

Charity Registration Number: 1058968
Company Registration Number: 3253584

The

Pituitary
FOUNDATION

**REPORT AND
ACCOUNTS**

30 June 2016

**THE PITUITARY FOUNDATION
(Limited by Guarantee)**

REPORT AND FINANCIAL STATEMENTS – For the year ended 30 June 2016

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THE PITUITARY FOUNDATION

LEGAL AND ADMINISTRATIVE INFORMATION

The Pituitary Foundation is a company limited by guarantee governed in accordance with its Memorandum and Articles of Association.

Charity Registration No:	1058968
Company Registration No:	3253584
Registered office:	86 Colston Street Bristol BS1 5BB
Trustees:	Mrs J West (Chair) Mr T Sumpster (Vice Chair) Dr E Macdonald (Hon Secretary) Mr M Beaven (Hon Treasurer) Dr S Baldeweg Ms H Frazer Mr M James Dr J Newell-Price Dr M Pharaoh Ms CE Thatcher
Company Secretary:	Dr E Macdonald
Chief Executive Officer:	Mrs MP Owen-Jones
Independent Examiner:	Nicholas Simkins FCA Chartered Accountant Moore Stephens LLP 35 Calthorpe Road Edgbaston Birmingham B15 1TS
Solicitors:	TLT Solicitors One Redcliffe Street Bristol BS1 6TP
Principal Bankers:	National Westminster Bank Plc Thornbury Branch PO Box 1369 Bristol BS35 9DD

The Pituitary Foundation

For the Year Ended 30 June 2016

The members of the Board of Trustees present their report and accounts for the year ended 30th June 2016.

1. OBJECTIVES AND ACTIVITIES

Core Aims

The Pituitary Foundation's vision is a world where every person affected by a pituitary condition has a timely diagnosis and access to the best treatment, information and support. In order to advance this vision, the Charity's mission is to:

- Provide information and caring support
- Improve public awareness and understanding
- Influence health and social care
- Develop local communities

whereby we aim to:

- Reduce time to diagnosis
- Improve quality of life of patients and their families and carers
- Reduce isolation amongst patients
- Reduce preventable incidents of death amongst pituitary patients

Our vision and goals for the future were set out in detail in our 2013-2016 Strategic Plan which was formally issued in September 2013 and has been updated for 2016-2019 during this Financial Year. We have continued following the four strategic pillars that identify facilitating the movement from our vision into fourteen realistic and achievable strategic goals. The four pillars are:

Effective Organisation

Awareness

Caring Support

Education

Effective Organisation

Developing the effectiveness of the charity continued to be central to our work during 2015-2016 and significant progress was made in this area during the year. Our goals for this Strategic Pillar are:

- Goal 1 – Increase diversification of funding and improve long-term sustainability
- Goal 2 – Create a strong staff and volunteering team
- Goal 3 – Improve evaluation and performance measurement
- Goal 4 – Improve facilities, internal processes and systems.

Awareness

During the year we continued with our diligent efforts to improve awareness and understanding of pituitary conditions. Our goals for this Strategic Pillar include:

- Goal 5 – Engage with stakeholders in key areas of our work
- Goal 6 – Influence policy and key decision makers
- Goal 7 – Improve general public awareness and understanding
- Goal 8 – Develop our brand and reputation.

Caring Support

The Foundation provides a large amount of information and both practical and emotional support services for anyone affected by pituitary conditions, helping patients, their families, friends and carers at all stages of their illness when they are in need of support. This year we have continued to see increasing demand for our services and this has largely driven our reorganisation plans. Our goals for this Strategic Pillar are:

- Goal 9 – Reach more patients
- Goal 10 – Develop our services to meet the needs of different demographics
- Goal 11 – Increase our presence in local communities throughout the UK and Republic of Ireland.

Education

The Pituitary Foundation For the Year Ended 30 June 2016

A key priority for The Pituitary Foundation is to provide information and education to health care professionals. Our goals under the Education Strategic Pillar are:

- Goal 12 – Drive improvements in education and training of healthcare professionals
- Goal 13 – Develop our understanding of patient experience and needs to inform our work
- Goal 14 – Promote research relating to pituitary conditions.

Volunteers

The Foundation is fortunate to have a widespread team of dedicated volunteers who take on a variety of roles to provide support and service to our community. These include:

- Area Co-ordinators of Local Support Groups
- Helpline Operators
- Forum Moderators
- National Office Volunteers
- Telephone Buddies
- Volunteer Campaigners
- Local Fundraising Group Co-ordinators
- Medical Committee
- Trustees.

Currently there are 122 volunteers working on behalf of the Foundation providing the equivalent of 10 full time staff which represents a true benefit of approximately £0.25M.

Further, we have a network of Local Support Groups around the United Kingdom, with one in the Republic of Ireland.

Investment Policy and Performance

The Foundation's Funds, both General and Restricted are maintained with our primary bankers, NatWest, in current accounts and a working reserve account and an additional current account is held with RBS. In addition, deposit accounts (to the maximum of the FSA Investor Compensation Scheme) are also held with RBS, CAF, Cater Allen, the Monmouthshire Building Society, Cambridge and Counties Bank, Julian Hodge Bank and Virgin Money. Funds are subject to regular review by our Finance Sub-Committee.

Grants paid out

£3,000 was provided as a grant towards the development of the Paediatric Clinical Management Guidelines on Rare Endocrine Tumours in Children, a project led by Dr Helen Spoudeas, Consultant Paediatric Neuroendocrinologist and Honorary Senior Lecturer at Great Ormond Street Hospital.

Public Benefit

The Trustees have considered the Charity Commission's requirement in respect of Public Benefit. In their view the charity meets, in full, the criteria to satisfy the test. The Trustees' Annual Report describes the activities undertaken to further its charitable purposes for the public benefit.

2. ACHIEVEMENTS AND PERFORMANCE

Effective Organisation

The Board of Trustees approved an Organisation Review Proposal in July 2015, which has resulted in the expansion of The Foundation across key areas, using some of our financial reserves to support the changes. This investment in the expansion will continue into 2016/17 with a break even position being forecast in 2017/18. The changes that have been implemented during this financial year aim to provide a strong and sustainable organisation for the long-term, which will meet both current and future growth demands.

New staff members have been recruited to join our team across the organisation. Investment has been made in the governance of the organisation, fundraising and patient services, with the ultimate aim that we will be able to continue developing our patient services now and in years to come. These changes mean that we will be able to increase the number of people we help, expand current patient and family services, introduce new services, increase our support of young people and their parents, improve health care professionals' engagement and education and increase awareness of pituitary conditions and patients' needs through more

The Pituitary Foundation For the Year Ended 30 June 2016

campaigning work in the years to come.

The organisation's performance continues to be measured as defined in the Strategic Plan and in this financial year 39 Key Performance Indicators (KPI) were identified in the Operational Plan. One was removed early in the year when a proposed project with a PhD student at Plymouth University researching the needs of children and young people with pituitary conditions was cancelled. Of the other 38, 34 (89%) have been fully achieved. Only 4 were not achieved all due to the limitation of staff resources.

Income for the Financial Year 2015-2016 fell below budget, with corporate donations and grants performing below expectation. These had both been identified as high risk and the investment in new key staff positions has targeted this area for the future. The events income was some £50,000 below the previous year but a significant amount of time was expended during this financial year on a major fundraising event which was held in October 2016 and hence is not fully accounted for in this year's figures. Our many loyal fundraisers took on many challenges including marathons, skydives, cycling, walks, and many other innovative events including an Edinburgh to Paris challenge, cycling from Edinburgh to Dover, kayaking across the Channel and running from Calais to Paris raising £20,000 for the charity. Awareness Month in October 2015, Springtime Teas, the lottery, raffles and merchandise through the online shop all continue to contribute handsomely to the income of The Foundation.

The "Isabella Andrews Appeal" launched 2 years ago continues to raise income for our charity through its annual Golf Day and its total now stands just shy of £20,000.

The lottery numbers are in slow decline since the paid marketing by Unity Lottery 2 years ago but a new leaflet has recently been produced using a pituitary patient as a case study to encourage more people to participate and other initiatives are underway to stem the decline. Whilst the legacy income this financial year is only £15,000, the Legacy Strategy now has 36 pledges with Legacy 'roadshows' continuing to take place at Local Support Groups.

Our Membership remains static at approximately 2,200 but our supporters, particularly amongst fundraisers, continues to grow. A membership cost analysis and audit is underway with changes to be implemented in the next financial year.

The Trustees wish to express their appreciation to all of our volunteer fundraisers who have worked exceedingly hard to assist our efforts to maintain help and support to our community.

The new IT system implemented in May 2014 together with online payment of bills and a new online HR system continue to improve the working efficiency of the organisation. Work started in this year also on preparing the charity for auto enrolment.

The Pituitary Foundation is committed to following high standards of fundraising practice. Our fundraisers are members of the Institute of Fundraising.

Awareness

We attended a number of healthcare conferences and events including the Society for Endocrinology Annual Conference, regional clinical update meetings and the annual Clinicopathological Conference on Pituitary Disease in London. At all these events we provide an information stand and engage with clinicians to widen their knowledge of the important work undertaken by The Foundation.

We continue to represent the patients view to pharmaceutical companies through workshops and presentations and we are a member of a project team addressing the late diagnosis of Pituitary diseases, the main causes and potential solutions.

We participated again in Rare Diseases Day and attended Rare Diseases UK receptions at the Welsh Assembly and the House of Common and joined the Rare Disease UK patient network forum in Wales. We also succeeded in helping gain approval from the All Wales Medicine Strategy Group's approval of medication for Welsh patients with uncontrolled Acromegaly.

The Pituitary Foundation For the Year Ended 30 June 2016

We chair the Scottish Endocrine Nurse Group Meeting and we are now a member of the NHS England Clinical Reference Group for Specialist Endocrine Conditions. We continue to play an active role as the UK representative at the World Alliance of Pituitary Organisations' Summit.

Our Campaigns and Policy Strategy was produced in April 2015 and runs until December 2016. In addition we now have 9 trained Volunteer Campaigners who are raising awareness in their local community and working with their local clinics.

We met our objective of three successful campaigns during this financial year. Awareness Month in October 2015 was the most popular Awareness Month ever with participation exceeding all expectations. The "Get Red Flagged" Campaign urged all patients on hydrocortisone to be registered with their Ambulance Service and some 385 factsheets and 60 clinic packs was circulated. Go Red days took place all over the UK with a large number of awareness stands and talks taking place.

The spring campaign in 2016 was to raise awareness about emergency hydrocortisone to ambulance staff by publicising a free e-learning module developed by a member of our Medical Committee. Paramedic Services are now using the module and we have been encouraged by the number of ambulance trusts that have contacted us.

Our latest campaign, 'Know your Insipidus from your Mellitus' has recently been launched highlighting how vital it is not to confuse Diabetes Insipidus with Diabetes Mellitus. This campaign is targeted at A&E staff, nurses and pharmacists.

Our two celebrity ambassadors, Mike Crawshaw and Stephen Campbell Moore continue to support our events and raise the profile of The Foundation.

Caring Support

The Patient Support and Information Helpline saw 636 calls, a small decrease on the previous year. Our recorded statistics for our Helpline emails reported a slight increase to 1,055 with a significant number of queries still coming via Facebook. The Endocrine Nurse Helpline saw a 6% increase with 529 calls being received during the year with each call lasting about 18 minutes.

Two of our publications were updated during this financial year, together with two new titles, one for teens and young adults about hypopituitarism and a much awaited publication on fatigue management. A successful internal audit was carried out on the publications and 4,548 copies of our publications were distributed during the year. This was less than the previous year, but downloads from the website have increased by 7%.

Pituitary Life continues to be published 3 times a year and goes from strength to strength. The Foundation receives consistent positive feedback about the quality of this publication and with an ever increasing offer of articles. It continues to be available electronically to members who have agreed to this and is also available for purchase through the online shop for non-members.

The Trustees wish to extend our gratitude to the many patients and family members who show great courage in sharing their stories with our community, as well as the many experts who offer their expertise by writing articles for *Pituitary Life*.

An extremely successful Conference was held in Leeds in April 2016 attended by over 200 delegates with over 95% of the event receiving excellent or good ratings. This continues an increasing trend each time the conference is held.

Social media continues to play a major role in fundraising as well as improving public awareness. The number of Twitter followers increased from just under 2,000 to over 2,600 and the number of people who like our Facebook increased by 47% over the year reaching nearly 3,600 at the year end.

The website continues to be very well accessed with over 637,000 sessions to the website during 2015-2016, an increase of nearly 14%. During this period 40% came from the UK with 60% from the US demonstrating our global appeal.

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The Young People and Parents' Group continues to grow and two successful workshops were held at the Conference. The Trustees are committed to developing the services for younger people in 2016-2017.

The online Cushing's Group now has 30 members and is going from strength to strength.

The Foundation has a network of 34 active Local Support Groups providing invaluable support and information to thousands of patients in the UK and the ROI.

Education

Staff and volunteers attended a number of healthcare conferences and events during the year, manning information stands and giving presentations. These events are very important allowing for engagement with clinicians and health care professionals, including endocrinologists, neurosurgeons and endocrine nurses. Awareness Month 2016 and the plans for 2016 will extend the dialogue to optometrists.

We continue to play a vital role in providing key information on pituitary conditions for the education of non endocrine specialist health care professionals.

3. FINANCIAL REVIEW

Last year The Trustees reported an increase in the stability of our financial position and our financial security and that Phase 3 of the review of the organisation had been completed in June 2015. As reported then the Trustees had agreed to fund the reorganisation proposed by the CEO in full. This required an investment of about £110,000 both in 2015/16 and 2016/17, with a break even position being forecast in 2017/18. The net expenditure over income of £115,613 is approximately in line with the agreed investment by the Trustees.

Financial management systems are in place and subsequent timely reporting mechanisms in operation with the Finance Committee meeting on a monthly basis.

Benefactors and other funders

The Foundation is indebted to those organisations that have funded our work through the year. These include:

- Novartis UK
- Pfizer
- Actavis UK Limited
- The Albert Hunt Trust
- The Kelton Trust
- Thompson Family Charitable Trust
- Chiasma
- Shire UK
- Medicys

We extend our thanks also to our Local Support Groups for their fundraising efforts and for generously supporting some of our national services and projects.

The Foundation enjoys an extraordinary amount of support from its community. We wish to extend our special thanks to those companies, trusts and organisations who offer ongoing, long-term financial support which is essential to the stability of our work.

It is crucial to emphasise our gratitude for the continued support of our many donors, subscribed members and those who engage in sponsored fundraising. These generous offerings from our community not only hearten our efforts to provide our service but, without them, The Foundation could not continue.

Incoming resources

In 2015-2016 The Foundation had an income of £335,774 compared to £578,888 in the previous financial year. Whilst this appears to be disappointing, it should be noted that nearly £200,000 of the income in the previous year was a legacy and although this income stream is being addressed in the Legacy Strategy, nonetheless it

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cannot be forecast with any confidence. In addition, the income from our major fund raising event, the Masquerade Ball, will appear in the income for the financial year 2016-2017.

Resources expended

Diligent control of existing expenditure was maintained and the Foundation staff have ensured that bought-in services are reviewed regularly to ensure best value for money. Phase 2 of the reorganisation implemented last year continues to show significant saving and performance enhancement in this financial year.

Policy and Performance

The Foundation's Funds, both General and Restricted are maintained with our primary bankers, NatWest, in current accounts and a working reserve account and an additional online current account is held with RBS. In addition, deposit accounts (to the maximum of the FSA Investor Compensation Scheme) are also held with RBS, CAF, Cater Allen, the Monmouthshire Building Society, Cambridge and Counties Bank, Hodge Bank and Virgin Money. Funds are subject to regular review by our Finance Sub-Committee.

The Trustees have a confident expectation that The Foundation will continue in operational existence for the foreseeable future and have, therefore, used the going concern basis in preparing the financial statements.

Reserves Policy

In determining a prudent level of free reserves, the Board takes into account that the total budgeted unrestricted expenditure is in the region of £450,000 and of the inevitable uncertainties which exist as a consequence of our dependence on voluntary giving and legacy income.

The policy is that free reserves should normally be between six to twelve months unrestricted operating expenditure which is equivalent to between £225k and £450k. The actual unrestricted reserves as at 30th June 2016 were £554,277 which is equivalent of nearly 15 months budgeted expenditure for the financial year 2016/17.

4. PLANS FOR THE FUTURE

Our vision and goals for the future are set out in detail in our 2016 - 2019 Strategic Plan (available on our website to download). We will continue following the four Strategic Pillars and our 13 identified goals and 36 KPIs have been identified for 2016-2017. In line with the agreed strategic plan and the reorganisation started in 2015-2016, a further £110,000 will be invested in 2016-2017 with a break even position being forecast for 2017-2018. The changes that have been implemented this financial year will provide a strong and sustainable organisation that will meet both current and future growth demands. The key posts that have been filled this year will focus on increasing income from various streams, including trusts, and ensure that we have a website that maximises online donations and purchases. These changes mean that we will be able to increase the number of people we help, expand current patient and family services, introduce new services, increase our support of young people and their parents, improve health care professionals' engagement and education and increase awareness of pituitary conditions and patients' needs through more campaigning work.

5. STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing Document

The Pituitary Foundation was established in 1994 and became a Company Limited by Guarantee and a Registered Charity in 1996. It is, therefore, governed by company law and the Charity Commission.

Its governing documents are its Memorandum and Articles of Association.

Membership is encouraged and is open to all who wish to support The Pituitary Foundation; however, the principle services provided are available to all who require them.

Appointment of trustees

At each General Meeting (GM), one third of the Trustees who are not officers retire by rotation. Any member of The Foundation may nominate any other member for a vacant Trustee position. If there are more nominations