees
Trustees' Responsibilities
Auditor

SECTION 1 - SORP HEADINGS

Structure, Governance and Management

General

The PSP Association (PSPA) is a charitable company limited by guarantee, incorporated on 19th April 1994 and registered as a Charity with the Charity Commission of England and Wales on 27th April 1994. In January 2010 PSPA received confirmation from The Office of the Scottish Charity Regulator (OSCR) that its application for separate registration with OSCR (recently required under Scottish Charity Law) had been successful. PSPA is established under a Memorandum of Association. This lays down the objects and powers of the company governed under its Articles of Association. In the event of the company being wound up, Members are required to contribute an amount not exceeding £1.

The structure and governance of the Charity are set out more fully in its Memorandum and Articles of Association.

Governance

The Directors of the Company are also Charity Trustees for the purposes of Charity law and under the Company's Articles are known as Members of the Executive Committee. The Charity is governed by this Committee, whose Members are elected to serve for a period of three years after which, if they wish, they can offer themselves for re-election for a further period at the next Annual General Meeting. The Executive Committee consists of a minimum of five and maximum of fifteen Members and the serving Chief Executive.

Our Trustees are all high calibre professionals, selected from a wide range of experience and background, including necessary business and medical skills with a mix of appropriate Charity skills relevant to the PSP Association. Selection is by invitation to those recommended to The Association through a variety of channels, whom the Chairman and/or Chief Executive identify as having the potential to fill skill gaps; and who are prepared to volunteer their services. CVs and other details are then circulated to all Trustees and a vote is taken at the subsequent AGM. Successful candidates are then appointed as new Trustees.

It must be pointed out that identification of suitable and willing candidates to become Trustees is becoming ever more challenging, as responsibilities and work load required of

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volunteer unpaid high grade personnel, often already working in stressful jobs, continue to grow.

Trustees recently changed the Charity's financial year from 1st July / 30th June to January 1st / December 31st. This change took place with effect from July 1st 2009. This explains why these accounts are for a period of 6 months only. The main reason for the change to the financial year was in order to capture income generation in the calendar year in which activity takes place.

The Executive Committee (ExCom) will continue to meet twice a year; in May/June and November, in London, the former meeting will now be followed by its Annual General Meeting (though this last adjusting 'six months' period's Report and Accounts covering the six month period 1st July to 31st December 2009 is to be taken at an AGM in July 2010). Its Financial Sub Committee consisting of the CEO, the Treasurer, a Trustee experienced in legal matters and PSPA's Director of Finance meets quarterly to review investments and the Charity's financial position set against budget plans. Minutes of Sub Committee meetings are forwarded to Trustees for final approval.

Management

The day to day management of PSPA is devolved to its Chief Executive and her Senior Management Team (SMT) of the Association.

The PSP Association Decision Making Process

The decision making process of the Charity is driven by Trustees' Biannual Meetings, at which the Charity's annual budget, research commitments and business plan are reviewed, together with "one-off" tabled agenda items. The reserves policy, salaries and fees, etc. are reviewed by the Trustees annually as a matter of good governance.

Investment Policy

The PSP Association's investment policy is managed in line with short term prevailing economic conditions combined with expectations regarding the medium and long term situation. It is monitored by the Association's Financial Sub Committee and approved by Trustees. This policy seeks to ensure necessary funds are always available to meet budgeted and forecast outgoings and minimum reserve levels by holding a balanced investment to provide:

- immediate access with 'going rate' interest for sufficient funds to meet immediate drawdown requirements
- a higher level of interest on funds committed but not immediately required
- a prudent mix of interest and growth on these funds/reserves not yet committed

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To achieve the above objectives the Charity has appointed Rathbones Investment Management Stockbrokers to manage our investment portfolio.

Objectives and Activities

The Mission of the PSP Association is the conquest of PSP (including Cortico Basal Degeneration (CBD), which if not a variant of PSP, is a closely related neurodegenerative disease). For the rest of the Report and Accounts, Readers are asked to recognise that any reference to PSP includes CBD, except where both are mentioned.

The Chief Executive is responsible to the Trustees for working toward and delivering PSPA's core objectives, which are to:

- Promote and sponsor research worldwide into the treatment and eventual cure of PSP and CBD
- Provide Information and Support to afflicted families, their carers and relevant professionals across Europe
- Raise Awareness of PSP and CBD amongst relevant professionals and the public at large, mainly in the UK

The Mission of The PSP Association is to conquer PSP and CBD.

Achievements and Performance

In another period of growth, the 'Achievements and Performance' of the PSP Association against budget are outlined in the Chairman's Report in Section 2; and are set out in detail in the Chief Executive's Report at Section 3. In summary, both achievements and performance have more than met the challenging targets set, with only the full time equivalent of 14.7 people working for PSPA.

Financial Review

The six month period of July to December 2009 was another successful period in the Association's growth and despite operating in an acutely challenging period of National / International recession, our income was only some £30,000 below budget, our best result for two years. In line with the strategy set by the Trustees at the June 2008 meeting, reserves are now based upon four months expenditure of the following year's budget.

Research remains one of the key priorities for the Association and in the six month period to 31 December 2009 £161,000 was expended toward ongoing research. No new research was taken on over the reporting period. It should be noted that The Association has a continuing commitment to fund new research into the cause, effective treatment and eventual cure of PSP, subject to availability of funds.

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As stated in The Association's objectives, expenditure on awareness, particularly amongst relevant health and welfare professionals, remains another key priority for the Charity. In this regard it had been hoped to increase the number of Development Officers (DO's). However, due to financial constraints, our plan to recruit additional DO's has been put on "hold" for the time being. The work undertaken by the Development Officers has been a major factor in raising awareness of PSP amongst these professionals, which in turn has led to an increase in the number of patients and families contacting us for help.

Plans for Future Periods - A New Five Year Plan

The Association's current Five Year Business Plan, written in 2007 and approved by Trustees at their November Meeting that year is being updated in light of the global recession, other events affecting growth and progress made over the last three years. A new Five Year Plan is in the drafting stage and is to be put forward for Trustees approval at the November 2010 Meeting. Meanwhile, emphasis is being given to boosting the Charity's fundraising capacity, particularly in the Donor Trust field. After deducting costs of the new fundraising team, salaries etc of employees, essential administration, we plan that, subject to formal Trustees' approval, remaining income will be divided equally between the Charity's three main objectives. This subject is addressed in more detail elsewhere in this Report.

SECTION 2 - CHAIRMAN'S STATEMENT

Overview

This report reflects a transitional period as the Charity moves from a 1st July to 30th June year to one coinciding with year end and hence just covers the six months from 1st July to 31st December 2009. During this period the PSP Association has continued its progress toward its three main objectives in the face of the sharp economic downturn which has had impact globally as well as on the charity world, over the past 18 months.

In research, we took on, in 2007, a raft of cutting edge research over a three year period, including involvement in some of the first clinical drug trials to be undertaken into the treatment of PSP. We also continue to make our annual contribution to the Sara Koe PSP Research Centre. Our Medical Advisory Panel consisting of leading neurologists from around the World, chaired by Professor Andrew Lees, has continued successfully to coordinate our research with that being undertaken in the USA, in the rest of Europe and elsewhere, as we seek to achieve our goals of earlier and better diagnosis as well as treatment and cure.

We have, particularly noting the size of our staff, once again provided an impressive range of information and support to afflicted families, carers and professionals across the UK and the rest of Europe. We have held another very successful annual Symposium, with International input. We also have held regular Local Support Groups across the country

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for those families afflicted by this disease, as well as growing our telephone counselling service, which lies at the heart of our Charity's work.

Perhaps however, our greatest success has been in raising public awareness of this devastating disease. For, without such awareness, people with PSP or CBD will often continue effectively to suffer a feeling of being abandoned by those who should be caring for them amongst the Health Care Community. This awareness, as reported in our last Report and Accounts, received a huge boost as a result of the BBC documentary drama 'A Short Stay in Switzerland' about a Doctor with PSP. This was first transmitted in January 2009 and has subsequently had several repeat transmissions. In total well over 5 million people have seen this programme, and, using the hyperlinks from the BBC's own web site to ours, many have visited our website at www.pspeur.org. Our recently upgraded web site has allowed us to reach not only a greater range of people but also economically to provide a wide range of now downloadable publications. For example, within just twelve weeks of the launch of our enhanced website, over 4,000 copies of our then new "Guide for Occupational Therapists" had been downloaded, potentially saving us over £8,000 in printing costs alone. More importantly, our web site continues to provide relevant, up to date materials for those providing support for PSP (and CBD) afflicted families, their carers and professionals.

Risk Assessment Statement

The worldwide economic downturn has created a particularly challenging period for the "charity world" as a whole. That we came through largely unscathed, more than making the tough targets we set ourselves, reflects well on the professional approach and tight budgetary control of The PSP Association over this difficult period. To achieve this has meant cutting back ruthlessly on aspirations. We are now focussing on major fundraising to achieve levels of income to enable us to meet these aspirations; thereby continuing to progress on our three key objectives. In research, we are now actively seeking opportunities and funding so that we can sponsor new projects; and have completed a Research Strategy Paper which is now going out on a wide distribution for consultation.

Before the start of the recession, Trustees decided the Charity had grown to a size that a reserve of four months rather than six months of the following year's planned expenditure is now sufficient; and to sponsor the considerable amount of research we wished to take on, that we should spend down to the lower figure. Having achieved our 'spend down', we now feel more able to approach Donor Trusts to help in our work and in new research. However, as the figures in our accounts reflect, we have prudently set more modest targets for the year ahead.

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Final Comments

Over the last six months our small team at Towcester has struggled valiantly to 'run the show' on a shoe string until we can afford the full complement of staff we need to continue to keep taking on the additional numbers flooding in and seeking our support, as we move on toward our objectives.

I remain as always impressed by the passionate, dynamic and active way the Charity has been managed and grown under the direction of my successor, who has assiduously worked long hours, as have our dedicated team in moving toward our goals. Until the bulk of the population of the UK are as aware of Progressive Supranuclear Palsy as they are of Motor Neurone Disease - to take a related disease of comparable size and devastation - those who are diagnosed with PSP (and those who should be, but are either misdiagnosed or not diagnosed at all) will continue to suffer second class care and second class treatment.

Brigadier Michael R Koe, OBE
Chairman

Date:

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SECTION 3 - CHIEF EXECUTIVE'S REPORT

PSP and the Formation of The PSP Association

Overview

As states in the Chairman's statement, this Report covers the Association's six month financial period from 1st July 2009 to December 31st 2009.

Increased demand for our services, as a result of our awareness work combined with a deep and protracted recession, has resulted in another very challenging period for the Association; however, it is good to be able to report that there have been some key successes, not least those in relation to raising awareness of PSP and CBD with the consequent increase in our subscriber numbers.

What is Progressive Supranuclear Palsy?

Progressive Supranuclear Palsy is a neurodegenerative disease, involving the progressive death of neurons (nerve endings) in the brain (mainly in the brain stem and basal ganglia). This degeneration usually starts, for reasons not yet fully understood, just above the nuclei - hence 'supranuclear'. The nuclei is the area in the brain controlling balance, movement, vision (particularly upgaze and downgaze), speech and ability to swallow; hence the main progressive symptoms of the disease.

Although PSP is a very individual disease and progresses at different speeds and different ways with different people, as it moves to its final stages, a patient is likely to be wheelchair bound, tube fed, on 24/7 care and unable to communicate with the world around, but with intellect largely intact. There can be behavioural changes in character, caused by the disease, which makes PSP an even tougher disease to handle. Average life expectancy is some seven years from onset, but with good care patients can live on a plateau for much longer.

Today, the position remains that tragically there is not only no cure for this disease, but even worse...no disease modifying treatment. Recent research confirms a prevalence (i.e. total number of diagnosed cases) across the UK of some 6.4 per 100,000 of population (that is circa 4,000 living patients diagnosed with the disease), However, as the incidence (i.e. number of people diagnosed annually) is 5.3:100,000 over the age of 50, this gives circa 1,200+ annually. On the basis that the disease from visible clinical onset to death is 7 years and that neurodegeneration is already symptomatically present at least one year earlier, this means at least 10,000 are living with PSP at any one time (based on an 8 year incidence figures). This means 6,000 are mis or undiagnosed at any one time. Even taking the lower figure, PSP is now recognised as being at least as common, as well as at least as devastating a

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neurodegenerative disease as its far better known 'cousin' Motor Neurone Disease (MND), and, potentially, PSP could be twice as common as MND. CBD is now thought to be half as common as PSP. Indeed we also know, from discussion with our neuro charity colleagues at Parkinson's Disease Association, that 5% of PD brains at post mortem stage are in fact PSP. If this were true of PD generally, there would be a further 6,500 potentially suffering from PSP. Likewise we know PSP is much misdiagnosed as Dementia; if 5% were true again, that would be another 35,000 people with PSP. The crux of the matter is not only the fact we have no idea of the true number of people suffering from this devastating disease, but even worse because of misdiagnosis thousands of people are potentially being denied appropriate care, support and palliation. A dreadful state of affairs for a first world country.

PSP was first described by three neurologists, Steele, Richardson and Olszewski – after whom the disease is sometimes called, with the acronym SRO, in 1964. Before then, it was generally considered to be a form of Parkinson's Disease, which it mimics in its early stages, and continued to be tucked away in its shadow, anyway until Dudley Moore courageously revealed in 1999 that he had PSP, from which he sadly died in 2002. Likewise, the late Nigel Dempster, (Journalist and Broadcaster) did much to help to raise awareness of PSP before his early tragic death from PSP in July 2007.

PSP is still, even now, sometimes referred to as Parkinson's Plus, although the two diseases are clinically, biologically and pathologically quite distinct and different, with different treatments and different prognosis. Despite this, some 30% of PSP patients joining the PSP Association have previously been diagnosed as having a Parkinson's Disease. Likewise, many are misdiagnosed as having, for example, Alzheimer's, MND, Multiple System Atrophy or Stroke, as these conditions are currently often very difficult to differentiate from PSP. Particularly in the early stages of these conditions clinical observation is the only means available on which to base a diagnosis today. There are no blood or fluid tests and MRI scanning is still insufficiently accurate to be used other than to support a clinician's diagnosis. Pathological examination is still the only sure means of confirming the accuracy of a diagnosis today, although in vivo diagnostic 'markers' are being researched with encouraging results. As these scanning techniques and proteomics and the knowledge of the workings of the brain advance, the differences between neurological diseases, their diagnosis, prognosis and pathology are becoming clearer and such markers may soon be available to support clinician's diagnoses.

Cortico Basal Degeneration (CBD)

CBD is a closely related 'tauopathy' to PSP. Indeed, some scientists consider that PSP and CBD are just but one disease, with variations in symptoms. (Neurodegenerative diseases, such as Alzheimer's, PSP and CBD are sometimes collectively called tauopathies, for, in each of these, a protein called 'tau' is deposited in tangles in the brain, as the disease progresses). Because CBD is rarer than PSP, The PSP Association, in January 2000, extended its 'umbrella' to include CBD afflicted families; whose numbers are insufficient to

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be able to have their own Association. We now send out literature, including our new Carers Information Pack (CIP) and provide support through our Nurses and Support Groups for such families. Throughout this report, readers should note that CBD is intended to be included when PSP is mentioned and in the cover we offer PSP afflicted families.

The PSP Association

The Association was first registered as a company limited by guarantee, then also as a Charity, in April 1994, by Brigadier Michael Koe OBE, and his late wife Sara after the latter was tragically diagnosed as having PSP. They set up the Association, with the help of influential friends, because of their concern over the isolation and despair of afflicted families coping with a brain disease, for which there was (and still is) no effective treatment and no cure; in which there appeared, at that time, to be little interest from the medical profession or the general public. This was partially because of the 'then-believed' comparative rareness, obscurity and difficulty of diagnosis of this disease. Sadly, Sara died from PSP in January 1995, since when the Association she helped to form has continued to grow remarkably well in size and capability.

The PSP Association's Mission and Business Plan Statements

Mission Statement

The mission of the PSP Association is the conquest of PSP (and CBD hereinafter subsumed within the title PSP) through effective research, education, welfare and communication. Key objectives are to:

- Promote and sponsor research worldwide into the cause, effective treatment and eventual cure of PSP
- Provide information and support to afflicted families across Europe
- Engender awareness of PSP, amongst relevant health and welfare professionals and the general public at large, mainly across the UK

Business Plan Statement

At the June 2007 meeting, Trustees approved a new Five-Year Business Plan put together by the PSP Association staff, to provide conservative guidance for forward planning from inclusive FY 2007/08 to FY 2011/12. It is good to report that performance is ahead of plans, notwithstanding the challenging economic situation. Consequently, the plan has over the past months been under review by PSPA's staff with an updated and enhanced iteration going forward for review by Trustees at the July 2010 Meeting. Formal approval of the new Five Year Plan is expected at the November 2010 ExCom.

Progress Report on Research

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Ongoing Research

General

The Mission of The PSP Association cannot be achieved without effective research into the cause, treatment and eventual cure of PSP; and progress in this is vital to sustain the hopes of PSP afflicted families. Promotion and sponsorship of research into PSP, within our means, is therefore crucial to our aim. There is, however, a financial balance that Trustees regularly need to reappraise, based on the annual overall Association income and careful risk analysis, not only of what the Charity can afford to sponsor in the way of research, but in the priority and likelihood of success of each piece of the proposed research.

The PSP Association is now forecasting to spend on research in the region of £235,000 in the next 12 month period and since it was formed in 1994, it has spent, up to the end of December 2009, in excess of £2.5 million. This sum has mainly been provided to sponsor Research Fellows and Research Assistants, selected by Peer Review Processes, using the Association of Medical Research Charity's (AMRC's) guidelines. Applicants are sought worldwide through advertisements in medical journals. The PSP Association, both through its Medical Advisory Panel and directly, works closely with its US sister Charity, CurePSP and other bodies, in coordinating research expenditure worldwide. The Association pays basic salaries of selected Fellows and Assistants, quarterly in arrears, with Universities and Institutes picking up all other costs. Consequently, this research not only provides very good value for money, but also leverages research funding from governmental agencies, by encouraging selected researchers to take a particular interest in PSP throughout their careers, and provides the catalyst to awareness amongst relevant professional bodies of both the disease and the Association. We have, for example, successfully pump-primed two separate pieces of research (by Dr Huw Morris and by Dr Rohan de Silva in the genetics field into PSP), each 'picking up' a Medical Research Council Award for over £1 million.

Over the almost 16 years of the PSP Association's existence, we have followed a carefully orchestrated research plan, monitored by our Medical Advisory Panel. Our initial programme involved:

- collection and collation of all existing research into PSP worldwide
- sending out questionnaires to PSP patients/carers
- sponsoring a UK wide prevalence study into PSP
- holding our first International Medical Workshop attended by leading scientists in the field from around the world (we held our seventh in July 2009)

This programme led to a genetic study, which identified the tau gene on chromosome 17 being involved in the development of the disease. Subsequent research into the tau gene

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has identified that the H1 haplotype (one of its sub-genes) is a necessary but not sufficient condition to develop PSP. This means that as over 50% of the UK population carries this gene, which in turn means that over 50% of the UK population is predisposed to suffer from PSP. Meanwhile pathological examination of brain tissue identified the areas of brain (such as the Pedunculo Pontine Nucleus) where there had been observable shrinkage. A clinician's difficult early differential diagnosis of PSP can now be supported (and the actual progress of the disease itself measured) and may well soon be able even to be confirmed, using these emerging MRI scanning techniques. Until recently, the effectiveness of treatments could not accurately be measured and a firm diagnosis can still only be made after the disease is well advanced, when repair becomes increasingly difficult.

As the disease advances, neurofibrillary tangles of the protein tau are formed in the brain. These contain an excess of phosphate (i.e. they are hyper-phosphorylated). Research into these sites and the search for enzymes which can reduce the level of phosphate, are in progress. Following this line of research, trials on transgenic mice in the USA have shown some drugs, such as lithium, have succeeded in 'slowing' this disease. Unfortunately despite this exciting step in the progress toward drug trials, as mice are not people and lithium itself is a highly toxic drug, whilst the mice were able to tolerate lithium regrettably those people enrolled on the lithium drug trial were not.

This report on PSP sponsored research concludes by highlighting:

- the coordination of research into PSP across the UK at the Sara Koe PSP Research Centre
- ongoing PSP Association sponsored research and research committed by Trustees before the end of the period, but not yet begun
- support from Donor Trusts
- the role of the of Consultant Advisor re Medical Awareness and Research

Coordination of Research across the UK at the Sara Koe PSP Research Centre

The Association committed, from April 2002, a sum of £100,000 per annum, rising with inflation (peaking at £140,000, a figure confirmed by Trustees each year for the following two years) toward the Sara Koe PSP Research Centre (SKRC) at the Institute of Neurology in London, the first such Centre in the world, sponsored by the Association and opened by our Patron, HRH The Duchess of Gloucester, GCVO. This sum has now has a run rate of £120,000 per annum for 2011/12 and the funds are to cover Research.

The Centre's main function is coordination of research worldwide into PSP. It is co-located at the now refurbished building at 1 Wakefield Street with the Queen Square Brain Bank (donated brains from PSP patients are collected and collated at the former and stored at the latter as a key resource for use in research) and with the Reta Lila Weston Institute of Neurology which moved from Windeyer Street also to be co-located in the refurbished

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building, all under the direction of Professor Andrew Lees, one of our Trustees, who chairs our Medical Advisory Panel. This co-location provides crucial critical mass for PSP research.

Research Committed prior to and during the six months ended 31 December 2009

Our FY 2009 Report and accounts contained details about the research projects we are supporting. A brief update of the committed projects is listed below.

SKRC - London Area

A further grant of £60,000 was allocated for six month period from January to June 2010 to principally cover Research.

Institute of Neurology - London Area

Dr Gavin Giovannoni and Ms Connie Luk started in 2005 a three year Research Project into Cerebrospinal Fluid (CSF), using proteomics to identify a biomarker for PSP. The PSP Association allocated £114,251 of which some £8,000 gross is still outstanding, and which is being carried forward.

SKRC - London

Professor Tarek Yousry focussed on post mortem imaging, particularly on areas like the Subthalamic Nucleus (STN), where shrinkage of brain tissues over time was particularly marked in PSP. Using high powered scanners (up to 9.4 Tesla), the intention of the research was to compare images obtained thereby radiologically, in much sharper detail than hitherto, and compare these images with results obtained histologically, thereby seeking to provide a mean of differential diagnosis and of monitoring the effects of drugs on PSP in clinical drug trials.

It was expected that such research would enable in vivo MRI scanning to become more effective and lead to its use on a diagnostic marker for earlier and better diagnosis. He sought funding to cover the cost of a Research Fellow and 40% of a Physician's post. He would arrange separately to cover the cost of the scanning itself and the histological workup. His research would cost the PSP Association £132,000 over three years of which £13,400 remains outstanding and is carried forward.

Oxford University

Richard Wade Martin was granted £25,000 over two years in order to research Haplotype regulation of alternative splicing of the MAPT locus. This has been jointly funded with Cure PSP in the States. It aims to identify the genetic differences in the tau gene resulting

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in some people being more likely to suffer from PSP than others. £12,500 gross remains outstanding.

France

Drs Philippe Damier and Pascal Derkinderon have been granted €20,000 to purchase valproic acid drugs in order to research tolerability and the neuro protective effect of this in people with PSP, over two years. The full sum remains outstanding and has been carried forward.

New / Extended Research

Institute of Neurology - London

Dr Gavin Giovannoni and Ms Connie Luk started in 2005 a three year Research Project into Cerebrospinal Fluid (CSF), using proteomics to identify a biomarker for PSP. The work has taken longer than initially expected; however, the preliminary results are looking encouraging so The Association agreed to fund a further year's research of £42,000. All is outstanding and being carried forward.

Support from Donor Trusts

The amount of research sponsored by the PSP Association has grown rapidly thanks to the generous support we have been given by Donor Trusts, Corporates and other Supporters.

The Role of The PSP Association's Consultant Advisor of Medical Awareness and Research

The PSP Association recruited a part time Consultant Advisor of Medical Awareness and Research (CAMAR) (Dr Angela Wilson) from September 2007 to:

1. direct and coordinate the Association's promotion and sponsorship of research into PSP working closely with Professor Andrew Lees, Chairman of Medical Advisory Panel;
2. following the Association of Medical Research Charities (of which the PSP Association is a member) guidelines; and
3. lead on the Associations development of media awareness, writing 'top down' articles in relative umbrella association's journals.

During the year Dr Wilson's time has predominantly been spent on undertaking a review of the work of the Sara Koe Research Centre.

Conclusion

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Taking account of ongoing delays in invoicing the PSPA by the Research establishments, new committed research and that in the pipeline, a figure for expenditure for FY 2010 has been calculated of some £235,000.

Progress Report on Support

Number of People with PSP across the UK

PSP remains a difficult disease to diagnose, particularly early in its progression. Even later in the disease, one of its sub-types can closely mimic Parkinson's Disease; and PSP is still often misdiagnosed as Alzheimer's, Motor Neurone, Multiple System Atrophy, Lewy Body Disease or a Stroke. Until an effective diagnostic marker can be designed, perhaps from blood samples or from cerebro-spinal fluid, the clinician is often faced with a very difficult diagnosis. Post-mortem analysis indicates that a clinician is doing well to achieve a better than 95% accuracy in diagnosis.

It is not surprising therefore, that PSP is often misdiagnosed and is believed to be heavily under-diagnosed. Recent research confirms an incidence of at least 5.3 per 100,000 of the population over the age of 50 and prevalence of 6.4 per 100,000, giving a figure of some 4,000 living diagnosed patients across the UK. Leading neurologists feel this is a considerable understatement of actual figures, which they believe, is well over 10,000 people living with PSP, most of whom sadly will have demanding and complex care and support needs particularly in the later stages of the disease. By the end of 2009 over 900 people with PSP and CBD and over 1,500 others, mostly direct carers, subscribed to the Association. These figures, of course exclude those 1,518 who joined the Association since it was established, but sadly died of PSP and those who joined to support them.

The PSP Association Care and Support Services

The PSP Association provides an efficient care, support and information service to patients, their carers and the relevant health and welfare professionals, helping to fill some of the many gaps in current state health and welfare provision for people with long-term neurological conditions. The Association provides information, including the provision of a comprehensive Carer's Information Pack, a 24/7 Telephone Counselling Service, Local Support Groups and other services, for those who join our Association. To help cover our costs, we ask a subscription of £25 a year (or £20 by standing order). The subscription is waived for those who consider they are unable to afford this amount. Our Director of Care and Support coordinates the work of our Nurse Specialists, our Development Officers and our Local Support Group Coordinators, as well as taking on the main responsibility for raising awareness of PSP and CBD within the nursing, therapist and social services health care area.

The PSP Association Website and Discussion Forum

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The PSP Association has a well established and recently updated comprehensive website at www.pspeur.org. There is a Discussion Forum, which provides an opportunity for those interested or with enquiries to post a message. Use of the Forum on our new web site has increased dramatically. Last year we reported that over 60 messages per month were being posted by the end of the reporting period, this year it is over 250 posting per month and almost 10,000 viewings!

Enquiries and Joining The PSP Association

Those joining the PSP Association:

- receive a Carer's Information Pack and other information about our work
- are contacted by one of our PSP Nurse Specialists
- are invited to join one of the PSP local telephone networks between carers.
- are invited to their most convenient Local Support Group.

The Association will also write to their GP, social worker, and any nurses and therapists involved in their direct support to offer further information or training.

Telephone Counselling Service

Our Telephone Counselling Service is at the heart of our service to people with PSP and their carers, providing nursing advice and emotional support on a 7-day 24-hour basis. It is manned by three PSP Nurse Specialists. Our Telephone Counselling Service handled over 4,200 calls (up from 3,800) from subscribers and health and welfare professionals directly involved with a patients care. Our Nurse Specialists also attend Movement Disorder Clinics in Newcastle, Manchester, Cambridge, Cardiff and London, with more planned in new locations.

Local Support Groups

The PSP Association held 67 Local Support Group meetings at 27 locations across the UK over the year. Over 600 patients and their carers attended and the meetings provided mutual support and access to our visiting team, consisting of a Nurse Specialist and at least one other member of the Care and Support Team.

Our Development Officers

We are establishing a team of ten Development Officers (DO's) across the UK, whose primary role will be raising awareness of PSP amongst relevant health and welfare professionals, as described later under Awareness. Their secondary role is in support of Local Support Groups - they attend these in their area and support its work and link, where possible, with carers and relevant health professionals. We currently have six

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Development Officers, covering Scotland, Northern Ireland, The East Midlands, England South Central, East Anglia and South West England / South Wales and will be recruiting a further four, with the first being in the South East of England, to provide full cover across the UK. It is hoped we can begin to increase our complement of DO's in 2010/11.

Annual Symposium

The Association holds its Annual Symposium in the Autumn, rotating its venue around the UK to give as equal an opportunity as possible for carers and therapists across the country to attend with minimum travel. In this period, our Symposium was held in Cardiff, on 16th September 2009. It was Chaired by Dr Huw Morris, a leading neurologist at The University of Cardiff. The presentations, to a well attended audience, were many, varied and all proved excellent, for example, that of Professor John Hardy on Genetics, Baroness Finlay on Palliative Care and Mrs Sylvia Denton, former President of the Royal College of Nursing on the difficulties of engaging with relevant health care professionals and the means by which these could be overcome.

This year, 2010, our Symposium will be held in London.

Europe and the Rest of the World

Within the limits of its capability and available funds, The PSP Association seeks to support the setting up and running of other PSP Associations across European countries. PSP Associations exist in France and Germany and Italy. As the European Federation of Neurological Alliance grows stronger, the European dimension, particularly of research into PSP, grows in importance. Outside Europe we continue to provide what support we can for PSP Groups in Australia and elsewhere. We continue to build up and strengthen our close relationship with our sister charities.

Progress Report on Awareness and Fundraising

Awareness

Over the last eighteen months, we have given a high priority to raising awareness of PSP and of our Association amongst relevant health and welfare professionals. We have already recruited six of a planned 10 Development Officers (DO's) in selected regions across the country, to build to ten, in order to cover the whole of the UK, in what was hoped to be the next couple of years. A worsening economic climate has delayed these plans for reasons of prudence. Their secondary roles are to monitor the implementation of the National Service Framework for Long-term Conditions with a focus on Neurological Conditions, as this affects PSP; and to develop our Local Support Groups within their regions.

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They will also liaise closely with the new emerging Regional Neurological Alliances being set up by the Neurological Alliance across England, part-funded by the Department of Health. The DO's have made significant progress to raise awareness of PSP and CBD within the Health and Welfare services. In the calendar year 2009 they have again provided well over 2,500 information packs, and arranged over 100 Regional PSP conferences / joint initiatives with other Charities, together with arranging over 50 training sessions given by PSP Nurses.

We continue to seek all opportunities through the press and other media to raise awareness of the general public across the UK of this disease, which still lies in the shadow of Parkinson's Disease, despite its now recognised prevalence, rapid progression and distressing symptoms. Even today, few of the public are aware that PSP is at least as common and at least as devastating as its far better known 'cousin', Motor Neurone Disease.

Since January 2009, we have been most fortunate to have help in raising awareness from two outside sources:

The BBC, in January 2009, transmitted a docu-drama "A short stay in Switzerland" which was viewed by over 5 million people in the UK. This programme has since been repeated on several occasions during 2009. The programme's focus was Dr Anne Turner, a GP, who tragically developed PSP and chose to end her life in January 2007, at Dignitas, in Switzerland. The BBC's "Helpline" was routed to The PSP Association's Head Office in Towcester and The Samaritans. Dr Anne Turner was played by the acclaimed actress, Ms Julie Walters. This, and the fact programme was trailed extensively in the preceding week, focusing on the illness "Progressive Supranuclear Palsy" made a significant difference to awareness. At our Trustees' Meeting in November 2009, Dr Turner's son was welcomed as a Trustee of the Charity. He is a Chartered Accountant and specialises in providing Specialist Advisory Services to corporates.

IPC Media, part of The Time Warner Group most kindly selected The PSP Association as its "charity of the year" for 2009. Not only did this mean that its staff would fundraise to help our cause, but additionally, it would publish case studies in a number of its periodicals to raise awareness of the diseases PSP and CBD. IPC staff undertook to try to raise £15,000 for us, to the eternal credit they raised over £40,000 a truly fantastic sum. Likewise articles in 6 magazines reaching well over 1 million people have helped us enormously in raising awareness of the devastating nature of PSP and CBD. Finally, the monies raised have proved hugely transformational for they have allowed us to purchase Blackbaud's Raiser's Edge, a bespoke charity software packages that will improve our management information system.

Fundraising

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Over the course of our six month period, the total income of The PSP Association from all sources (including subscriptions, interest and dividends) as well as from fundraising and from events which the Association organised or in which we participated amounted to some £462,337 as shown in these financial statements. This included significant donations from The John Ellerman Foundation, The Benham Charitable Settlement, The Lady Hind Trust and The Harry Cureton Charitable Trust, together with IPC Media (Part of the Time Warner Group).

The 2009 Flora London Marathon saw some 101 runners take to the streets on our behalf and together they raised some £140,000 (net). Some of these proceeds were received in the period ended 31 December 2009 and by that date all outstanding monies been received. We are very appreciative of their efforts in training and taking part and perhaps hardest of all, collecting such an impressive total in sponsorship. We would like to thank all members for their support of our fundraising efforts throughout the year.

Our subscribers, their families and friends have once again been extraordinarily generous in raising funds for us and we would like to pay tribute to them for their efforts, which are often undertaken in addition to the very demanding role of carer for a patient. We are particularly grateful to those families who ask for donations to the Association in place of floral tributes in memory of loved ones.

Conclusion

If The PSP Association was as well established pro-rata as another, not dissimilar charity which is itself statistically caring for 5,000 people with an alternate terminal neurodegenerative illness (albeit that charity is twice our age), then our Association (which is potentially caring for 10,000 with PSP and 5,000 with CBD) and which has the equivalent of just 14.7 full time staff, would have 450 staff, and instead of an income of some £800,000 p.a. it would have £40m per year! Clearly there is a gap to close...and how much more could we do for those in desperate need of help, with a greater resource!

In recognition of the fact that the Association is achieving so much with comparatively so few, I should like to pay tribute to all those involved internally, be they Staff, Trustees or our much valued Patrons. Likewise, I thank our loyal band of Subscribers, Friends, Corporates and Donor Trusts who are instrumental in our fundraising. Were it not for the fact the Charity has such a collective "team" of support, our progress would most certainly not be as great as it is.

Finally, it behoves me to again pay special tribute to Brigadier Michael Koe, OBE, the Charity's co-founder, and now Chairman of Trustees, for without his initial inspiration, accompanied there after by his long standing dedication to PSPA, there would be no charity.

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Jane M Hardy FCIB FRSA
Chief Executive

Date:

SECTION 4 - TREASURER'S REPORT

The Trustees

The Trustees who served the Charity during the period were as follows:

Brigadier Michael R Koe OBE
Mr N Down
Mr J A Fenwick
Mr P B Glithero
Mr R C Kirby (resigned 11 November 2009)
Mr J M Koe (resigned 11 November 2009)
Mr S R Koe
Professor A J Lees MD, FRCP
Mr A G P Tusa
Mrs D Chamberlain (formerly Lady Turner)
Mr C R M Kemball
Mr J D Sutton
Mr R J Koe (appointed 11 November 2009)
Mr E T Turner (appointed 11 November 2009)

Responsibilities of the Trustees

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The members of the Executive Committee of The PSP Association are responsible for the policy and strategy of The PSP Association. Trustees have a special responsibility to ensure that all aspects of The Association's activities are properly conducted and carried out in full compliance with The Association's Memorandum and Article of Association, although the day-to-day management is the responsibility of the Chief Executive and SMT. During the year ended 30 June 2009, the Executive Committee met twice and once in our current six month reporting period.

The Trustees are also responsible for preparing the Trustees' Annual Report, the Chairman's Statement and the Financial Statements in accordance with applicable law and United Kingdom Generally Accepted Accounting Practice.

Company law requires the Trustees to prepare financial statements for each financial period, which give a true and fair view of the state of affairs of the Charity and of the surplus or deficit of the Charity for that period.

In preparing these financial statements, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- make judgements and estimates that are reasonable and prudent; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

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

In so far as the Trustees are aware:

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

Auditor

A resolution to re-appoint Harris & Co as auditor for the ensuing year will be proposed at the Annual General Meeting.

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Signed on behalf of the Trustees:

Mr P B Glithero, FCA, Trustee Director
PSP House
167 Watling Street West
Towcester
Northants
N12 6BX

Date:

**INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF
THE PSP ASSOCIATION**

We have audited the financial statements of The PSP Association for the six months ended 31 December 2009 which comprise the Statement of Financial Activities, the Income and Expenditure Account, the Balance Sheet and the related notes. These financial statements have been prepared under the accounting policies set out therein.

This report is made solely to the Charity'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 Charity'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

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law, we do not accept or assume responsibility to anyone other than the Charity and the Charity's members as a body, for our audit work, for this report, or for the opinions we have formed.

Respective responsibilities of trustees and auditors

The Trustees' (who are also the Directors of The PSP 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 adequate 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

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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 Charity's circumstances, consistently applied and adequately disclosed.

We planned and performed our audit so as to obtain all 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 period then ended;
- the financial statements have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice;
- 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.

.....
P J Harris BA Hons FCA
Senior Statutory Auditor
For and on behalf of
Harris & Co. Chartered Accountants
and Statutory Auditors

2 Pavilion Court
600 Pavilion Drive
Northampton Business Park
Northampton
NN4 7SL

Date:

**THE PSP ASSOCIATION
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PERIOD ENDED 31 DECEMBER 2009**

STATEMENT OF FINANCIAL ACTIVITIES

	Note	Unrestricted Funds £	Restricted Funds £	Total Funds Dec 2009 £	Total Funds June 2009 £
INCOMING RESOURCES					
Incoming resources from generating funds:					
Voluntary income	2	369,720	92,617	462,337	770,057
Investment income	3	392	-	392	31,246
TOTAL INCOMING RESOURCES		<u>370,112</u>	<u>92,617</u>	<u>462,729</u>	<u>801,303</u>
RESOURCES EXPENDED					
Costs of generating voluntary income					
	4	(78,132)	-	(78,132)	(156,003)
Charitable activities	5/6	(323,087)	(92,617)	(415,704)	(995,860)
TOTAL RESOURCES EXPENDED		<u>(401,219)</u>	<u>(92,617)</u>	<u>(493,836)</u>	<u>(1,151,863)</u>
NET INCOMING RESOURCES BEFORE OTHER RECOGNISED GAINS AND LOSSES					
		(31,107)	-	(31,107)	(350,560)
OTHER RECOGNISED GAINS AND LOSSES					
Gains on investment assets	11	7,042	-	7,042	-
Losses on investment assets	11	-	-	-	(26,679)
NET MOVEMENT IN FUNDS		<u>(24,065)</u>	<u>-</u>	<u>(24,065)</u>	<u>(377,239)</u>
RECONCILIATION OF FUNDS					
Total funds brought forward					
		<u>803,658</u>	<u>-</u>	<u>803,658</u>	<u>1,180,897</u>
TOTAL FUNDS CARRIED FORWARD		<u>779,593</u>	<u>-</u>	<u>779,593</u>	<u>803,658</u>

The notes on pages 28 to 37 form part of these financial statements

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STATEMENT OF FINANCIAL ACTIVITIES

All of the above amounts relate to continuing activities.

The notes on pages 28 to 37 form part of these financial statements

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INCOME AND EXPENDITURE ACCOUNT

	Note	Dec 2009 £	June 2009 £
INCOME		462,337	770,057
TOTAL EXPENDITURE		<u>(493,836)</u>	<u>(1,151,863)</u>
OPERATING DEFICIT		(31,499)	(381,806)
OTHER INCOME			
Interest receivable and similar income	3	<u>392</u>	<u>31,246</u>
		392	31,246
NET DEFICIT FOR THE FINANCIAL YEAR		<u>(31,107)</u>	<u>(350,560)</u>

All of the above amounts relate to continuing activities.

The notes on pages 28 to 37 form part of these financial statements

**THE PSP ASSOCIATION
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STATEMENT OF TOTAL RECOGNISED GAINS AND LOSSES

	Note	Dec 2009 £	June 2009 £
Net deficit for the financial year		(31,107)	(350,560)
Gains on revaluation of investment assets	11	7,042	-
Losses on revaluation of investments assets	11	<u>-</u>	<u>(26,679)</u>
Total gains and losses recognised since the last annual report		<u>(24,065)</u>	<u>(377,239)</u>

The notes on pages 28 to 37 form part of these financial statements

**THE PSP ASSOCIATION
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BALANCE SHEET

**31 DECEMBER 2009
REGISTRATION NUMBER 2920581**

	Note	Dec 2009 £	£	June 2009 £
FIXED ASSETS				
Tangible assets	10		584,011	589,988
Investments	11		81,263	74,221
			665,274	664,209
CURRENT ASSETS				
Debtors	12	8,364		28,442
Cash at bank		271,292		332,465
		279,656		360,907
CREDITORS: Amounts falling due within one year	13	(165,337)		(221,458)
NET CURRENT ASSETS			114,319	139,449
TOTAL ASSETS LESS CURRENT LIABILITIES			779,593	803,658
NET ASSETS			779,593	803,658
FUNDS				
Unrestricted income funds				
14			779,593	803,658
TOTAL FUNDS			779,593	803,658

These financial statements were approved by the members of the committee on the and are signed on their behalf by:

P B Glithero FCA
Trustee Director

The notes on pages 28 to 37 form part of these financial statements

**THE PSP ASSOCIATION
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BALANCE SHEET

**31 DECEMBER 2009
REGISTRATION NUMBER 2920581**

The notes on pages 28 to 37 form part of these financial statements

**THE PSP ASSOCIATION
COMPANY LIMITED BY GUARANTEE
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NOTES TO THE FINANCIAL STATEMENTS

1. ACCOUNTING POLICIES

Basis of Accounting

The financial statements have been prepared under the historical cost convention, except for investments which are included at market value and the revaluation of certain fixed assets, and in accordance with applicable United Kingdom accounting standards, the Statement of Recommended Practice "Accounting and Reporting by Charities" issued in March 2005 (SORP 2005) and the Companies Act 2006.

Cash Flow Statement

The Trustees have taken advantage of the exemption in Financial Reporting Standard No 1 (revised) from including a cash flow statement in the financial statements on the grounds that the Charity is small.

Investments

Investments are stated at market value at the balance sheet date. The SOFA includes the net gains and losses arising on revaluations and disposals throughout the year.

Fund Accounting

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

Designated funds comprise unrestricted funds that have been set aside by the Trustees for particular purposes. The aim and use of each designated fund is set out in the notes to the financial statements. Restricted funds are funds which are to be used in accordance with specific restrictions imposed by donors or which have been raised by the Charity for particular purposes. The cost of raising and administering such funds are charged against the specific fund. The aim and use of each restricted fund is set out in the notes to the financial statements.

Endowment funds represent those assets which must be held permanently by the Charity, principally investments. Income arising on the endowment funds can be used in accordance with the objects of the Charity and is included as unrestricted income. Any capital gains or losses arising on the investments form part of the fund. Investment management charges and legal advice relating to the fund are charged against the fund.

**THE PSP ASSOCIATION
COMPANY LIMITED BY GUARANTEE
PERIOD ENDED 31 DECEMBER 2009**

NOTES TO THE FINANCIAL STATEMENTS

Investment income and gains are allocated to the appropriate fund.

**THE PSP ASSOCIATION
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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. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with use of the resources.

Fund-raising costs are those incurred in seeking voluntary contributions and do not include the costs of disseminating information in support of the charitable activities. Support costs are those costs incurred directly in support of expenditure on objects of the Charity and include project management carried out at Headquarters. Management and administration costs are those incurred in connection with administration of the Charity and compliance with constitutional and statutory requirements.

Commitments made to fund research work undertaken during the accounting period are recognised in the financial statements as a resource expended.

Commitments made to fund research in future accounting periods are included in commitments in the notes to the financial statements.

Fixed Assets and Depreciation

Tangible fixed assets are recorded at cost, including incidental costs of acquiring the asset.

Depreciation is provided so as to write off the cost of the fixed asset (with the exception of freehold land), less its estimated residual value, over their expected useful lives using the following basis:

Freehold Buildings	50 years straight line
Fixtures and fittings	15% reducing balance

Freehold land is not depreciated. No depreciation is provided on freehold buildings in the year of purchase.

Incoming Resources

All incoming resources are included in the SOFA when the Charity becomes legally entitled to the income and the monetary value can be measured with sufficient reliability. Where incoming resources have related expenditure the incoming resources and related expenditure are recorded gross in the SOFA. For legacies, entitlement is the earlier of the Charity being notified of an impending distribution or the legacy being received.

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Incoming resources from tax reclaims are included in the SOFA at the same time as the gift to which they relate.

Gifts in kind donated for distribution are included at a reasonable estimate of their value to the Charity and recognised as income when they are distributed to the projects. Gifts donated for resale are included as income when they are sold. Donated facilities are included at the value to the Charity where this can be quantified and a third party is bearing the cost. No amounts are included in the financial statements for services donated by volunteers.

Company Status

The Charity is a company limited by guarantee. The members of the company are the Trustees named on page 20. In the event of the Charity being wound up, the liability in respect of the guarantee is limited to £1 per member of the Charity.

**THE PSP ASSOCIATION
COMPANY LIMITED BY GUARANTEE
PERIOD ENDED 31 DECEMBER 2009**

2. VOLUNTARY INCOME

	Unrestricted Funds	Restricted Funds	Total Funds Dec 2009	Total Funds June 2009
	£	£	£	£
Donations				
Personal donations	304,230	13,217	317,447	650,009
Company donations	24,931	-	24,931	12,665
Gift aid tax reclaimed	21,559	-	21,559	46,623
Donor trust	19,000	79,400	98,400	60,760
	<u>369,720</u>	<u>92,617</u>	<u>462,337</u>	<u>770,057</u>

3. INVESTMENT INCOME

	Unrestricted Funds	Total Funds Dec 2009	Total Funds June 2009
	£	£	£
Bank interest receivable	<u>392</u>	<u>392</u>	<u>31,246</u>

4. COSTS OF GENERATING VOLUNTARY INCOME

	Unrestricted Funds	Total Funds Dec 2009	Total Funds June 2009
	£	£	£
Administrative expenses	<u>78,132</u>	<u>78,132</u>	<u>156,003</u>

5. COSTS OF CHARITABLE ACTIVITIES & FUNDRAISING BY FUND TYPE

Unrestricted Funds	Restricted Funds	Total Funds Dec 2009	Total Funds June 2009
£	£	£	£

**THE PSP ASSOCIATION
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 PERIOD ENDED 31 DECEMBER 2009**

Research activities	94,205	15,217	109,422	400,338
Care costs	35,865	77,400	113,265	199,452
Awareness	80,235	-	80,235	149,764
Fundraising	<u>112,782</u>	<u>-</u>	<u>112,782</u>	<u>246,306</u>
	<u>323,087</u>	<u>92,617</u>	<u>415,704</u>	<u>995,860</u>

**THE PSP ASSOCIATION
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6. COSTS OF CHARITABLE ACTIVITIES & FUNDRAISING BY ACTIVITY TYPE MET FROM UNRESTRICTED FUNDS

	Research activities £	Care Costs £	Awareness	Fundraising £	Administration costs £	Total Funds Dec 2009 £	Total Funds June 2009 £
Purchases	85,318	-	36,968	-	7,416	129,702	569,951
Wages and salaries (note 8)	8,887	35,865	25,238	76,871	23,331	170,192	290,042
Events	-	-	8,230	3,075	-	11,305	33,840
Symposium	-	-	-	-	-	-	6,063
Awareness	-	-	6,571	32,836	-	39,407	33,240
Telephone Counselling	-	-	-	-	-	-	41,166
Office utilities	-	-	-	-	6,567	6,567	12,784
Office repairs & maintenance	-	-	-	-	10,102	10,102	56,825
Administration costs	-	-	3,228	-	14,227	17,455	19,423
Insurance	-	-	-	-	420	420	2,530
IT expenditure	-	-	-	-	2,121	2,121	9,631
Audit fees	-	-	-	-	1,528	1,528	1,293
Legal & professional	-	-	-	-	863	863	1,966
Depreciation & disposals	-	-	-	-	11,557	11,557	13,509
	<u>94,205</u>	<u>35,865</u>	<u>80,235</u>	<u>112,782</u>	<u>78,132</u>	<u>401,219</u>	<u>1,092,263</u>

NB Apparent anomalies in comparative figures for expenditure on charitable activities in the accounting periods detailed are in the main due to the variations in restricted and unrestricted income.

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6.1 COSTS OF CHARITABLE ACTIVITIES MET FROM RESTRICTED FUNDS

	Dec 2009 £	June 2009 £
Research Activities	15,217	26,075
Care Costs	77,400	33,500
Awareness	-	25
	<u>92,617</u>	<u>59,600</u>

7. NET INCOMING RESOURCES FOR THE YEAR

This is stated after charging:

	Dec 2009 £	June 2009 £
Depreciation	6,370	13,509
Deficit on disposal of assets	5,187	-
Auditors' remuneration: - audit of the financial statements	1,528	1,293
	<u>13,085</u>	<u>14,802</u>

8. STAFF COSTS AND EMOLUMENTS

Total staff costs were as follows:

	Dec 2009 £	June 2009 £
Wages & salaries – unrestricted funds (note 6)	170,192	290,042
Wages & salaries – restricted funds	9,230	-
Total wages and salaries	<u>179,422</u>	<u>290,042</u>

Included in the totals above are social security costs of £16,529 (June 2009: £29,531). There was no Directors' remuneration during the year.

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Particulars of employees:

The average number of employees during the period, calculated on the basis of full-time equivalents, was as follows:

	Dec 2009 No.	June 2009 No.
Number of administrative staff	4	4
Number of management staff	4	4
	<u>8</u>	<u>8</u>

The move to the new premises in Towcester has enabled the Association re-organise and recruit additional staff. Although the ratio of management to other staff now appears high, the managers are also managing the consultants and growing the number of volunteers.

No employee received emoluments of more than £65,000 per annum during the period (June 2009 - £65,000).

Trustees' emoluments:

The Trustees received no remuneration or expenses whilst fulfilling their duties.

9. TAXATION

All of the Charity's income is applied for charitable purposes and therefore the Charity is exempt from corporation tax.

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10. TANGIBLE FIXED ASSETS

	Freehold Property £	Fixtures& Fittings £	Total £
COST			
At 1 July 2009	574,773	59,864	634,637
Additions	-	5,580	5,580
Disposals	-	(14,257)	(14,257)
At 31 December 2009	<u>574,773</u>	<u>51,187</u>	<u>625,960</u>
DEPRECIATION			
At 01 July 2009	16,000	28,649	44,649
Charge for the year	4,000	2,370	6,370
Eliminated on disposals	-	(9,070)	(9,070)
At 31 December 2009	<u>20,000</u>	<u>21,949</u>	<u>41,949</u>
NET BOOK VALUE			
At 31 December 2009	<u>554,773</u>	<u>29,238</u>	<u>584,011</u>
At 30 June 2009	<u>558,773</u>	<u>31,215</u>	<u>589,988</u>

There was no significant difference between the book value and market value of the freehold property at the balance sheet date.

11. INVESTMENTS

Movement in market value	Dec 2009 £	June 2009 £
Market value at 1 July 2009	74,221	100,900
Net gains on revaluations in the year	7,042	-

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Net losses on revaluations in the year	-	(26,679)
	<u>81,263</u>	<u>74,221</u>

Analysis of investments at 31 December 2009 between funds

	Unrestricted Funds £	Restricted Funds £	Total Funds Dec 2009 £	Total Funds June 2009 £
Listed investments				
Rathbones Investment Management Limited	<u>81,263</u>	<u>-</u>	<u>81,263</u>	<u>74,221</u>

The investments are held for their investment returns. All investments are listed.

12. DEBTORS

	Dec 2009 £	June 2009 £
Prepayments and accrued income	<u>8,364</u>	<u>28,442</u>

13. CREDITORS: Amounts falling due within one year

	Dec 2009 £	June 2009 £
Taxation and social security	9,749	8,211
Wages control account	20,879	19,535
Other creditors	17,881	18,912
Accruals	116,828	174,800

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165,337	221,458
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14. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	Tangible fixed assets £	Investments £	Net current assets £	Total £
Unrestricted Funds:	584,011	81,263	114,319	779,593

15. COMMITMENTS

The Association has entered into commitments to fund a number of research projects, the budgeted cost of which over the next five years is:

	Dec 2009 £	June 2009 £
Committed to but not provided in the financial statements	305,300	327,352

Of the above, firm commitments for the next two years amount to £305,300 (June 2009: £327,352).

16. INDEMNITY INSURANCE

The Charity paid for the insurance premiums to indemnify Directors and senior staff from any loss arising from neglect or defaults of Directors or staff and any consequent loss. The cost to the Charity was £420 (June 2009: £840).

17. RELATED PARTY TRANSACTIONS

Professor Andrew Lees, who is a Trustee of the Association, is Director of the Sara Koe Research Centre and is also a Director of the Rita Leila Weston Institute of Neurological Studies. Both are based at the Institute of Neurology, Queen's Square, London at

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University College London (“UCL”), where he is also a Professor in the National Hospital for Neurology and Neurosurgery.

During the six month period to 31 December 2009, the Association made grants, approved by the Trustees, of £72,296 (2009 - £143,904) to the Sara Koe Research Centre and £NIL (2009 - £NIL) to the Rita Leila Weston Institute. The Association also funded a number of ongoing research projects being undertaken at UCL and £39,938 was paid, as approved grants, to UCL in the six month period ended 31 December 2009 (June 2009 - £43,305).