Vision

Our vision is of a world where every person affected by a pituitary condition has a timely diagnosis and access to the best treatment, information and support.

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Achievements against our four Strategic Pillars in 2013/2014:

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Welcome

The Pituitary Foundation is the UK’s leading charity providing support to people affected by disorders of the pituitary gland such as Acromegaly, Cushing’s, Prolactinoma, Diabetes Insipidus and Hypopituitarism. It is estimated that there are at least 70,000 people with a pituitary condition in the United Kingdom. In 2014, we celebrated twenty years since the charity was established, to help and support those affected by rare pituitary conditions. To mark this important occasion we were delighted to honour the original founders of the charity with honorary life memberships: Professor John Wass, Professor Stafford Lightman, Ms Sue Thorn, Ms Ann Bailey and Ms Gail Weingartner.

In September 2013, our three year Strategic Plan was formally issued, setting out in detail our vision and goals for the future. The primary objective of the Strategic Plan was to give the charity a clear and agreed direction and purpose for the period 2013 – 2016 and to communicate this to our staff, our volunteers, members, healthcare professionals, donors and everyone who gives support, or indeed benefit from the work of the charity. This Annual Review identifies the progress and achievements we have made during 2013/14 against our Strategy and our four Strategic Pillars: Effective Organisation, Awareness, Caring Support and Education.

The last 20 years has seen The Foundation making a significant difference to the lives of many pituitary patients. The future for the charity and the beneficiaries we serve is looking positive and we are pleased to report that income raised this year, has surpassed all previous years, and the resulting surplus will enable us to bring our ambitious future plans to fruition, allowing us to expand our services and reach more and more people who need our help.

All of our achievements outlined in this Review have only been possible because of the hard work and dedication of so many people. We would particularly like to thank our dedicated team of staff who, though small in number, continue to deliver so much under a lot of pressure, our network of Local Support Groups, our volunteers, trustees, benefactors, donors, members and those who have chosen to remember us in their Wills.

We are still a young charity and there is still much work to do and challenges to face. Our ambitious plans depend upon the voluntary donations, grants, memberships and generosity of our supporters but we will continue to build on our current achievements and drive towards meeting our vision of a world where every person affected by a pituitary condition has a timely diagnosis and access to the best treatment, information and support.

Menai Owen-Jones Chief Executive Officer
Jenny West Chair of Trustees

20 years has seen The Foundation making a significant difference to the lives of many pituitary patients.
DEVELOPING THE EFFECTIVENESS of the charity was central to our work during 2013/14 and notable 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

2013/14 was the most successful fundraising year in the history of the charity. We saw positive developments across our fundraising portfolio as we continue to diversify our income streams. Revenue from events almost doubled during this period and donations to The Foundation increased by over 50%. Many fundraisers took on extreme challenges participating in marathons, triathlons, walks, cycling, skydives and many other events. The North Wales Zip Slide event saw 30 participants raise over £5,000. Pituitary Awareness Month during October 2013 raised over £10,000. Income from Springtime Teas, Christmas cards, merchandise, the lottery and raffles continue to contribute generously to the income of The Foundation and the online shop has aided these sales, receiving over 700 orders in a year and generating over £10,000.

Two specific appeals were organised during the year. The "Isabella Andrews Appeal" was supported by friends and family of Isabella, a young girl born with a non-functioning pituitary gland, and raised over £10,000. An IT Appeal was instigated also to raise funds to replace the charity’s very old IT system.
and thanks to a very generous donation of £10,000 from The Clothworkers’ Foundation, we met the target needed to successfully update our IT system.

A very successful lottery marketing campaign was undertaken and resulted in our player base increasing from 131 to 566. A Regular Giving Scheme “Brick-by-Brick”, was launched in June 2014. Funding from Trusts increased significantly this year compared to the previous year, but work continues on researching and approaching trusts and corporate foundations. We successfully secured “Charity of the Year” with two companies; Bradley Estate Agents and Severn Bay Corporate Solutions. A three year Legacy Strategy has also been implemented and 17 legacy pledges have already been received.

The implementation of the Strategic Plan has necessitated a complete review of the organisation in order to ensure that sufficient and effective resources are in place to deliver our Strategy. Phases one and two of the reorganisation were completed in September 2014 and work is continuing on phase three in the 2014/15 financial year. This has resulted in the post of Business Controller being made redundant in September 2014 and the financial and some human resources aspects of the business being outsourced to specialist support companies. A new Assistant Administrator post was also introduced during the year to provide support to membership, fundraising and the services functions.

A two year Volunteer Strategy was introduced in April 2013 and is already showing results. New office volunteers have been recruited and The Foundation now has 110 volunteers in total. Some of these volunteers run our Local Support Groups, a unique service provided only to pituitary patients in the UK and Republic of Ireland. A very successful Volunteer Training Weekend was held.
Our volunteers provide approximately the work of **10** full-time equivalent staff.

in November 2013 with all workshops receiving an “excellent” or “good” rating from the 66 volunteers who attended.

All volunteers offer their time, effort and energy with generosity of spirit and dedication to service. Their hard work means our community feels less isolated, better understood and have access to a listening ear and more information about their sometimes bewildering, and often frightening journey. Our volunteers provide approximately the work of 10 full-time equivalent staff and we have a very high retention rate in comparison with other larger charities. Over half of our volunteers can be described as long standing and have been volunteering for five years or more.

To improve our organisation’s performance measurement, 38 Key Performance Indicators (KPIs) were specified in the Operational Plan for July 2013 to June 2014, underpinning the Strategy. 29 of these were fully achieved during the year with four partly achieved - 86% of the KPIs were either fully or partly achieved.

A new IT system was successfully implemented in May 2014, with money successfully raised from an appeal. This has greatly improved the working efficiency of the organisation and has also allowed secure remote access to the network to aid some home working and access by key volunteers.

“Thank you for all the work that went in to make the event such a success. I enjoyed meeting people and the event made me feel more valued and part of a supportive team.”

Volunteer Lucy Clifton gets involved in our campaigning work.
During this 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

We attended a number of healthcare conferences and events, such as the Society for Endocrinology BES Annual Conference, several regional clinical update meetings and the annual Clinicopathological Conference on Pituitary Disease in London, where we engaged with clinicians and provided information stands.

We continued our work in representing the patient’s perspective to pharmaceutical companies through workshops, meetings and presentations. We participated in the Organising Committee of the Global Patients Advocacy Meeting held in October 2013 in Zurich. Our Head of Patient and Family Services was also a patient representative on the NHS Specialist Endocrinology Clinical Reference Group.

These are all important opportunities for us to share, not only about our services This increases awareness and understanding, strengthens relationships and opens dialogues.

Pituitary Foundation members take part in an Awareness Walk in Cardiff in 2013.
and support, but also about the pituitary experience. This increases awareness and understanding, strengthens relationships and opens dialogues. It also allows us to learn what is happening in the field of endocrinology, discover new research and treatments, and network with not only medical professionals but also the pharmaceutical industry.

We participated in Rare Diseases Day once again in 2014, which included contacting our members, volunteers and other supporters through various communication channels, to encourage them to take part to raise awareness of rare diseases e.g. circulating a rare diseases letter writing campaign and online surveys. We also attended Rare Diseases UK Receptions at the Welsh Assembly and the House of Commons.

We also started to further develop our policy and campaigns work during the year, which included researching politicians across the UK with an interest in rare diseases and starting our engagement work with them.

Awareness Month 2013 in October had the theme “What is the pituitary?” and was aimed at raising awareness about what the pituitary gland does and what are the associated conditions. Over 800 hard copies of two new informative educational posters were distributed and electronic copies reached over 10,000 people. Hundreds of willing supporters undertook many activities in order to raise awareness of the impact on patients and their families of pituitary conditions.
pituitary conditions including writing to their MPs, holding information stands at hospital clinics, giving talks to local organisations as well as raising the awareness through fundraising events.

We are delighted to welcome also, two celebrity ambassadors to The Foundation to help raise awareness of our charity and its work amongst the general public, Mike Crawshaw and Stephen Campbell Moore. Mike Crawshaw is part of leading vocal harmony group “The Overtones” and was introduced to the charity in May 2013 when he took part in the zip slide event that The Foundation organised at Chepstow, in support of family friends whose young daughter Isabella was born with a non-functioning pituitary gland. The band have already been helping in terms of raising awareness of the charity, as they have a number of fan clubs around the World, and in fact a number of The Overtones fans, or “Toners” as they are affectionately known, have already taken part in a series of running events across the country for The Foundation.

Stephen Campbell Moore who, is himself a pituitary patient, is an English actor of both stage and screen, appearing alongside Joely Richardson in the British television drama Wallis and Edward. Stephen has already given his backing to our Regular Giving Scheme.

Our new logo and colour scheme that was introduced with our new website last year has now been implemented across the vast majority of our publications and communications. The feedback from members and the public has been very positive.

We are delighted to welcome two celebrity ambassadors to The Foundation.

“Pituitary illness is a chronic condition and no matter how many hormones we take to ameliorate it, some of us – from time to time or even chronically – have to cope with the loss of energy, memory, initiative, confidence, will power, employment, status or a combination of them. Sometimes we just feel fatigue or ill.”

Martin, pituitary patient, summer 2013 edition Pituitary Life
Caring support

We provide a choice of information, practical and emotional support services to help anyone affected by pituitary conditions. We help patients, their families, friends and carers at any stage of their illness when they need our support; whether they are seeking a diagnosis, newly diagnosed or already along their journey. This year we continued to see increasing demand for our support services and we pursued our aim of expanding our services to meet the needs of different demographics. Our Strategic Goals under the Caring Support 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

The Information and Patient Support Helpline saw 678 calls and the Endocrine Nurse Helpline received 392 calls, a 10% increase on last year. On average our Endocrine Nurse spends 20 minutes talking to each enquirer on the phone. Our Helpline Email Support Service continues to grow in popularity.

On average, our Endocrine Nurse spends 20 minutes talking to each enquirer on the phone.

“I have just telephoned Alison, the Endocrine Nurse, for the second time since my diagnosis. I don’t know what she does, but she makes everything so much clearer – one call to Alison for advice makes everything so much easier to understand and process. Thank you for this invaluable service.”

Feedback from Endocrine Nurse Helpline caller
with a 24% increase in 2013/14 – 1,450 Helpline emails were answered during this time.

10 of our 30 publication titles were updated during this financial year. 4,500 hard copies of our publications were distributed; a 10% increase on 2012/13.

We also had a successful audit in late 2013 in order to retain the Information Standard Quality Mark for patient support information.

*Pituitary Life* magazine continues to be published three times a year and consistently achieves excellent feedback. Each edition is full of informative articles, including a variety of stories from patients, medical updates and professional articles.

We continue to extend our reach via social media and it plays a major role in fundraising as well as improving public awareness. Twitter and Facebook have helped us to gain many new supporters and volunteers from the general public as well as reaching many new patients and their families. The number of Twitter followers grew to almost 2,000, double that at the end of the last financial year. The number of people who liked our Facebook more than doubled reaching 2,456 at the year end.

The new website has now been live for over a year and has brought significant improvements in terms of reach, visual appeal, wealth of information, ease of

The average number of visits to our website is 14,000 per month.

*Pituitary patient, Emily.*
The first time Pituitary Life arrived at our home, I was very reluctant to read anything. It was about a week or so later that I finally picked it up and started to read it. I became entranced; I read every article, every word written. This was the first time I truly realised that my illness was not the end of the World.”

Stephen, hypopituitarism patient, summer 2013 edition Pituitary Life

use and income generation. The average number of visits to our website is 14,000 per month which shows that we are reaching more people, both in the UK and also further afield, with our website statistics showing its global reach.

The new Young People and Parents’ Group continues to grow. Our Head of Patient and Family Services is working with a paediatric nurse at Alder Hey to promote a families programme with endocrine nurses and we introduced new representatives onto our Medical Committee. We will continue developing our services for younger people in 2014/15.

We now have a successful network of 31 Local Support Groups across the country who provide invaluable support and information to thousands of patients and their families in their locality.

Twitter followers grew to almost 2,000 double that at the end of the last financial year. The number of people who ‘liked’ our Facebook more than doubled reaching 2,456 at the year end.

We now have a successful network of 31 Local Support Groups across the country.
PROVIDING INFORMATION AND education to health care professionals about pituitary conditions is a key priority for The Pituitary Foundation. 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

Staff and volunteers attended a number of healthcare conferences and events during the year, with information stands and they also provided talks. At these events we engaged with a number of clinicians and health care professionals, including endocrine nurses and endocrinologists. We continued our work increasing awareness amongst the ambulance service and we now have a new ambulance personnel representative on our Medical Committee, Andy Baines, an Advanced Paramedic at North West Ambulance Service.

2,702 publications in total were distributed to hospitals during 2013/14. We introduced new useful resource packs for endocrine clinics too. The purpose of the packs is to provide resources to help clinicians to educate patients about their conditions. The resource packs contain a variety of publications, at a discounted cost, for clinics to share with their patients. We are pleased to report that 13 clinic resource packs were ordered during 2013/14, which surpassed our target for the year.

We continue to develop our understanding of patient experience and regularly gather feedback from patients accessing our services, such as our Helplines. The Foundation agreed to be a study partner to a KU Leuven University study exploring how patients affected by rare conditions and their carers define “value” when considering new medicines. The Board of Trustees also agreed to part-fund a PhD project researching the needs of children and young people, which commenced in October 2014. Part of the difficulty in understanding the effect pituitary conditions can have on patients is the dearth of research looking at the needs of patients with pituitary conditions and how they manage their care (Jackson, Morris & Ashley, 2008). This shortage of knowledge extends to the study of children with pituitary conditions, where even less is known about their needs than in the adult population. More detailed information is required to assess the psychosocial functioning and needs of children with pituitary conditions. It is essential to the care of children with pituitary conditions that there is a greater understanding of how they feel about their conditions, the specific needs that they have and any concerns they have about managing their condition. These elements are important for ensuring treatment adherence and clinic retention and also for The Pituitary Foundation to understand the needs of children and young people to help inform the future development of our patient and family services.

"Eight years ago I suffered pituitary apoplexy and had emergency surgery for a previously undiagnosed pituitary tumour. This left me needing hydrocortisone, thyroxine and later, growth hormone. Eventually, I was able to come off hydrocortisone, but in 2007, a routine scan showed my tumour had returned and I needed further surgery (two lots because of CSF leak) and of course radiotherapy. Now I have DI too and replace hydrocortisone, thyroxine, GH and oestrogen/progesterone. It’s five years since my last surgery and I feel that I have finally got everything balanced."

Karen’s Story, Autumn 2013 Pituitary Life
Financial report

W e reported last year that The Foundation had managed to increase the stability of our financial position and our financial security. This year has seen that stability increase further with The Foundation reporting the highest income in its history. This has been through the dedication and professionalism of our staff and The Foundation is indebted to them.

The Foundation’s financial performance for this year showed a surplus of £138,437, compared to a surplus of £90,887 in 2012/13. This was achieved through the generosity of a member who left The Foundation a significant legacy in their Will and also due to excellent performance in donations and events fundraising.

Our income overall increased by £95,988 (26%) on 2012/13 and excluding legacies income increased by £56,091 (23%). This demonstrates the much improved position that The Foundation is in today. Expenditure in 2013/14 has increased by £48,438 on the previous year, but it is 7% under the planned expenditure budget for the year and costs continue to be well managed.

This very positive performance has been achieved during the slow economic recovery in the country and the hard work that has gone into achieving this excellent performance should not be underestimated.

For every £1 donated to the charity, 85p goes directly to help patients.

In 2013/14 we raised £466,022

<table>
<thead>
<tr>
<th>Legacy</th>
<th>£165,854</th>
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</thead>
<tbody>
<tr>
<td>Donations</td>
<td>£118,082</td>
</tr>
<tr>
<td>Grants</td>
<td>£78,735</td>
</tr>
<tr>
<td>Membership</td>
<td>£53,339</td>
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<tr>
<td>Activities for generating funds</td>
<td>£24,343</td>
</tr>
<tr>
<td>Gift aid</td>
<td>£12,246</td>
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<tr>
<td>Regional activities</td>
<td>£9,185</td>
</tr>
<tr>
<td>Investments</td>
<td>£4,238</td>
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</tbody>
</table>

In 2013/14 we spent £327,585

| Charitable activities: advice, info & patient support | £258,766 |
| Cost of generating funds | £40,775 |
| Regional activities (LSGs) | £18,595 |
| Governance costs | £9,449 |
### Income

<table>
<thead>
<tr>
<th></th>
<th>2013/14</th>
<th>2012/13</th>
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</thead>
<tbody>
<tr>
<td>Donations</td>
<td>£118,082.00</td>
<td>£114,254.00</td>
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<tr>
<td>Legacy</td>
<td>£165,854.00</td>
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<tr>
<td>Membership</td>
<td>£53,339.00</td>
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<tr>
<td>Gift Aid</td>
<td>£12,246.00</td>
<td>£11,300.00</td>
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<tr>
<td>Activities for generating funds</td>
<td>£24,343.00</td>
<td>£8,393.00</td>
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<tr>
<td>Investments</td>
<td>£4,238.00</td>
<td>£2,332.00</td>
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<tr>
<td>Grants</td>
<td>£78,735.00</td>
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<tr>
<td>Regional Activities (LSGs)</td>
<td>£9,185.00</td>
<td>£16,260.00</td>
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<tr>
<td><strong>Total income</strong></td>
<td><strong>£466,022.00</strong></td>
<td><strong>£370,034.00</strong></td>
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### Expenditure

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<tr>
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<th>2013/14</th>
<th>2012/13</th>
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<tbody>
<tr>
<td>Cost of generating funds</td>
<td>£40,775.00</td>
<td>£27,325.00</td>
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<tr>
<td>Charitable activities: advice, info &amp; patient support</td>
<td>£258,766.00</td>
<td>£232,217.00</td>
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<tr>
<td>Regional activities (LSGs)</td>
<td>£18,595.00</td>
<td>£10,801.00</td>
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<tr>
<td>Governance costs</td>
<td>£9,449.00</td>
<td>£8,804.00</td>
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<tr>
<td><strong>Total expenditure</strong></td>
<td><strong>£327,585.00</strong></td>
<td><strong>£279,147.00</strong></td>
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### Net incoming resources before transfers

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<th>2013/14</th>
<th>2012/13</th>
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<tbody>
<tr>
<td>Net incoming resources before transfers</td>
<td>£138,437.00</td>
<td>£90,887.00</td>
</tr>
<tr>
<td>Transfer between funds</td>
<td>-</td>
<td>-</td>
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<tr>
<td><strong>Net incoming resources</strong></td>
<td><strong>£138,437.00</strong></td>
<td><strong>£90,887.00</strong></td>
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### Total funds carried forward as at 30 June 2014

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<tr>
<th></th>
<th>2013/14</th>
<th>2012/13</th>
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<tr>
<td><strong>Total funds carried forward as at 30 June 2014</strong></td>
<td><strong>£467,622.00</strong></td>
<td><strong>£329,185.00</strong></td>
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This financial summary is extracted from our full accounts for 2013/14 which are available on our website [www.pituitary.org.uk](http://www.pituitary.org.uk)
Mission
In order to advance our 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.

Trustees
Mrs Jenny West (Chairman)
Mr Mike James (Vice Chair)
Mr Aidan Pennington (Hon Secretary)
Mr Mike Beaven (Hon Treasurer)
Dr Stephanie Baldeweg
Ms Hilary Frazer
Dr John Newell-Price
Dr Mark Pharaoh
Ms Claire Thatcher
Mr Tom Sumpster
Dr Ezra Macdonald

Staff
At report date The Foundation employed seven members of staff, (full-time equivalent 6.1):
Chief Executive Officer Miss Menai Owen-Jones
Head of Patient and Family Services Mrs Pat McBride
Fundraising and Marketing Manager Mr Jay Sheppard
Foundation Administrator Mr Martin Cookson
Endocrine Specialist Nurse Mrs Alison Milne
Volunteers, Campaigns & Projects Manager Miss Rosa Watkin
Assistant Administrator Ms Emily Graham

Contact information
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www.pituitary.org.uk
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Admin line 0845 450 0376 (landline 0117 370 1316)
Charity Registration Number: 1058968
Company Registration Number: 3253584