



**THE PITUITARY
FOUNDATION**

*working to support
pituitary patients*



**HYPOPITUITARISM
AND REPLACEMENT
THERAPY**

THE PITUITARY FOUNDATION

AIMS AND OBJECTIVES

Most disorders of the pituitary gland are relatively rare, but they are often puzzling and sometimes distressing, both for patients and for families and friends. The Pituitary Foundation aims to help in several ways:

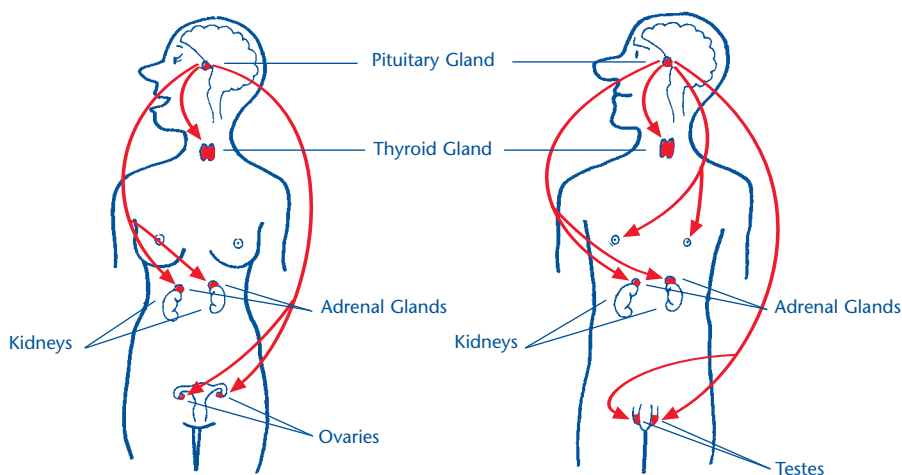
- By providing information and support to patients and their families and carers. Because most of these disorders are rare, many patients have had little or no opportunity to meet and talk with others who have already been through the same experience. We are building a network of people in different parts of the country and with experience of different pituitary disorders, with the aim of mutual support and communication. We hope this will help to dispel some myths and relieve patients' anxieties.
- By acting as a source of information on lifestyle issues faced by sufferers from pituitary disorders. Information provided by the Foundation will include details of life and travel insurance, entitlement to free prescriptions, pension arrangements, employment issues, travel recommendations, and advice regarding possible driving restrictions.
- By increasing public awareness of pituitary disorders which, because of their rarity, can be bewildering. This educational role will enable anyone concerned with pituitary problems to be updated rapidly on new advances and we are fortunate in having several of the country's leading experts as advisers to the group.

To sum up, whatever your involvement with a pituitary problem – whether as patient, family member or friend – we hope that The Pituitary Foundation will lead to a new sharing of experience which will help all those affected to meet the daily challenges of their own individual disorder with renewed confidence and optimism, in the knowledge that others have faced the same challenges before.

WHAT IS REPLACEMENT THERAPY?

Replacement therapy is the name used to describe any medical treatment which replaces a hormone which your body is not making for itself, or of which it is not making enough. A number of these hormones are made by your pituitary gland.

Your pituitary is an important gland and is often referred to as the 'master gland', because it controls several other hormone glands, including the thyroid, adrenals and reproductive glands. It is usually about the size of a pea and is situated in a bony hollow beneath the base of your brain and just behind the bridge of your nose. The pituitary in turn is controlled by a part of the brain called the hypothalamus. When your pituitary is functioning normally it produces the following hormones:



Adrenocorticotrophic hormone. This may also be referred to as ACTH, or corticotrophin. This hormone stimulates your adrenal glands (situated just above your kidneys) to produce the body's main steroid hormone called cortisol. The adrenal hormones help us to cope with stress.

Anti-diuretic hormone (ADH). This hormone is secreted from the back part of your pituitary (or 'posterior pituitary'), and it is sent from your pituitary to your kidneys to limit the volume of urine produced. It is also known as vasopressin.

Gonadotrophins. This is a name which covers two sex hormones made by the pituitary - luteinising hormone (often referred to as LH) and follicle stimulating hormone (FSH). In women, these hormones are sent by the pituitary to the ovaries, where they control the production of female hormones (oestrogen and progesterone) and stimulate ovulation. They are thus essential for a normal menstrual cycle and for fertility. In men, the pituitary sends them to the testes, where LH stimulates the production of the male hormone testosterone, and FSH is important in sperm production.

Growth hormone. This is often abbreviated to GH. In children this hormone is essential for a normal rate of growth. In adult life growth hormone may be important for a number of functions including normal energy levels and maintaining normal strength of muscle and bones.

Prolactin. This hormone stimulates the breasts to make milk. It is present all the time in men and in women, but is secreted in large amounts during pregnancy and breastfeeding.

Thyroid stimulating hormone. You may also hear this referred to as TSH, or sometimes as thyrotrophin. As its name suggests, this hormone stimulates your thyroid gland (located near your windpipe) to secrete its own hormone, which is called thyroxine. The thyroid gland controls many body functions, including heart rate and temperature. Lack of thyroid hormone is referred to as hypothyroidism.

WHY DO SOME PEOPLE NEED REPLACEMENT THERAPY?

Considering the complex multiple functions of the pituitary, it's not surprising that it sometimes fails to work properly! If your pituitary is not producing one or more of its hormones, or not producing enough, then this condition is known as hypopituitarism. It is most often caused by a benign (i.e. not cancerous) tumour of the pituitary gland itself, or of the brain in the region of the hypothalamus. If you have a pituitary tumour, it may cause pituitary

underactivity by the direct pressure of the tumour mass on the normal pituitary, or by the effects of surgical or X-ray treatment which you have undergone to treat the tumour. Less frequently, hypopituitarism can be caused by infections (such as meningitis) in or around the brain, by severe blood loss (particularly after pregnancy), by head injury, or by various rare diseases such as hypophysitis or sarcoidosis.

ADRENOCORTICOTROPIC HORMONE (ACTH)

ACTH controls the adrenal glands and steroid hormone production.

WHAT ARE THE SYMPTOMS OF LACK OF ACTH?

Fatigue is a common symptom, as is a general feeling of loss of physical well-being and vigour. You may also feel dizzy. Some patients also suffer from nausea and diarrhoea.

HOW IS IT DIAGNOSED?

If severe, ACTH deficiency may be obvious from a single blood test, but usually you will need to attend a specialist clinic as a day patient for tests referred to as 'dynamic'. This means that you will have a blood test initially and then several more after you have been given something to stimulate the hormone. Most clinics either use an artificial version of the ACTH hormone or a test which reduces your blood sugar level. The test will show how your hormone level reacts over a period of time.

HOW IS IT TREATED?

Treatment is by taking the adrenal hormone, cortisol, which is referred to as 'hydrocortisone' when it is made into a tablet. It is taken in tablet form, usually two or three times daily. Your GP will prescribe these, but you will still need to see your specialist from time to time for monitoring. Some clinics take blood samples in a way similar to the dynamic tests described above, and others rely on a normal medical examination with blood pressure check and so on. Occasionally other drugs are prescribed as alternatives to hydrocortisone. These include prednisolone or cortisone acetate. Your endocrinologist should tell you how to increase the dose of hydrocortisone yourself during any other serious or stressful illness

(e.g. 'flu', routine operations, diarrhoea and vomiting). This is very important since the body normally makes a lot of steroid hormone under these circumstances. You should also carry a 'steroid card' and/or MedicAlert bracelet to warn other doctors that you need steroid replacement during illness.

ANTI-DIURETIC HORMONE (VASOPRESSIN)

Anti-diuretic hormone controls the production of urine.

Lack of anti-diuretic hormone leads to an illness called diabetes insipidus, where patients feel very thirsty and are constantly having to pass urine, including during the night. This condition can be treated by use of a drug called desmopressin, or DDAVP. This is covered in detail in another Pituitary Foundation leaflet, entitled *Diabetes Insipidus*.



GONADOTROPHINS

Gonadotrophins control the ovary or testes and sex hormones.

WHAT ARE THE SYMPTOMS OF LACK OF GONADOTROPHINS?

In women, lack of gonadotrophins usually causes disturbance to the menstrual cycle or even complete loss of periods. You may find you also lose interest in sex. In men, impotence and loss of sexual drive may be experienced. Infertility can be involved in both sexes. Both sexes, but particularly men, may notice a loss of hair stimulated by sex hormones (pubic, under-arm, body and facial hair). You may

also feel generally under the weather. Prolonged loss of sex hormones for many years often leads to brittle bones or osteoporosis.

HOW IS IT DIAGNOSED?

As with most of the hormone deficiencies, you will be given one or more blood tests. These will indicate whether your sex hormone levels are below normal.

HOW IS IT TREATED?

Because a lack of gonadotrophins prevents your ovaries or testes from producing the correct sex hormones, treatment is usually with these hormones. For women, this usually means taking a variety of tablets which contain variable amounts of oestrogens and progestogens, which are the main hormones produced by the ovaries. Sometimes, instead of tablets, doctors prescribe other forms of treatment such as skin patches, as some patients find they get on better with these than with tablets. For men, the main sex hormone is testosterone, and this will be replaced by one of a number of means, often by injections every two to four weeks, or by tablets or skin patches. If you are trying to have a family, extra specialist help will be needed to help eggs to mature in the ovaries, or to produce sperm in the testes. See the section on infertility in our leaflet on *The Pituitary Gland*.

GROWTH HORMONE

Growth hormone controls growth in children and aspects of general metabolism in adults.

WHAT ARE THE SYMPTOMS OF LACK OF GROWTH HORMONE?

In children, lack of growth hormone inhibits the child's growth. The child will be smaller than other children of his or her age and may look younger, but will be normally proportioned. About a third of children with growth hormone deficiency are also overweight. This is because growth hormone also controls the fat under the skin. These children are not necessarily overeating. It is important to ensure they receive a balanced diet and a reasonable amount of

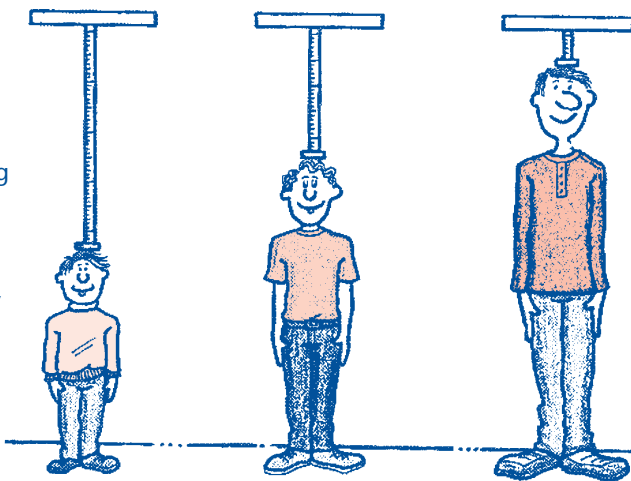
exercise. Further details can be obtained from the Child Growth Foundation (their address is at the back of this leaflet).

In adults, growth hormone is involved in maintenance of normal body weight and energy levels and in maintaining the strength of muscles and bones. Therefore, lack of growth hormone can cause depression, loss of energy and a decrease in muscle strength in some patients (see our leaflet on *Adult Growth Hormone Replacement*).

HOW IS IT DIAGNOSED?

If a child is suspected to lack growth hormone, he or she will normally be sent for tests to a specialist centre, usually as an outpatient. Very careful measurements of height and rate of growth will be taken.

There are a number of possible tests to find out how much growth hormone is being produced. These include blood tests or urine tests (which may have to be carried out at specific times of the day). Some centres also use an insulin tolerance test (ITT), which may cause your child to feel a little hot and sweaty as well as hungry. The ITT test may also be used for adults.



HOW IS IT TREATED?

Nowadays, replacement growth hormones are produced synthetically and are identical to natural human growth hormone. The growth hormone is usually supplied as a powder which you mix with a liquid before use. It is normally given as a daily injection, often before going to bed, at a dose which your specialist will have

calculated to take into account your size and weight (or that of your child). Be sure you have understood the specialist's instructions about quantities to be used. The drug may well be supplied on an ongoing basis by your GP.

There are various tips about the best ways to persuade a child to accept these daily injections and, again, the Child Growth Foundation is a good source of advice and support. If your child is receiving growth hormone treatment it does not necessarily follow that he or she will also need treatment to stimulate the onset of puberty, but around half of such children will need this extra treatment.

In adulthood, a growth hormone deficiency can lead to a number of symptoms which result in a decreased quality of life in some (but not all) patients. An increasing number of adult patients are therefore treated with growth hormone replacement by daily injection, and some notice a substantial improvement in their energy, strength and overall quality of life on treatment.

Replacement involves daily injections, often given by a 'pen' device. Growth hormone is expensive and this often leads to discussions between your specialist, GP and Health Authority about who should prescribe the treatment (or whether it should be provided at all) – if this problem affects you then please contact the Foundation for advice.

PROLACTIN

Prolactin stimulates milk production – and suppresses the effects of gonadotrophins.

WHAT ARE THE SYMPTOMS OF TOO LITTLE OR TOO MUCH PROLACTIN?

There are usually few symptoms and few problems. The exception is after pregnancy, when a lack of prolactin may mean that the mother does not produce breast milk.

However, unlike other pituitary hormones, prolactin is controlled by the secretion of a compound by the hypothalamus which acts as a brake on the pituitary's secretion of prolactin. In the case of pituitary tumours that decrease access of hypothalamic hormones to the pituitary gland, this brake is reduced and thus the secretion of prolactin increases. This means that patients with hypopituitarism

may actually suffer from excessive levels of prolactin in spite of being deficient in other hormones. A high prolactin level may decrease libido and interfere with normal sex hormone levels and periods, or erections.

HOW IS IT TREATED?

No treatment is usually required for a low prolactin. If you do not make breast milk after your baby is born, other methods of feeding will be recommended. Do not worry about this, as modern feeds will ensure that your baby receives all the nutrients he or she needs. If a high prolactin ('hyperprolactinaemia') is causing problems then it may need to be controlled by a drug such as bromocriptine or cabergoline which acts in the same way as the brain chemical which normally switches off prolactin. These drugs may also be used to decrease the size of a prolactinoma (see our leaflet on *Prolactinoma*).

THYROID STIMULATING HORMONE

TSH controls the thyroid gland and thyroid hormone production.

WHAT ARE THE SYMPTOMS OF LACK OF TSH?

Fatigue is a very common symptom when your thyroid gland is underactive. As mentioned above, a lack of TSH from your pituitary is one possible cause of this. You may also gain weight, even though you know you are not eating more or exercising less, and you may generally feel listless and unwell. Your skin and hair may become dry and you may lose interest in sex.

HOW IS IT DIAGNOSED?

If your doctor thinks you may not be producing enough TSH, you may be given blood tests either by your GP or at a specialist clinic. This test measures your level of the hormone thyroxine.

HOW IS IT TREATED?

If lack of TSH from your pituitary is preventing your thyroid gland from functioning properly, then you will be prescribed the thyroid hormone, thyroxine. You will normally take these in the form of tablets once daily. These tablets will be prescribed by your GP, who will adjust the dose according to symptoms and the results of blood tests.

AFTERCARE

It is possible that your condition will require long-term monitoring and this will be shared by your endocrinologist and GP. Because pituitary conditions are relatively rare, you might find that you will be the only patient with hypopituitarism your GP is treating and (s)he might find it helpful to have a copy of our *Pituitary Disease Factfile for General Practitioners*.

HOW WILL REPLACEMENT THERAPY AFFECT MY LIFESTYLE?

PRESCRIPTIONS

If you will have to take hydrocortisone, thyroxine or desmopressin permanently you will get free prescriptions for all medicines. You will need a Prescription Charge Exemption Certificate (FP92) which you can get from your Health Authority. To obtain the certificate you must complete form FP92A (EC92A in Scotland) which is available from your doctor, hospital or pharmacist. The form (which will need to be signed by your doctor) tells you what to do. These certificates only last for a finite period after which they must be renewed. Your Health Authority *may* automatically send out an application for renewal.

Information about free prescriptions and the full list of medical conditions which qualify for exemption from prescription charges can be found in leaflet HC11, available from pharmacies and main Post Offices. If you are not sure whether you are entitled to free prescriptions, you must pay for your prescription and ask for a NHS receipt (form FP57) when you pay; you can't get one at a later date. This form tells you how to get your money back.

From April 1999, people between 16 and 60 who claim free prescriptions will be asked to provide proof that they are entitled to do so *every time* they collect a prescription. For further information, phone the **Free Prescription Advice Line** on **0800 91 77 711**.

DRIVING

You have a legal obligation to advise the Driver and Vehicle Licensing Agency (DVLA) if there is any reason why you should not drive. Many patients with pituitary conditions will find there is no

restriction on their driving, but you should check with your GP. The only condition likely to affect you are problems with your eyesight. Your doctor or specialist will give you full advice. They may also seek extra advice from the DVLA by contacting the Medical Adviser, The Drivers' Medical Branch, 2 Sandringham Park, Swansea Vale, Llansamlet, Swansea SA6 8QD. Tel: 0870 0600 0301.

INSURANCE AND PENSIONS

Your insurance or pension provider will want medical reports and each case will be assessed individually. It is likely that you will be accepted by the company, but there may well be extra premiums to pay. Company policies vary widely and you may need to shop around. Do not be disheartened if the first response is disappointing. If you would like independent advice from a broker who is aware of the main pituitary disorders, contact John Kane or Simon Foote at Lansdowne Financial Services, Bracken House, 14-16 Christchurch Road, Bournemouth BH1 3NJ. Tel: 01202 558445; e-mail: lib@exchange.uk.com; website: www.lansdowneinsurance.co.uk

EMPLOYMENT PROBLEMS

Contact the Disability Employment Adviser (or DEA) at your local Jobcentre. DEAs are members of Placing, Assessment and Counselling Teams (PACTs) who are specially trained to recognise and help overcome severe employment difficulties associated with health problems or disability. They are able to discuss with you the type of work you can do, and help prepare you for finding work. Look under 'Employment Service' in the phone book to find the local Jobcentre.

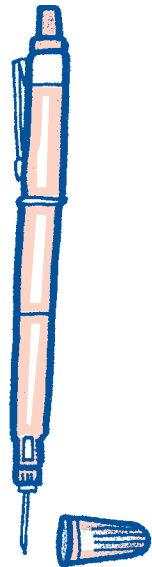
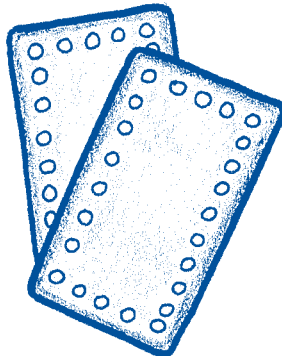
Your DEA will not be able to advise you on benefits – for this look under 'Benefits Agency' in the phone book to find your local office.

MEDICALERT®

It is a good idea to wear a MedicAlert® bracelet or equivalent as the information on it will help doctors if you have an accident and are unconscious. An application form can be obtained from the MedicAlert Foundation, 12 Bridgwharf, 156 Caledonian Road, London N1 9UU. Tel: 0800 581420.

COMMON QUESTIONS

- *Will I have to take my hormone replacement tablets for ever?*
Yes, most probably. The exception may be sex hormones replacement in the elderly (but there is no real 'upper age limit').
- *Are there any long-term side effects?*
Replacement therapy is a natural form of treatment and there are not usually any problems as long as treatment is monitored.
- *Do I need to keep my medication in the fridge?*
Growth hormone commonly needs to be kept refrigerated, as does desmopressin (not the tablet form). Other pituitary hormones do not. Check with your doctor or chemist for full details. For desmopressin, see also our leaflet entitled *Diabetes Insipidus*.
- *I've heard that growth hormone treatment can cause a severe brain disease. Is this true?*
This is not a problem with the modern artificially-produced growth hormone which has been in exclusive use since 1985.



WHAT HYPOPITUITARISM AND REPLACEMENT THERAPY HAVE MEANT TO ME

ONE PATIENT'S STORY

Several years after I retired I collapsed suddenly and was taken to hospital. They could not find anything wrong with me, but this continued to happen several more times over the next two years or so.

One day, I was watching television and all of a sudden I felt ill and the room started going round. I collapsed again and my wife phoned for an ambulance. In hospital I was examined by an astute doctor who noticed I had no hair under my arms. He said he thought I had a hormone problem.

The next day I was transferred to another hospital for a scan which showed that I had a growth on my pituitary gland. I was referred to a specialist in an endocrine clinic where I had a blood test which showed that my hormone level was low. I was immediately prescribed prednisolone tablets, which I will take for the rest of my life.

After taking these tablets for about five weeks I was strong enough to have an operation on my pituitary gland. After the operation I was transferred back to my endocrine clinic which I attend every six months. In addition I see my own doctor every six weeks. They were all surprised that I had not suffered from headaches, but the only time I did was the week of the operation!

The endocrinologist told me the prednisolone tablets would make a new man of me and they have! You can't make an eighty-three year old into a twenty-one year old, but in the nine years since the operation and the beginning of replacement therapy I have enjoyed good health and am very active.

JOHN

OTHER SUPPORT ORGANISATIONS

There are a number of excellent specialist help groups. These include:

CHILD, P O Box 154, Hounslow, Middlesex TW5 0EZ. Tel: 020 8992 5522. Provides advice and support to people with infertility problems.

CHILD GROWTH FOUNDATION, 2 Mayfield Road, Chiswick, London W4 1PW. Tel: 020 8995 0257. Provides support to parents of children with growth disorders.

ISSUE - NATIONAL INFERTILITY ASSOCIATION, St George's Rectory, Tower Street, Birmingham B19 3RL. Tel: 0121 359 4887. Offers help, information and support to infertile couples.

OTHER READING MATERIAL

Growth and Growth Disorders: available from the Child Growth Foundation, as above.

Growth hormone deficiency – a guide: available from the Child Growth Foundation, as above.

Puberty and the growth hormone deficient child: available from the Child Growth Foundation, as above.

GLOSSARY

Adrenocorticotrophic hormone Often abbreviated to ACTH. This hormone is produced by the pituitary gland and tells the adrenal glands to produce cortisol.

Adrenal glands These are glands which are situated just above the kidneys, and which produce various hormones, including cortisol and adrenaline.

Amenorrhoea Absence of menstrual periods.

Anti-diuretic hormone A hormone which your pituitary sends to your kidneys to limit the volume of urine produced. It is also known as ADH or vasopressin.

Benign tumour A growth which is not cancerous.

Cortisol	One of the main hormones produced by the adrenal glands, which controls a number of functions and is particularly important in times of illness and stress.
Desmopressin	This is the name for medication which replaces anti-diuretic hormone.
Endocrine system	The body-wide system of hormone-secreting glands, and the hormones they secrete, which control many aspects of life, including growth and reproduction.
Endocrinologist	A doctor who specialises in treatment of diseases of the endocrine system.
Gonads	The reproductive organs - ovaries in a woman, testes (testicles) in a man.
Gonadotrophins	This is a collective term for FSH and LH, the pituitary hormones which stimulate the gonads.
Growth hormone	A hormone produced by the pituitary gland (mainly while you are asleep), which controls rate of growth in children. Even after growth has ceased, growth hormone has important effects during adult life.
Hydrocortisone	A drug which replaces natural cortisol.
Hypopituitarism	Underactivity of the pituitary gland causing reduced production of pituitary hormones.
Hypothalamus	The part of the brain which controls pituitary hormone production.
Hypothyroidism	Underactivity of the thyroid gland.
Oestrogens	Female hormones, produced by the ovaries.
Pituitary gland	A gland, as small as a pea, located at the base of the brain. It controls the hormone production of many other glands in the body.
Progesterone	Female hormone, produced by the ovaries.

Prolactin	A hormone often called the 'milk hormone' because its main function is to stimulate the breasts after childbirth. However, men also have prolactin, although the reasons for this are not clear.
Testosterone	The main sex hormone in men, produced by the testes.
Thyroid gland	A gland which lies over the windpipe and just below the larynx. It produces hormones which are essential to numerous body processes.
Thyroid stimulating hormone	A hormone which your pituitary sends to your thyroid gland to stimulate production of thyroxine.
Thyrotrophin	Thyroid stimulating hormone.
Thyroxine	A hormone produced by the thyroid gland.
Vasopressin	See anti-diuretic hormone.

OTHER LEAFLETS PRODUCED BY THE PITUITARY FOUNDATION

- Acromegaly
- Adult Growth Hormone Replacement
- Cushing's
- Diabetes Insipidus
- Kallmann's Syndrome
- Male Hypogonadism and Infertility
- Pituitary Disease Factfile for General Practitioners
- Pituitary Surgery & Radiotherapy
- Prolactinoma
- The Pituitary Gland

THE PITUITARY FOUNDATION REQUEST FOR FURTHER INFORMATION

Name

Address

Post Code

The Pituitary Foundation produces a range of leaflets. If you would like to receive any of these please tick the relevant box(es) and they will be sent to you without delay. Alternatively, visit our website on www.pituitary.org.uk

- | | |
|--|--------------------------|
| Acromegaly | <input type="checkbox"/> |
| Adult Growth Hormone Replacement | <input type="checkbox"/> |
| Cushing's | <input type="checkbox"/> |
| Diabetes Insipidus | <input type="checkbox"/> |
| Hypopituitarism and Replacement Therapy | <input type="checkbox"/> |
| Kallmann's Syndrome | <input type="checkbox"/> |
| Male Hypogonadism and Infertility | <input type="checkbox"/> |
| Pituitary Disease Factfile for General Practitioners | <input type="checkbox"/> |
| Pituitary Surgery & Radiotherapy | <input type="checkbox"/> |
| Prolactinoma | <input type="checkbox"/> |
| The Pituitary Gland | <input type="checkbox"/> |

Please let us know whether you are:

- | | | | |
|-----------|--------------------------|-----------------------------------|--------------------------|
| A patient | <input type="checkbox"/> | A friend or relative of a patient | <input type="checkbox"/> |
| A GP | <input type="checkbox"/> | A specialist | <input type="checkbox"/> |
| A nurse | <input type="checkbox"/> | Other (please specify) | <input type="text"/> |

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I enclose a voluntary donation of £

Signed Date

Please return this form to:
The Pituitary Foundation, PO Box 1944, Bristol BS99 2UB UK

This leaflet has been prepared for patients with hypopituitarism.
We would like to emphasise that all patients are different and
you should always seek advice from your specialist or GP.

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