Photo Calendar Competition Results

A Patient’s Great Adventures

Benefits Update

www.pituitary.org.uk
Distress Thermometer Survey

You are invited to share your experiences and opinions with us by completing the enclosed survey in your magazine (which should take no more than half an hour) and returning this to us at The Foundation using the envelope included.

Research has shown that high levels of patient distress may not be identified during consultations with healthcare professionals (HCPs), resulting in significant patient dissatisfaction with care and additional use of primary and secondary care services.

A distress thermometer is a structured way for a nurse or other HCP to discuss with a patient some of the concerns (practical, emotional, physical and psychological) that they may be experiencing. A distress thermometer offers patients a list of common difficulties. After the patient has completed the distress thermometer it can then be used collaboratively by the patient & HCP to discuss options for dealing with the difficulties causing the most distress for the patient. It is already widely and effectively used in oncology services. Pituitary tumours, though almost always benign, are now included with other central nervous system tumours in cancer services. It therefore seems appropriate to adapt this oncology tool for use with pituitary patients.

Recent research undertaken at the Hurstwood Park Neurological Centre (HPNC) in Haywards Heath has identified that the current list of symptoms on the oncology Distress Thermometer are potentially inappropriate for use with a pituitary population. Further support for this is found within research carried out in 2008 for the Pituitary Foundation, which provided a lengthy list of problems & symptoms associated with pituitary conditions, many of which do not feature on the existing oncology Distress Thermometer.

We do welcome sponsorship for this event and for information about this, or if you know of a company who could help, please contact Menai Owen-Jones on 0117 370 1316 or menai@pituitary.org.uk

The purpose of this research therefore is to generate an appropriate “Problem List” for a pituitary Distress Thermometer for use with pituitary patients. As a first stage, we want to find out how you feel your pituitary condition is affecting you and the common problems and difficulties you face. This information will help us to develop a Distress Thermometer which ultimately will help your medical team to improve the services you receive to help you manage your condition better.

If you decide to complete and return this survey, please be assured that any information you give will be kept confidential and anonymous. The Consent Form which identifies you will be kept securely and separately from the survey answers.

Thank you very much for your time and your help.

National Pituitary Conference 2013

We are currently planning for our next Conference, which we hope to hold in April 2013 in Birmingham. The 2013 Conference in Sheffield was a huge success, which we will build on to make this even better (and bigger)! There will be breaks out sessions offered, for a choice of different workshops with speakers. Teens and families of younger patients will be catered for too. More information will be provided in the next edition of Pituitary Life magazine, which is due out in late September.

We do welcome sponsorship for this event and for information about this, or if you know of a company who could help, please contact Menai Owen-Jones on 0117 370 1318 or menai@pituitary.org.uk

Dear Members of The Pituitary Foundation,

I have been asked to write in Pituitary Life, to say hello to you all and introduce myself as the new Outreach Volunteer Support Co-ordinator. I started with the Foundation on 12th March and have been thoroughly enjoying the role so far. I know that I have spoken to specifically the volunteers already, but to those I have not yet had contact with, I would like to say that I am really looking forward to working with you all. I am co-ordinating the volunteer programme and here to support volunteers and the Local Support Groups, so do contact me whenever you need information, support, or resources and I will always do my best to help. Equally, I am the person to contact regarding booklet orders, the overall volunteer programme, and I also work with Pat to deliver the Foundation’s patient support services. I am involved in services such as the Helpline.

Back in 2010-2011, I used to be a volunteer for The Pituitary Foundation in the National Support Office and I am so pleased to be back as an employee. In the meantime, I worked for 13 months as Project Officer for a charity called South West Foundation who support the community and voluntary sector through conducting research, training, and small grants. I had to visit many different small community organisations, ranging from health support groups to community youth groups, and I acted as the support trainer in delivering Community Researcher Training. My other responsibilities included grant assessment, fundraising, and conference/event planning which addressed community development issues and communities influencing

parliament. Throughout the last two years and alongside studying for my degree, I have volunteered for various charities which I have always really enjoyed; these included Macmillan, Water Aid, The Big Issue and being a peer support mentor at my university.

In these first few months with the Pituitary Foundation I have been busy with various tasks involved with running the volunteer programme, and working with current volunteers and Local Support Groups, alongside trying to find, advertise for and recruit volunteers. I have been supporting Area Co-ordinators and volunteers, producing Volunteer News magazine and have attended the Volunteer Fair in London. So far, I have visited the Bristol, Oxford, Cardiff and Birmingham support groups who have all made me feel very welcome. I have other trips to Local Support Groups planned and hopefully other groups depending on my other work responsibilities. I have completed my Telephone Helpline training courses in London and begun my helpline shifts; I have been working on applications for funding and other project work and been busy learning as much as I can to improve my understanding of pituitary conditions. We are also beginning work on planning the next annual conference in 2013 too, which looks to be another very exciting and worthwhile day.

Do feel free to contact me if I can be of any help, my direct number is 0117 370 1316, or dial the main admin line and press 1.

Alternatively my email is rosa@pituitary.org.uk

I hope you enjoy this issue of Pituitary Life which Pat has been working very hard on as always!

Best wishes,
Rosa

Outreach Volunteer Support Co-ordinator

Common Problems

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Hello from Rosa

Outreach Volunteer Support Co-ordinator

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Best wishes,
Rosa
Charity Calendar 2013 Results

Photo Competition

By Volunteer, Mike Griffin

On behalf of the judges, may I thank everyone who submitted some wonderful pictures to our competition. We received 275 entries in total! Judging was an enjoyable, yet difficult job, as there were some excellent and varied entries. All entries were judged anonymously. In the end, we chose 16 winning photos: 12 will be printed in The Pituitary Foundation’s 2013 calendar and the other 4 photos will feature as images on the charity’s new notelets merchandise, which will be available soon.

Congratulations to our overall photo competition winner, Russell Watkins, whose atmospheric entry ‘Winter Sunrise’ greatly impressed us and was judged as the best overall photo. Well done also to the other winners for their entries.

We were impressed with the number of entries in the under 16s sections, with less than 8% of the total from this age group.

Obviously the success of this competition will be judged from the funds raised through the sale of the 2013 calendar, but we must not forget that it brings a chance of drawing people’s attention to the important part that The Pituitary Foundation plays in our lives.

We were honoured to judge the competition. Thank you for your support and sharing your world with us.

Republic of Ireland

Saturday 29th September

This group’s AGM will be held at Stillorgan Park Hotel, Stillorgan Road, Co Dublin. Complimentary soup and sandwiches will be available in the hotel for all attendees from midnight. The meeting will begin at 2.00 pm promptly until approximately 4.30 pm.

The main speaker this year will be Mr. Mohsen Javadipour, Consultant Neurosurgeon, Beaumont Hospital Dublin. The title of his talk will be ‘Advances in surgery for pituitary patients’. We wish to say a HUGE thank you to this group for the very generous donation of £1,500 to The Pituitary Foundation for our new website; the money is thoroughly appreciated.

Salisbury

Their next meeting at Salisbury District Hospital is in Room D on Thursday 19th July 2012 19.30pm. The group held an ‘Open Garden’ fundraising event on June 3rd, and a fundraising auction as part of Awareness Month will be held on 20th October 2012 – at Hampsword Golf & Country Club, for 7.00 pm, ‘Tickets £30 (Pigwashum Supper inc) Plus, Mike & Teresa Beaver organised a Spring Time Tea on 26th May 2012. For venue details contact Salisbury AC Annie, or see our website.

Solent

This Local Support Group meets in the Garden Room at Cosham Community Centre, Wootton Street, Cosham

Dates are as follows:

- Saturday 7th July 2012 at 10.30 am
- Saturday 4th August 2012 at 10.00 am
- Saturday 1st Dec 2012 at 10.00 am.

The group meet on The Isle of Wight too - The Lake Community Centre on Saturday 14th July at 10:30 am.

Birmingham

Their Spring Time Tea event was held along with their usual meeting at the Morris Centre at the Queen Elizabeth Hospital in Edgbaston on Sat 26th May. Next meeting will be on Saturday 26th September – speaker to be confirmed.

Newcastle

The second meeting organised by AC Martin Crosby was held on Saturday 9th June 2012, in the Large Staff Room, Peacock Hall, Royal Victoria Infirmary, Newcastle-upon-Tyne. For future dates of this group please contact Rosa.

Liverpool

A HUGE thank you to the group who are donating £2,000 for The Pituitary Foundation to reprint our Employment and Male Hormones booklets plus money towards Pituitary Life! The money was raised through regular bag packing events in a local supermarket, which were very kindly organised by Ryan, who is a grandson of a local patient. The money is very much appreciated. In general, Liverpool is continuing with their successful monthly meetings and in April the medical students attended with their tutor to talk with pituitary patients, which was a great success.

Oxford

Oxford Group’s meeting in May included a talk from Professor Ashley Grossman. Professor Grossman is the current Professor of Endocrinology at OCDM in Oxford and St. Bartholomew’s in London. Their meeting in July also has another speaker, Professor John Wass (Consultant Endocrinologist). Thanks to Dr. Niko Kuntzviti, they are also hoping to hold a Saturday morning meeting in October (to be confirmed), with a couple of workshops on pituitary-related subjects.

Pre-order your 2013 calendar now!

A4 full colour Pituitary Foundation calendar £7.50 (including postage and packaging)

Calendars will be available from end of July 2012.

How to pre-order

By cheque: Send a cheque to us at The Pituitary Foundation, 86 Colston Street, Bristol, BS1 5BB. Please write ‘2013 calendar’ on your envelope and remember to include your contact details with your cheque.

Over the phone: With a credit or debit card by calling 0117 370 1317

Online: Visit the merchandise section on our website www.pituitary.org.uk
We are often asked if The Pituitary Foundation works with other organisations. We work alongside various charities and organisations and often refer patients to other organisations when appropriate. For example, one charity we work alongside is the Child Growth Foundation, who specialise in aspects of growth. We asked Jenny Child, their Membership Secretary/Parent Advisor, to tell us more about what their charity does:

The Child Growth Foundation offers support and advice to anyone concerned about any aspect of growth and oversees support groups for the following growth conditions:

- Growth Hormone Deficiency (GHD) and Multiple Pituitary Hormone Deficiency (MHPD)
- Russell Silver Syndrome (RSS) and Intrauterine Growth Retardation (IUGR) and Small for Gestational Age (SGA)
- Premature Sexual Maturation (PSM)
- Sotos Syndrome
- Bone Dysplasias

Russell Silver Syndrome is very rare; it is very difficult to put a number on this but estimates are in the region of 1 in 50,000 births. The term IUGR probably represents a spectrum of conditions (some of which are described as Russell Silver syndrome) resulting from abnormal foetal growth. The child who has IUGR, but has not experienced catch-up growth during their first year, will remain small for their age and probably very thin. The early years are extremely difficult with very poor growth, feeding difficulties, hypoglycaemia and many other problems.

Their final height may be in the region of 157cm (5’2”) for a boy and 144cm (4’9”) for a girl. GH has been shown to be beneficial both in the short term, and the long-term, with final height increased by up to 14cm (5’5”). As a result GH is now licensed after 4 years of age for children born SGA who fail to show catch-up growth and who are short both compared to the normal population and their parents.

There are more than 100 forms of Bone dysplasias, of which Achondroplasia and Hypochondroplasia are two of the most common. Other bone disorders are rarer; some affect limbs only, some the trunk and others both. To date, none of these conditions have any specific treatment, although surgical limb lengthening is potentially the most promising, while, again, the use of growth hormone is being evaluated in clinical trials.

Premature Sexual Maturation (PSM) is a rare condition affecting the gonads, adrenal or other glands and causing premature sexual maturation. The child grows at a faster rate than normal and develops secondary sexual characteristics (such as pubic hair, penile enlargement or breast development) at an inappropriately early age. This condition is much more commonly found in girls than it is in boys.

Sotos Syndrome is an uncommon condition that affects approximately one in fourteen thousand of the population. In approximately ninety percent of cases, the clinical diagnosis is confirmed using a genetic test to detect an abnormality on the NSD1 gene. Some individuals may be diagnosed at birth but many others do not receive a diagnosis until well into childhood.

Growth Hormone Deficiency means the patient doesn’t produce growth hormone to grow. With daily hormone injections, patients grow within normal parameters.

Multiple Pituitary Hormone Deficiency means the patient is deficient in many different hormones needed to sustain life. Replacement hormones are required to help the patient grow and lead a normal life.

We produce two newsletters each year, available to all of our members and hold an annual convention, usually in October. This is a popular event and not only is it a day for patients and parents to gather information and talk to leading doctors and health professionals; it is also invaluable for meeting and talking to other people going through similar problems. It is very much a family event with the children cared for and entertained by childcare professionals. The evening is spent networking and having fun and joining in with the family disco/entertainment.

If you would like more information about the Child Growth Foundation, please contact Jenny Child at jenny.cgf@btopenworld.com or telephone 02089120723.

Looking back over the years

Whilst reflecting back over the history of the Foundation we must not forget you, our supporters, who make our work possible. We extend our sincere thanks to everyone for their support over the past 28 years; you have contributed and helped so much, in many ways - in time, effort, commitment and funds. We really could not continue helping patients and families without you.

Maria bakes cakes!

Thank you so very much Maria for supporting us with your kind donation. This is an incredible feat for a young patient to do and we appreciate all your efforts on our behalf. Well done!
Raising awareness

A bonnie time in Edinburgh!

The sun shone all weekend during our recent visit to Scotland for the Edinburgh Marathon Festival (EMF) 2012. A team of 15 runners, including some patients, family members and friends took to the cobbled streets of Edinburgh in the 5km, 10km, half and full marathon events.

It was a blissfully hot weekend for spectators, but rather too hot for our runners, with temperatures soaring upwards of 26°C (79°F)! However, they carried on regardless and we thank them all for their tremendous efforts.

Amongst the runners was one of our staff members, Mike Waterlow, who successfully completed his first ever half marathon event. Well done Mike!

Conrad Pope from Kenilworth also completed his second marathon for The Foundation living in the locality. Some EMF runners and their families also joined us too for a bite to eat and a cup of tea. We thoroughly enjoyed meeting EMF runners and their families also, including some patients, family members and friends.

The atmosphere on the streets of Edinburgh was amazing, especially on the morning of the half and full marathon. Everywhere you looked there were runners in charity running vests, preparing for their events, doing their stretches, with bottles of sports drinks, plasters and half eaten bananas everywhere! There was a real buzz and a sense of purpose. The crowds were out early at the start to cheer on the runners and locals came out in droves as well, which really helped the participants through the last few painful miles.

Whilst in Edinburgh, we also organised an afternoon tea event which gave us an opportunity to meet with Members and supporters of The Foundation in the locality. Some EMF runners and their families also joined us too for a bite to eat and a cup of tea. We thoroughly enjoyed meeting everyone throughout the weekend and thank you for taking the time to come and meet with us.

We extend our thanks also to our Edinburgh and Glasgow Local Support Groups for helping with the EMF 2012.

One patient shares his great adventure

Martin Coveney, a pituitary patient from Southampton, recently trekked up to Everest Base Camp at 5,500 metres, having had three pituitary tumours removed and takes, what he describes as a ‘gland slam,’ of replacement hormones.

Martin endured trek freezing temperatures (minus 29°C at coldest) and rarefied atmosphere; at one stage he suffered badly from altitude sickness, with the treks taking upwards of 10 hours a day to reach 5,500 metre heights.

Martin said: “I seemed to suffer from tiredness a lot more than my trekking group, which was a bonus as I slept all through the nights whilst others (non-pituitary people) were awake in freezing accommodation, I also slept for a full 36 hours on my return to UK; the only times I woke were by my mid 20’s. Later on I became an avid fan of the Tour De France watching it on television each year and one year even going over to France to see it from the roadside. In the last few years, with access to the Eurosport channel I have expanded to watching more and more cycling events each year, all watched from the comfort of my sofa at home. Becoming quite knowledgeable about the sport I imagined myself out on a bike, but did nothing about it. Two years ago in 2010, I underwent pituitary surgery and was off work for about 10 weeks. During that time I brought a Trek hybrid bike and started cycling as a way of regaining my fitness, fairly short distances to start with and then building up. In 2011 I began tackling more challenging routes and entered the 26 mile Ythan Cycle Run at Fyvie, and the 25 mile route at the Alford Sportive. I was beginning to like cycling again, so much so that in August last year I replaced my hybrid bike with a proper road bike with carbon frame and haven’t looked back. I have now completed several cycles in the 50-70km distance range, but the 100km route at Alford Sportive in May; at age 52, was the longest cycle I’ve attempted.”

David says...

“David Richards is from Scotland and a member of the Aberdeen Local Support Group and The Pituitary Foundation. At the end of May he took on the huge challenge of a 100km (62 miles) cycle ride! The route climbed to a total of some 1300m (4300ft) and took around four hours 20 minutes to complete. His route began at the Grampian Transport Museum Sportive in Alford on Saturday 26th May, and included hill gradients that were up to 14% in places!”

David explains that beside the personal challenge of the 100km cycle ride, his other principle aim is to do with inspiring others. The Pituitary Foundation is hugely thankful to David for taking on such a challenge to raise money for us!
**Hats off to generous company**

London based hatters company, James Lock and Co Ltd, has generously donated £1,000. The company, an old established family owned retail business sells hats and millinery. Began in 1676 it has a worldwide reputation for providing customers with a headwear which they will enjoy owning and wearing for many years.

Nigel Macdonald, Chairman of James Lock and Co Ltd, said: “We are a small business, employing just under 20 people, and whilst doing all we can to ensure that the business is profitable and continues to survive for perhaps another 336 years is a key aim, it is not our only one. We enjoy being part of a worldwide community of customers and potential customers and benefiting from their existence and support. So we try to find ways, however small, where we might be able to make a difference. Our charitable giving is modest, but we aim to support different charities which are themselves doing vital work, often not receiving the high level of public awareness that their work deserves. The whole team, Directors, Management and Staff are consulted about which we should support.”

Nigel continued: “The valuable work of the Pituitary Foundation falls exactly into this category, and it was drawn to our attention by one of our Directors. We recognise that our donation is small, but we hope it will provide some support for your important work.”

**A.P Chant scores a strike!**

We extend our thanks to A.P Chant building services, based in Dorset, who recently donated £445 to The Pituitary Foundation. We were one of two chosen charities who benefitted from their fundraising during the past year. The company’s staff undertook various activities to help us, including organising a charity bowling night. Well done and thank you!

**Dancing for Pleasure Club**

Collette Dynan is a patient and keen member of her local dancing club in Ennis, Republic of Ireland. Collette very kindly put in a request for a donation to be made to The Foundation as part of their charitable giving and this was generously agreed. A cheque for £100 was donated, which is much appreciated.

**Foundation is a raffle winner!**

Thank you very much to Angela McClean from Aberdeen for nominating The Pituitary Foundation to benefit from a Raffle held at her work, BP Clair oil field, at the end of last year. We received a fantastic cheque for £750, which is greatly appreciated. Well done!

**Can you offer a pledge?**

Annie Bushen, a trustee of The Foundation and Area Co-ordinator for the Salisbury Local Support Group, is organising a charity auction on Saturday, 20th October 2012 at Hamptworth Golf and Country Club. If you, or someone you know, can offer an auction item or pledge for the event please contact Annie on stephenbushenz51@btinternet.com or 03722 710890.

Tickets for the evening are £10 (including a Ploughman Type Supper) and are also available by contacting Annie.

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**Sponsor a booklet!**

The need for our support is increasing.

Last year we distributed nearly 8,000 booklets. This averages at 21 booklets a day! Our booklets are a valued service. They are vitally important to many who use them, especially newly diagnosed patients. You may yourself, at some point, have read or accessed our booklets, and so you know how useful they really are.

"After receiving your booklets in the past, I read them through from cover to cover. This was the first time since I was diagnosed that things were explained clearly and in a patient friendly way. I am so grateful that the foundation produces these. The quality of information is superb and I don’t feel alone. Thank you in very much”.

Please help us to continue providing our booklets and making a real difference to pituitary patients.

Each booklet on average costs £2 to write, design, print and then distribute. Please would you consider helping us by sponsoring one of our booklets below?

We are running low in stock of these booklets and they will need to be reprinted shortly.

In return for your generosity we will happily print your name (or a name of your choice) in the booklet. Thank you!

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**Donation Amount**

- £20.00
- £40.00
- £66.00
- £200.00
- £400.00
- £660.00

**Gift Aid**: I am a UK tax payer

**The booklet you would like to sponsor**

- Living with Infertility
- Your Journey: Living with and managing a pituitary condition
- Relationships and communication

**Name to appear in booklet**

If you would prefer for your donation to be anonymous, then please let us know.

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**Your Name (Mr/Mrs/Miss/Ms)**

**Home Address**

**Post Code**

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**Telephone Number**

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The story of one of our supporters, Kate Chia

In 2005 I ran the London Marathon and managed to raise a huge £6678.80 for The Pituitary Foundation. At this time, The Pituitary Foundation was struggling to keep afloat so I was particularly proud to help and contribute to the charity. Back then we had to set up The Pituitary Foundation from scratch with the “just giving” website; it hadn’t been used before. I was then able to raise funds quickly AND get my employer to generously match the funds raised!

This was a special moment in my life as not only did it considerably help the charity, but it meant so much to my mother, Maricia, who’d been through so much with her Cushing’s.

Mum was diagnosed with Cushing’s in 2003. Her case was particularly hard to diagnose too as she didn’t have all the typical symptoms; after nearly one year in various hospitals, and with symptoms that were always challenging the doctors, her “cyclical” Cushing’s condition was eventually brought under control. Mum is now 74 and still relies very much on her daily medication, however the battle is still not over and during the last 2 years especially we’re seeing many of the early day symptoms returning. She’s a very special lady who’s worked so hard all her life, suffered a great deal in her early years (as well, with the loss of her dear husband in 1984) and has always thought of others before herself.

Sometimes it helps to talk to someone who has been there themselves...

Do you have a Telephone Buddy for extra support?

In case any members are not aware The Pituitary Foundation runs a Telephone Buddies scheme; these buddies are trained volunteer patients and carers situated throughout the UK who are available for you to phone. These volunteers are there to listen to you and share experiences. They do not give medical advice but speak from personal experience and offer helpful support. The Foundation can see this is a really worthwhile service and would love to see more patients and carers using it. The service is free and aimed at anyone who wants to talk to someone who really understands what they are going through, as we will match you with a Telephone Buddy who has the same condition or has experienced similar issues.

To be matched with a Telephone Buddy please call the helpline on 0845 450 0735, or email helpline@pituitary.org.uk or rosaw@pituitary.org.uk

Rosa Watkin (Outreach Volunteer Support Co-ordinator) Please do get in touch

Diagnostic Tests in Pituitary

Professor John P Monson MD FRCP FRCPI

Q: Why are they carried out every year / six months?
A: Regular assessments of pituitary function are important in the follow up of patients who have received radiotherapy (annually) and in the follow up of treated but unsecured functioning pituitary tumours. Basal blood tests will be used to follow up adequacy of treatment with thyroxine, GH and testosterone

Q: Why can it take so long to receive your results?
A: Results of investigations should be available within two weeks. The results should then be communicated to the GP. Many consultants will copy results to patients with an explanation of their significance and this is desirable...
Moving from incapacity benefit onto employment and support allowance

Howard Pearce Benefits specialist at CABS (and pituitary patient)

F

or many years, the government has paid incapacity benefit to people who are unable to work because of a health problem. In order to qualify for incapacity benefit, you needed to have been working and paying National Insurance contributions for up to twelve years, and then become unable, unwilling or unable to work. Part of the process usually involved having a medical with a doctor approved by the Department of Work and Pensions, who would allocate you a number of points, depending on your physical and psychological limitations. If you scored enough points, you were considered unfit for work and could claim incapacity benefit, or another benefit such as income support if you had little or no other income and did not have the required National Insurance contributions.

More recently, the government has introduced employment and support allowance (usually shortened to ESA) for people unable to work because of a health problem. For this, you do not necessarily need to be up to date with National Insurance contributions. All new claimants go onto ESA, and people currently claiming incapacity benefit are gradually being moved onto ESA. Once again, you have to undertake a medical and have to gain sufficient points for physical and psychological difficulties in order to continue to qualify for ESA.

Official information on ESA can be found on the direct.gov website: http://www.direct.gov.uk/en/MoneyTaxAndBenefits/TaxCreditsAndOtherSupport/ESA50andSupportAfterESA50/index.htm

The points scoring system was deliberately made tougher for ESA than for incapacity benefit. Then a new ESA scoring system was introduced in which it is even more difficult to gain sufficient points. Many people who have been on incapacity benefit will not qualify for ESA, and instead will be classified as fit for work. This is deliberate government policy, first introduced by the Department of Work and Pensions, so it is even more difficult to gain sufficient points over the 17 questions. This could mean that people with certain conditions, including any embarrassment ones. As pituitary-related symptoms tend to be different for everyone, it is a good idea to mention your particular symptoms and difficulties you might have going to a wheelchair users. For example you may only be able to walk a few steps, but if you can manually propel your wheelchair 200 metres (on the flat), then you will score 6 points for mobility.

For question 1, you could also score 9 points if you cannot climb or descend two steps, using a handrail, but without help from someone else. In order to qualify for work, you need to score a total of at least 15 points over the 17 questions. This could be 15 points for one question, or a 9 for one question and a 6 for another question, or three questions each with a score of 6. It is useful to have access to the scoring system when completing the ESA50 form. It can be downloaded from the Disability Rights UK website noted above, or is given as a table in the Disability Rights Handbook, which is published annually. When you see what they are, you will allocate points for, it makes it easier to decide what to write in the answers boxes.

The ESA50 form relate to the following abilities

1. Mental health problems, learning difficulties, etc
2. Delusional or bizarre behaviour – minor planned change and unexpected changes
3. Starting and completing personal actions – due to intrusive thoughts, mental health problems, learning difficulties, etc
4. Coping with change – minor planned change and unexpected changes
5. Getting about – anxiety so that someone will not go out alone
6. Social anxiety – meeting people
7. Confronting or dealing with – relationship this relates to any behaviour that an employer would not like, such as yelling, excessive swearing, throwing things, getting into fights, falling asleep, stealing, starking, etc
8. Pituitary-related problems will not be able to score 15 points or more, and will be classified as fit for work. This includes people who may have been receiving incapacity benefit for years. I am such a person myself, I claimed incapacity benefit because of pituitary-related problems for about ten years, but I knew that I would qualify for ESA, and would possibly score zero on their points system. Whether or not a person gains enough points will depend on how their pituitary problem affects them, and
A few people with more serious problems will be put into the “support group”. They will get a few pounds a week more ESA paid, and will not have to go to the Jobcentre. Unless you have other serious health problems, it is unlikely that many pituitary people will be put into the support group.

One common symptom of a pituitary problem is that you fall asleep almost without warning. This is one symptom that will probably not gain you any points. Unless it is so severe that you fall asleep almost with no warning and fall asleep three times a day, you would probably fall asleep at work.

After the ESA50 form has been completed and sent off, a letter will arrive with an appointment at a local centre for a medical. The appointment is likely to be three months after the letter was sent. You might have little time to discuss with the medical practitioner everything that is wrong with you. The medical practitioner will know very little about pituitary problems. They say that they are assessing what you can do and what you cannot do, rather than attempting to diagnose and treat you, and that they do not need to be an expert on every condition. It means that you have to tell them all of your problems. If you do not tell them, they will assume that you have no problems.

Typically, they will ask you about how you spend your days, how you travelled to the medical, how you go shopping, about your hobbies, and so on. Finding out more about you, to provide information that can later be used to assess you against the 17 questions. Tell them as much as you can, and make it as clear as you can, to reduce the risk of them assessing you incorrectly.

They may also ask you to go onto a couch, lift your legs and arms, or other physical tasks. If anything they ask you to do is difficult or painful, let them know.

Sometimes the medical professional is foreign. This can cause problems if their English is not good enough. They can recognise a broken leg, but sometimes they do not understand well enough what you are trying to say. They do not understand about psychological difficulties, for example.

Afterwards, if you are at all concerned about what happened at the medical, it is a good idea to write some notes of what was asked and what your answers were. If someone was with you at the medical, they can help in producing notes, because they may remember what you have forgotten.

The letter will say one of three things:

- That you have been assessed and put into the support group, and do not have to attend at the Jobcentre, and that you will be paid at the appropriate rate for the ESA support group.
- That you have been assessed and put into the limited capability for work group, and that you will have to attend an interview at the Jobcentre and that you will be paid at the appropriate rate for the ESA work-related activity group.

- That you have not been awarded sufficient points and that payment of your ESA will stop. Usually this is soon followed by a second letter telling you how many points (if any) you were awarded, and for which of the 17 questions. Sometimes there is also a summary of the report of the decision maker, explaining why they did or did not give you points. They also tell you that you can appeal.

Is it worth putting in an appeal? Definitely. Have a look at the points system and think about how many points you think you could have received. You might think that you should have gained at least 15 points, then appeal. You can appeal simply by writing a letter and sending it to the Department of Work and Pensions. You may want to add a formal refusal letter. Or you can use the form in the back of the booklet GL24. If you think our decision is wrong.

When I put in an appeal, I always make sure that the person's name and National Insurance number is clearly stated on each sheet of paper, because then if one sheet happens to become separated they can put it back into the correct file. It also allows them to start about what the person's medical condition is, and how it affects them. I then list all of the places where I think that they should have gained additional points, with statements such as this:

Walking – at least 6 points – Due to fatigue I cannot walk far as 200 metres without having to stop for a rest. It would then be half an hour before I am able to walk far again.

You can continue to claim ESA at the basic rate while your appeal is heard. Or you can claim jobseeker's allowance instead. It depends on your particular circumstances which option is preferable; get some advice about this from a benefits expert or your local citizens' advice bureau.

When you put in an appeal, or a request for a reassessment, they will first look at the points you have been assessed as having. Then they will look at how many letters you send in from your GP or your consultant, it is very unlikely that they will change their decision at this stage. You will receive a letter saying that they have not changed their decision. Quite commonly they will insist that the Atos medical professional who saw you at the medical is thoroughly trained to assess your ability to work. They may know more about this than your GP, your consultant, and anyone else you have called on, even if they have a Nobel Prize for medicine.

Together with the letter you will receive a huge pile of paperwork about your appeal, with copies of your ESA50 form, the report from the medical professional, the decision maker's report and any reports or letters from your GP and consultant. Check the paperwork carefully, and make a note of any errors in the report from your medical. They are often inaccurate and often inconsistent. For example, they may say that you are not comfortable for 45 minutes at the medical and so had no problems sitting. Then in the next sentence they say that the person stood up three times.

The best comment I have seen written by a client on their medical report was a woman who read that she had appeared calm and uninterested at the medical. The woman had added her own comment: “Should have had more smoke. Don’t despair. They almost always turn you down at this stage. But you have a much better chance when you get to the appeal tribunal. A week or so later you will receive an enquiry form, which has to be sent back within two weeks. Send it back and ask for an oral hearing at a tribunal.

When the appeal is finally heard, and three or more months or more after the medical, remember to tell the people on the panel what you are like on a bad day, not just how you feel on the day of the appeal tribunal. They will ask questions, and will remind you that they are interested in your health around the date of the medical and the decision-making, not how you are now. This matters if your health has become much better or much worse.

Can an appeal be successful? Definitely. At the tribunal I was able to win with a client a few days ago, he went in with no points at all, and came out with 15 points. The one before that, a young woman who had scored only 6 points following her medical. She was unable to go to the tribunal herself because she didn’t go far enough from her health centre. She therefore phoned and handed the panel members a sheet of paper suggesting where they could give the woman extra points. They read it, conferred, and upped her score to 18 points without asking a single question.

If you win the appeal, you will backdate the award so that you will get all of the money lost since they turned you down. It may be six to eight weeks before you get the money, but it will come eventually.

If you lose the appeal, then you need to claim jobseeker's allowance. But if your health gets worse, possibly as a result of the stress of being turned down for ESA, you can claim ESA again.
“Doctor, I don’t think these pills are working”  Robert’s story

He later, great, Spike Milligan, in his final act of black humour, insisted that the inscription on his headstone should read ‘I told you I was ill’. I have never been a great believer in ‘I told you so’, but when the news of my pituitary tumour was relayed to me by my GP; it was all I could do to stop myself letting rip into those within the medical profession who had placed my pleas for help by prescribing anti-depressants for too many years to remember.

Since my early thirties, and for more than a dozen years, my work and family had suffered along with me. My employers accepted that I was reacting to stress and tried, as much as was possible in my management position, to accommodate and alleviate my problem. This involved taking areas of responsibility away from me, which only served to fuel my own skewed view on my inadequacies and lack of competence. Dark times followed, and inevitably, after three months away from work, my illness cost me my job. The strain on my wife and three sons was something I could not measure, and in some ways we are all still paying a price.

Feelings of isolation

It was in 1996 that my doctor, after the briefest of consultations, started me on the anti-depressant route and recommended me to a counsellor. Admittedly, there had been some symptoms akin to depression. From long bouts of low mood, feelings of isolation and emotional emptiness to outbreaks of anger, lapses of concentration and fluctuating sleep and dietary patterns. Airing my feelings to a complete stranger felt like I had a little to alleviate my growing problems. The counselling had ceased after a year, although it had made sense at the time, and I believe in my heart that it was all I could do. It was in 1996 that my doctor, after the briefest of consultations, started me on the anti-depressant route and recommended me to a counsellor. Admittedly, there had been some symptoms akin to depression. From long bouts of low mood, feelings of isolation and emotional emptiness to outbreaks of anger, lapses of concentration and fluctuating sleep and dietary patterns. Airing my feelings to a complete stranger felt like I had a little to alleviate my growing problems. The counselling had ceased after a year, although it had made sense at the time, and I believe in my heart that it was all I could do.

Vision problems

During the winter of 2007/08 I started to have pain in the right side of my face, especially around the eye. After a visit to the optician’s proved inconclusive I was referred to the ophthalmic department at my local hospital. They found nothing wrong with my vision and in turn, referred me on to the Ear, Nose and Throat department. Again, they could find no explanation, but arranged for me to have an MRI scan in preparation for sending me on to the Neurosurgery Department.

So it was in May 2008 and completely by accident, that I was finally diagnosed with a pituitary adenoma and rather than fear the prognosis, I grabbed the chance to discover what had been the cause of the much prolonged malaise in my thoughts and moods. The pituitary or ‘master gland’ effectively, or in my case inefficiently, controls all the hormones produced in the body. It is situated in a bony hollow at the base of the skull under the middle of the brain. My tumour, although benign, had overridden this and taken command, leaving me out of control, agonisingly believing that I was mentally ill and tragically suicidal at times. Tragic for those close to me, who had to deal with picking up the pieces of my two failed attempts, as best they knew how.

My best guess is that the ‘alien in my head’ had been around for 15 or more years before being detected, and my first reaction was one of relief that there was a logical explanation for why I had felt and acted like I had, for so long. Before being properly diagnosed I had also gained approximately thirty kilograms in weight over the preceding 18 months, despite having no appetite. Regular blood tests failed to pick anything up. Specific tests showed that I had a particular type of tumour, called a prolactinoma, which is a benign growth that produces an excess amount of the hormone prolactin. Prolactin has many different functions in the body, including controlling milk production and helping to regulate the function of the reproductive system. As well as the flood of prolactin, my tumour also interfered with and lessened the production of other vital hormones, such as testosterone. The combined effect had physically impacted on my weight gain and libido, but psychologically had tormented me for almost half of my adult life.

Reassess my life

The news that I had a condition that was ‘treatable’ and which could reassess my life and values. Unfortunately, this meant that my twenty-six year relationship with my wife was effectively over. We had been making each other miserable for as long as I could recall. The children were all adults by this time, but our split hit them hard. Two of the three are still not talking to me, which hurts deeply. The neurosurgeon explained that surgery was an alternative; however, there was medication that should be tried first. He referred me to an endocrinologist and over the next three years my hormone levels were brought under control using drugs known as dopamine agonists. Everyday life became infinitely more bearable, although regular visits to the hospital became the norm. Frequent MRI scans revealed however that the tumour was not shrinking as anticipated. My constant headaches and nausea resulted in being placed back in the hands of the neurosurgeon earlier this year for a procedure known as an endoscopic transphenoidal removal. This operation involves the surgeon making a hole through the sinus cavity, via the nose, and utilising a camera to help locate and strip out the intrusive growth. Thankfully, the surgery was successful, and unbelievably I was at home with my new partner and her two daughters within a couple of days. All of the major symptoms have gone, which means I now am in a position to write this piece and hopefully begin a new chapter in my life. I am going to give writing a good try, and with the continual monitoring provided by my consultants, leave the door closed on further ‘alien invasion’.

Wrong diagnoses

I cannot close my story without thanking the incredible Endocrine team and Neurosurgery department at The Royal Hallamshire Teaching Hospital in Sheffield, without whose care and attention, I could not have coped. Pituitary tumours and resulting endocrine issues are not an everyday occurrence for GPs, so being wrongly diagnosed with a condition that they do know i.e., depression or stress, that can be treated by prescription, is bound to occur. I would recommend to anyone who feels that their own problems might be hormonally linked, that they seek specific blood tests and also check out the following websites: www.pituitary.org.uk and www.yourhormones.info where I found not only the information that helped me understand my condition, but also a community of other sufferers prepared to share their experiences.

Into the arms of Angels – Jane’s story

I am American by birth, a British resident by choice and a long time advocate of the National Health Service – in theory. It always seemed such a civilised approach to health care, unlike the system in America, where good health care is too often associated with personal wealth. Of course, there is always the option of private health insurance in the States, but the insurance is almost always provided through one’s job; so, if you find yourself too ill to work, you lose your benefits just when you need them. This is the story of how a believer in the theory of the NHS became a supporter of the practical application of this system.

On 6 June 2001, I found myself sitting in the office of Mr J Singh, neurosurgeon at North Staffordshire Hospital in Stoke-on-Trent. My husband Tim and I stared at the scans stuck onto lighted walls – grainy black and white images that resembled a generic skull. The inscription on the grave is in Gaelic; it reads “I told you I was ill”.

When I arrived for my second appointment in early July I was followed by a much worse set of symptoms of severe headaches which were so bad they seemed to appear literally overnight. One day I was fine and the next day I noticed a rapid deterioration in the vision of my right eye. That was on 10 May 2001. Within the following two
The nursing staff on Ward 23 includes about thirty nurses with eight on duty at any given time. I cannot mention them all individually, but they were all appreciated. My opinion of the NHS is at an all time high, full of passion and thanks.

I recall with such clarity the moment in Mr Singh’s office when we received the diagnosis – brain tumour, pituitary adenoma. Now I am at home in recovery, and my vision has returned to normal. I want to shout, “It’s over!” I pause. I feel that I am looking into Mr Singh’s office. I see another couple seated in front of the lit wall. They are receiving the news that I’d received that June day. They are frightened. Their journey is just beginning. I want to tell them that all will be well if they can manage to simply relax and allow themselves to fall into the arms of the angels…

...continues ↓
and a young health care assistant told the curtains around my bed were drawn to eat and sleep, they finally decided to ward being sick whilst people were trying after spending a day in the Admissions arranged for me to be admitted to our immediately. He examined me and practice, who asked us to go to his house Saturday morning, David phoned the I was so weak by this stage, that one Blood tests knew best.

When I reached Perth, my cousin took me straight to their doctors who gave me an injection to stop the sickness. I When I reached Perth, my cousin took me straight to their doctors who gave me an injection to stop the sickness. I

Vision back to normal
Within a few weeks I had been seen by Professor Wass and on 1st April 1999 had the operation to remove the tumour when we touched down in Singapore. Thankfully I was met at Heathrow by our son, Simon, who was shocked by my appearance. My husband was getting more and more frustrated as he knew there was something really wrong with me. Our daughter, Debbie, who is a Nurse Practitioner, kept nagging us to go to A & E, but we thought our GPs knew best.

Blood tests
I was so weak by this stage, that one Saturday morning, David phoned the doctors and spoke to the head of our practice, who asked us to go to his house immediately. He examined me and arranged for me to be admitted to our local hospital Heatherwood in Ascot, Berkshire. I looked and felt awful and after spending a day in the Admissions ward being sick whilst people were trying to eat and sleep, they finally decided to give me blood tests and an MRI scan. When I came back from the MRI scan, the curtains around my bed were drawn and a young health care assistant told me to be brave! I was spoken to by a Portuguese Registrar who informed me I had a brain tumour, and pointed to where it was. She told me they were discharging me and they would be in touch. Because of the way I was told and the fact her English was not very good, my husband and I were in shock and didn’t understand what was going on. This was a Friday and on the Monday morning, my husband phoned the Endocrine Consultant who explained everything to us and arranged for us to see him. He told me that he wanted to refer me to the Radcliffe Infirmary in Oxford to be under Professor Wass, as he was a leading Consultant Endocrinologist – also, as I almost certainly needed an operation to remove the tumour, this operation would be performed by Chris Adams who was a leading neurosurgeon.

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The Pituitary Foundation
86-88 Colston Street, Bristol, BS1 5BB
helpline@pituitary.org.uk
www.pituitary.org.uk

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